



**Alzheimer's Disease  
International**

*The global voice on dementia*

# World Alzheimer Report 2022

Life after diagnosis:  
Navigating treatment, care and support







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# **World Alzheimer Report 2022**

Life after diagnosis:  
Navigating treatment, care and support

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## Glossary of terms

**Activities of daily living (ADL)** – the activities we do every day, including instrumental tasks such as planning an outing, paying bills, taking medications, calling family and friends and basic tasks like dressing, eating, and using the bathroom.

**Alcohol-related dementia** – alcohol consumption is a risk factor for dementia and cognitive decline. Excessive and prolonged use can lead to substantial volume loss in both grey and white matter associated with cognitive deficits and, in extreme cases, with dementia.

**Alzheimer's disease (AD)** – Alzheimer's disease is the most common and well-known form of dementia, accounting for 60-80% of all cases. Brain cells and nerves are disrupted by abnormal proteins, resulting in the disruption of the transmitters which carry messages in the brain, particularly those responsible for storing memories.

**Anhedonia** – the inability to feel joy or pleasure, a symptom of depression that may be present in people diagnosed with dementia.

**Anosognosia** – a lack of self-awareness about having a disability. This condition is very common in dementia as it is linked to Alzheimer's disease pathophysiology in vulnerable structures.

**Aphasia** – the inability to comprehend or formulate language due to damage to specific regions of the brain. It can be acute such as after a stroke, or progressive, like in some types of dementia including Alzheimer's disease and Frontotemporal Dementia.

**Apraxia** – the inability to perform previously familiar movements, such as tying one's shoelaces, or having difficulty producing speech (speech apraxia). Apraxia can be neurological symptoms of dementia.

**APOE e4 gene** – this allele is present in approximately 15% of people and increases the risk for Alzheimer's disease and lowers the age of onset. Having this gene is a risk factor for dementia but does not mean that Alzheimer's disease is inevitable. Some people have two copies of the e4 gene (homozygotes or ApoE-ε4), or more commonly, one copy (heterozygotes).

**Atypical dementia** – the clinical diagnosis of individuals with a progressive cognitive and functional decline dominated by non-amnesic symptoms or/and young onset (<65 years old).

**Care plan** – a roadmap indicating how people living with dementia would receive care throughout the progression of their condition, preferably devised with input from the person with dementia and their informal carers, taking into account cultural, gender, ethnic, racial and health factors, as well as life interests.

**Cognition** – mental processes involved in gaining or using knowledge and comprehension. These processes include thinking, knowing, remembering, judging and problem-solving. Some dementias have more impact on some aspects of cognition (such as remembering recent events) than others.

**Cognitive stimulation therapy (CST)** – manualised group intervention for people living with mild-to-moderate dementia, aimed at improving cognitive function through themed group activities that implicitly stimulate skills.

**Corticobasal syndrome** – a condition characterised by a progressive cognitive and asymmetric motor degeneration characterised by various combinations of akinesia, rigidity, dystonia, focal myoclonus, ideomotor apraxia, and alien-limb phenomena. Alzheimer's disease and aggregates of 4R-tau protein are frequently causes of this syndrome.

**Dementia** – a condition that groups symptoms of impaired memory, thinking, behaviour and emotional control problems resulting in a loss of autonomy. There are many classifications of dementia.

**Disease-modifying treatment (DMT)** – drugs that can modify pathophysiological factors of an illness or condition, slowing down or reversing its progression. In contrast, symptomatic treatments or drugs alleviate certain symptoms without addressing the root cause(s) of the condition.

**Down syndrome (DS)** – Down syndrome (DS) is caused by a triplication of chromosome 21 and the most frequent cause of intellectual disability of genetic origin. As life expectancy has increased for people with DS, so has the incidence of age-associated health problems, most notably young or early-onset Alzheimer's disease.

**Early/young onset dementia** – any dementia beginning before the age of 65. Approximately 1 person in every 1,000 under the age of 65 develops dementia.

**Frontotemporal dementia (FTD)** – one of the subgroups of the larger frontotemporal lobar degeneration (FTLD) family, it accounts for approximately 10% of dementia cases. Its symptoms include changes in speech, personality, behaviour, poor impulse control, and coordination.

**Global action plan on dementia (GAPD)** - The Global action plan on the public health response to dementia 2017-2025 is a WHO initiative that aims to improve the lives of people with dementia, their carers, and families, while decreasing the impact of dementia on communities and countries.

**High-income countries (HIC)** - a country with over US\$12,696 Gross National Income per capita, according to the World Bank 2020 classification.

**Iatrogenesis** - complications or unintended adverse consequences to a patient caused by healthcare professionals, whether due to wrongful diagnosis, intervention, error, or negligence.

**Incidence** - the measurable rate or probability of an occurrence, such as a disease, in a defined population within a specific timeframe. In other words, the number of new cases of a disease diagnosed within a population.

**Lewy body dementia (LBD)** - or dementia with Lewy bodies, designates dementias characterised by the neuronal accumulation of abnormal alpha-synuclein, in the form of Lewy bodies. Dementia with Lewy bodies and Parkinson's disease dementia are examples of Lewy body dementias. Half or more of people with Lewy body disease also develop signs and symptoms of Parkinson's disease.

**Lower-income countries (LIC)** - a country with less than US\$1,045 Gross National Income per capita, according to the World Bank 2020 classification.

**Middle-income countries** - a country with between US\$1,045 to \$12,695 Gross National Income per capita, according to the World Bank 2020 classification.

**Mild Cognitive Impairment (MCI)** - the stage between the expected cognitive decline of normal aging and the more serious decline of dementia.

**Mixed dementia** - the condition where abnormalities characteristic of more than one type of dementia occur simultaneously. For example, individuals can have both Alzheimer's disease and Vascular dementia together.

**Monoclonal antibodies (mAbs)** - an antibody produced by a single clone of cells or cell line and consisting of identical antibody molecules.

**Neurodegeneration** - degeneration of the neurons in the brain. Many neurodegenerative diseases - including Alzheimer's disease, Parkinson's disease, and Huntington's disease - occur as a result of neurodegenerative processes.

**Neuropsychiatric symptoms (NPS)** - in dementia, these symptoms can include apathy, anxiety, agitation, depression, impulsivity, loss of social cognition, hallucinations and delusions, sleep behaviours or disturbances. They can be addressed through non-pharmacological treatment strategies alone, or in combination with pharmacological treatment.

**Neurology** - the branch of medicine or biology that deals with the anatomy, functions, and organic disorders of nerves and the nervous system.

**Parkinson Disease Dementia** - Parkinson's disease (PD) is the second most common neurodegenerative disease after Alzheimer's disease. While it mainly affects movement and balance, dementia is a common complication associated with the condition.

**Post-diagnosis support (PDS)** - an umbrella term encompassing the variety of official and informal services and information aimed at promoting the health, social, and psychological wellbeing of people with dementia and their carers after a diagnosis. Integrated treatment, care, and support are the pillars of effective post-diagnosis models.

**Posterior cortical atrophy** - a neurodegenerative syndrome characterised by predominant and progressive loss of visual and other sensory functions - such as space and object misperception, apraxia, environmental agnosia and diminished reading and face perception - while memory, language and insight are relatively preserved.

**Prevalence** - the measurable proportion of an occurrence, such as a disease, within a defined population and within a specific timeframe. In other words, the percentage of cases of a disease diagnosed within a population.

**Primary progressive aphasia (PPA)** - a heterogeneous neurodegenerative disorder usually linked to Alzheimer's disease or Frontotemporal lobe degeneration, PPA is characterised by progressive, distinctive language impairments that evolve into communicative skill disruption impacting daily living activities and communication.

**Progressive supranuclear palsy (PSP)** - a brain disorder mainly characterised by impaired balance affecting body movement, walking (falls), and uncontrolled eye movements. It results from damage to the brain's nerve cells that control thinking and mobility. These motor-based symptoms are frequently accompanied by memory and thinking problems.

**Psychosocial** - the combined influence that psychological factors and the surrounding social environment have on individual's physical and mental wellness and their ability to function.

**Randomised clinical trial (RCT)** – a research study in which the participants are divided at random into separate groups that compare different treatments or other interventions, in order to compare the effects of the treatments more equitably.

**Risk factors** – health conditions or characteristics associated to the development of a condition, often linked to lifestyle, age and family history.

**Synergism** – interaction between two drugs that causes the total effect of the drugs to be greater than the sum of the individual effects of each drug.

**Tau** – proteins that stabilize microtubules. Hyperphosphorylated tau may accumulate in neurons, forming neurofibrillary tangles, leading to degeneration in a wide variety of disorders including Alzheimer's disease.

**Typical dementia** – the clinical diagnosis of individuals who are 65 years old and older with a progressive cognitive and functional decline dominated by amnesic symptoms.

**Vascular dementia** – vascular disease occurs when blood vessels are damaged, blocked or weakened and therefore prevent the adequate supply of oxygen and nutrients. When the blood flow is disrupted and results in an insufficient oxygen supply to the brain, cells are likely to die. This may lead to a series of mini strokes (infarcts) and possible vascular dementia. Vascular dementia alone or in combination with Alzheimer's disease accounts for 20%-30% of all cases of dementia.

**Very late onset dementia** – any dementia beginning after 85 years old. Dementia among the oldest is often related to multiple neuropathologic changes or diagnoses.

**World Health Organization (WHO)** – the United Nations health agency responsible for directing and coordinating matters relating to and promoting international public health, including non-communicable chronic diseases and syndromes such as dementia.

## Foreword

Paola Barbarino, Chief Executive Officer, Alzheimer's Disease International

In my introduction to last year's World Alzheimer's report on diagnosis, I made it clear that we should not encourage people to have a diagnosis if post-diagnostic support is not available. You only need to read the early chapters of this report, in which people living with dementia and families from all over the world talk of their experience, to understand why.



*"Dementia has been traditionally viewed through a narrow biomedical lens [...] Relying solely on such framework [...] can result in stigmatisation and disregard the reality that people with dementia are whole people, capable of participating in meaningful social connections."*

We also explore it, as ever, from a variety of perspectives, be they gender, race, culture, socioeconomic status and so on. It never ceases to amaze me when, talking to interested people, they realise that they have been looking at dementia through the lens of their own cultural experience, and that there is a whole world out there for whom the experience is wholly different. Inequalities, unfortunately, are still rife.

Two quotes from this report contextualise this in a nutshell.

*"I was despondent, at the end of my rope, and to be perfectly honest, if you think that I did not consider suicide several times, you would be quite incorrect; then my husband would be someone else's problem, not mine!"* Linda Grossman, wife and caregiver, Canada (Chapter 3)

*"I was met with a lot of resistance and resentment from my siblings, none of whom had processed the reality of the diagnosis and the colossal changes that came with it. I abandoned my life and sacrificed my and my child's wellbeing to give full-time care to my mother while others continued with their lives as if nothing had happened."* Maikutlo Mabille, daughter and caregiver, Botswana (Chapter 3)

I first realised that doctors were not trained to deliver such diagnoses at a meeting in Slovenia many years ago, when a very articulate GP talked about her realisation that she had been wrecking families by offering a diagnosis without post-diagnosis support. Last year, we talked of doctors' angst when they have not been trained in conveying such an important piece of news. This report tackles the other side: *receiving* a diagnosis.

But this report is so much more than that. We do not limit ourselves to describing the issue with its related aura of negativity, we also try to present the entire gamut of ideas, solutions, alternatives, strategies, and tools currently available to care professionals to improve the life of families after a diagnosis. As Tamara Sussman puts it so well in her essay (Chapter 3):

For example, in the essay by Ishtar Govia et al. (Chapter 5) about the stark realities faced by families in Jamaica:

*"The option of placing family members into a care home is out of reach for many, as the average cost is over 90% of the typical household income. [...] For families in the lowest income bracket, abandoning their family member with dementia at a public hospital may seem to them the most affordable and manageable solution to long-term care."*

The report also invites the reader to look at post-diagnosis support through philosophically different viewpoints. One example is the fundamental difference between western and eastern attitudes to autonomy and collectivism – which, in the West, can lead to individuals going for their diagnosis alone and the family feeling excluded, whilst in the east entire families can be involved in the diagnostic experience whilst the person diagnosed can feel excluded (see Catherine Ferrier's essay on advance care planning for dementia in Chapter 7, a theme that recurs in multiple essays).

There are also huge practical pearls of wisdom, such as the enlightening essay by Matt del Vecchio (Chapter 8) on important considerations to bear in mind when choosing a care home. I am sure many people living with dementia and families will find this of great value.

But to really understand what this report is about, I advise you to read Kellyn Lee's essay (Chapter 9). I wish everyone would read these inspirational pages. I hear good and bad stories about care experiences, but reading this essay

makes it easy to understand that we all must try harder. Understanding the causes of confusion, agitation, and – in some cases – of aggression in people living with dementia is possible and can inspire solutions that ultimately bring great joy and fulfillment to care, and lessen the guilt that so many carers still feel.

This report deals with all stages of dementia, from early to late, and does not shy away from complex, touchy, and controversial topics – like the use of antipsychotic medication, living wills, euthanasia, and palliative care. We have tried as much as possible to be true to reality, and reality in the realm of dementia is a very complex set of factors indeed. But families and people living with dementia need to jostle with these realities every day, so that begs the question: why can't governments do the same and face the fact that dementia is not going away, is becoming a bigger and bigger issue, and we all need to do something about it?

I believe post-diagnosis support and care is the reason why so many governments are scared to implement national plans for dementia. It is perceived as too costly. This report should prove once and for all that post-diagnosis support is mightily implementable within our existing infrastructures and it does not have to cost the earth.

However, healthcare professionals, especially in primary care settings, and the general public need to KNOW that this information exists and where to find it. As the authors

of the report point out, education is key. But to paraphrase Nori Graham in her essay (Chapter 2), the information is out there, has been out there for ages, so why do people still struggle to find it?

ADI, our members, and Alzheimer's and dementia associations all over the world know that it is not enough to publish information once and expect change to happen instantaneously. Information needs to be pushed out repeatedly, made easy to find and digest, so that it can become knowledge and, eventually, wisdom. We are human beings and what make us different is that we can write and share so we can learn and improve constantly.

We at ADI will continue to identify best practices, raise awareness, and distribute this information, but we need more of you to do the right thing. We need more compassion and understanding, we need more commitment to do better. As you step out doing your job every day, each new person you meet is an opportunity to broaden our global advocacy.

Please join the movement – together we can do so much.

**Paola Barbarino**

CEO, Alzheimer's Disease International  
*London, September 2022*

## Executive summary

**A**s laid out in the *World Alzheimer Report 2021: Journey through the diagnosis of dementia*, a companion to this year's report, access to a diagnosis remains the exception rather than the norm for people living with dementia. Alzheimer's Disease International (ADI) estimates that 75% of people with dementia are not diagnosed globally, with that rate believed to rise as high as 90% in some lower- and middle-income countries. The number of people living with dementia – estimated to stand at 55 million in 2019 – is expected to rise to 139 million in 2050, according to the most recent World Health Organization (WHO) figures.

But diagnosis is only the first, albeit arduous, step on the journey. Integrated treatment, care, and support are the pillars of effective post-diagnosis models. Post-diagnosis support – an umbrella term encompassing the variety of official and informal services and information aimed at promoting the health, social, and psychological wellbeing of people with dementia and their carers after a diagnosis – is often a daunting field to navigate, particularly when the systems meant to provide such support are confusing, limited, or outright non-existent depending on where one lives.

This World Alzheimer Report 2022 is, to our knowledge, the most comprehensive exploration of post-diagnosis dementia support across the globe to date. ADI always knew that undertaking this endeavour would be challenging and multifaceted, but little did we know how eye-opening, rich, and instructive the content would be.

ADI worked closely with McGill University to compile this hefty report, composed of insightful expert essays. These essays are underpinned by a survey that weaves in the voices of 'real people' living with dementia, their carers, and care professionals, to bring further authenticity and to ground the report in reality.

This report tackles far-ranging issues of dementia care and support through 24 chapters divided into eight thematic sections: Understanding the significance of staging dementia (Chapter 1), the challenges and decisions occurring at each stage (Part II) and the specificities of different types of dementias (Part VI); delving into the impact of diagnosis on people living with dementia, their carers, relatives, and communities (Part I); addressing the symptoms and changes commonly associated with dementia (Part III), and the pharmacological and non-pharmacological interventions that can help people living with dementia and their carers (Parts IV and V); showcasing international and national perspectives on models of care (Part VII); and laying the groundwork for forward-thinking, principled approaches to dementia, necessary in order to move the needle forward (Part VIII).

The WHO's 2017 Global action plan on the public health response to dementia (which lays a framework for the organisation's 194 member states to improve the lives of people with dementia, their families, and communities by 2025 through seven action areas) is past its halfway point with less than three years remaining until its completion. Yet the targets set by the WHO are far from being reached, with dementia far too often falling by the wayside amid governments' myriad of considerations.

Let us be clear: we know dementia is a complex condition and as a global health priority, it is competing with a plethora of other urgent needs stemming from a pandemic that has wreaked havoc on global health and long-term care sectors and governments. But this report has only served to reinforce what ADI and many readers will already know – that we have to do more, and we have to do it now. People living with dementia and their families deserve better.

This is a substantial report that readers will undoubtedly need to dip in and out of over time. But in pouring over the content and data, key recurrent themes have surfaced that provide a clear guideline and framework for priorities in future.

The most repeated theme throughout the report is the importance of person-centred care. This phrase has become so commonplace in dementia care parlance that it risks becoming a cliché. But here we mean it in its strictest sense: that care must focus on the unique situation of each individual and build from there. Each person deserves care and support that meets their unique needs and provides access to the right information at the right time so they can make choices about the entire trajectory of their care. We see over and over again in the report that the best way to do this is through a care plan that describes the type of support an individual needs, how this support will be provided and by whom. A simple care plan can help map out a very complex journey.

An equally important theme is support for those who care for people living with dementia, whether they be family or friends. Providing carers with essential dementia education and helping them to develop a 'toolbox' of knowledge and practical tips to better understand and cope with the changes ahead is a subject of many expert essays. Similarly, there is recognition that carers, many of whom are women, need support in coping with the unique pressures that come with their evolving role.

The report also reveals the evolving role of clinicians as they support families throughout the entire dementia journey. Post-diagnosis care models explored in the report describe the importance of having one individual – a key worker or navigator – who can work alongside

a person living with dementia and their family and help them navigate complicated care pathways, linking them to the right help at the right time. Models described here show how this role can evolve over time, from being a community or social worker to a nurse to a more specialised palliative care practitioner. But it is clear that the role of clinicians needs to evolve as well, to facilitate their ongoing involvement and support throughout the post-diagnosis journey in care planning, treatment and monitoring. These models have shown promising outcomes and cost effectiveness.

These three groups – people living with dementia, carers, and health and long-term care professionals – form an important triadic care relationship that requires equilibrium to thrive. A robust post-diagnosis care model can

provide the solid framework to strengthen and enable this relationship to flourish, bringing better health outcomes that in the long run create a more stable, effective, and cost-efficient health and long-term care economy.

Finally, threaded across and within almost all essays is the importance and need for increased dementia education and training for all, but especially for health and long-term care professionals. The report is full of examples of good practice of life learning and practice development to ensure that they are enabled to build their competencies and update their practices.

## Recommendations

### National dementia plans need to become a policy priority

- Governments must urgently build robust models of post-diagnosis support that are tested, funded, monitored, and fine-tuned. Linking them to key action areas of WHO's Global action plan on dementia provides a framework for design – focusing on treatment, care, support, education, risk reduction and innovation. Government involvement in building these systems will ensure that improvements to post-diagnosis support models will be easier to implement.

### Person-centred care must become the norm

- People with dementia should have access to personalised care plans that enable them, along with their carers, to make informed choices, plan for the future, and participate in shared decision-making about the care they receive.

### Care should be culturally appropriate and gender inclusive

- Cognitive interventions should be developed in ways that are tailored to individual needs and circumstances – taking into consideration cultural, gender, sexual, ethnic, racial and health factors, life interests, and the wishes of care partners.

### Support for carers must be prioritised

- Governments must support health and long-term care systems to provide carers, many of whom are women, with the information, education, services, resources, and support they need to continue their caregiving role. This includes access to respite and employment protection for those combining work and caring roles. Caring is an important, if often undervalued, role that comes with high levels of stress and anxiety, and much more needs to be done to make sure that carers are able to carry their duties without sacrificing their financial, social, and mental wellbeing.

### Care needs to be coordinated and accessible

- Healthcare systems should develop a case management approach, in which an appropriately trained professional (key worker/navigator/nurse) can liaise and connect with multidisciplinary teams to help people living with dementia

and their carers navigate the often-complex post-diagnosis care pathway at each stage of the dementia journey. Evidence shows this has promise in terms of better outcomes and health-care costs.

### We must continue to challenge stigma and raise awareness – it remains a severe barrier

- National awareness campaigns must tackle stigma and lack of education on dementia, as this continues to be a barrier to accessing diagnosis and post-diagnosis support. Many countries still report a general lack of knowledge, awareness, and understanding among healthcare professionals, and governments must act to alleviate this.

### Education must be improved and expanded

- On a global level, there is an urgent need to improve and expand dementia education, training, and professional development for clinicians and other health and long-term care professionals in post-diagnostic management and support from both pharmacological and non-pharmacological standpoints. Life-long learning, starting early in schools, extended through to specialist courses in universities and medical schools, and continuing throughout health professionals' careers, can break stigma and encourage deeper understanding and expertise.

### Further trials of cost-effective and evidenced-based psychosocial interventions are needed

- Nonpharmacological interventions, such as Cognitive Stimulation Therapy (CST) and Cognitive Rehabilitation, should be further researched and implemented as possible cost-effective and impactful interventions globally.

### Risk reduction must be bolstered

- Governments are urged to promote population-based approaches, combined with education about individual dementia risk factors, to encourage public engagement in behavioural and lifestyle changes to reduce the risk of dementia. Risk reduction and rehabilitation are life-long strategies that include post-diagnosis stages.

## Survey methodology and analysis

When ADI and McGill began preparing this second volume of the World Alzheimer Report series on diagnosis and post-diagnosis support, we wanted to underpin the expert essays with the experiences and voices of 'real people' who are affected by dementia – those who are living with a diagnosis or are caring for someone who has one, be they friends, family members or professionals.

The surveys carried out for this report were never meant to be exhaustive. Rather, they were meant to provide a snapshot – to illustrate what some people are experiencing across the globe at a time when the number of people with dementia is on the rise, all while we still await disease-modifying treatments, and only 39 national dementia plans exist worldwide despite WHO targets aiming to have at least 149 by 2025.

We wanted to ground this World Alzheimer Report 2022 in this reality – to share a glimpse of the range of experiences, and to shine a light on why post-diagnosis support is so important, because access to it, or lack thereof, impacts people in profound ways.

### Methodology

Three surveys were carried out targeting specific groups concerning their journey after a diagnosis of dementia – informal carers, professional carers, and persons living with dementia. These surveys were conducted concurrently between May and July 2022 and accessible in seven languages (English, Chinese, Spanish, French, Portuguese, Japanese, and Arabic). ADI amplified the survey via its website, social media, mailing list, and through ADI member associations. We also provided QR codes at our 35<sup>th</sup> Global ADI Conference in June 2022 to facilitate participation. The quantitative and qualitative responses featured in this report were obtained from 1,669 informal carers in 68 countries, 893 professional carers in 69 countries, and 365 people with dementia from 41 countries. Analysis of the collected survey data was conducted using Python 3.8 [1] implemented in the Anaconda Software Distribution, version 4.10.3 [2]. The respondents were asked a series of single- and multiple-choice questions, as well as one open-ended question about their experience. Some of these answers are quoted throughout the report, as well as on page 32, to show the variety of experiences, points of view and feelings of people navigating the journey of dementia.

### Respondents

Of those who responded to the survey that targeted people living with dementia, 62% identified as female and 37% as male, with people identifying as non-binary and those preferring not to say making up a combined

1% (0.5% each). Respondents were on average 70 ± 12 years of age, with 28% coming from lower-income countries. Nearly half of those who responded (49%) indicated they were in the mid/moderate stages of dementia, with slightly fewer (39%) identifying as having early/mild stage dementia. Eight percent of respondents identified as having advanced dementia, while roughly 4% indicated they did not know their stage of illness. The respondents with dementia were almost evenly split between those completing the survey on their own (56%) and with the help of another person (44%).

The overwhelming majority of informal carers identified as female (82%), 17% as male, and 1% identifying as either non-binary or preferring not to say. The average age and standard deviation of these informal carers was 58 ± 12 years, while 32% of respondents came from a lower-income country. Overall, 40% of carers who responded to the survey indicated they cared for their loved one on a full-time basis, whereas 31% responded that they were part-time carers and not living with their loved one. Twenty-three percent of carers indicated they receive help in their caring role, and therefore considered themselves part-time carers.

Regarding the survey targeted at professional carers, 78% of respondents identified as female, 21% as male, 0.6% as non-binary and 0.4% preferring not to say. They were on average younger than informal caregivers, with a mean of 47 years of age and a standard deviation of 13 years. A similar geographical spread was present, with 33% of respondents coming from lower-income countries.

### Some key themes

To provide a framework and evidence base for the three surveys, McGill and ADI decided to ground the survey questions in key priorities listed within the post-diagnostic action areas of WHO's Global action plan on dementia [3]. Although we include various data throughout the report, here we indicate some themed responses.

#### Coordinated and integrated care

People living with dementia in both high- and lower-income countries indicated that they most often received the same types of information upon receiving a diagnosis. Across this survey group, 52% indicated that they were prescribed a dementia-specific medication (donepezil, rivastigmine, galantamine, memantine or similar). Thirty-four percent were advised to contact their local Alzheimer or dementia association (or other organisation), and 28% were advised on nutrition and exercise.

Like respondents with dementia, informal carers across both lower- and higher-income countries indicated that they received similar information at the time of diagnosis. Sixty-three percent indicated their loved one was prescribed a dementia-specific medication and 46% were advised to contact their local Alzheimer's or dementia association. In terms of the next most common type of information provided, this differed across lower- and higher-income countries, with 38% of those who responded from lower-income countries indicating they were given information on nutrition and exercise, whilst 38% of those from higher-income countries indicated they were provided with information booklets.

A surprising number of people living with dementia indicated they had not been offered post-diagnosis support beyond the initial information provided immediately after their diagnosis. In lower-income countries, 45% indicated they had not been offered support, while 55% reported they had. In higher-income countries, although 63% reported having been offered post-diagnosis support, 37% indicated they were offered nothing.

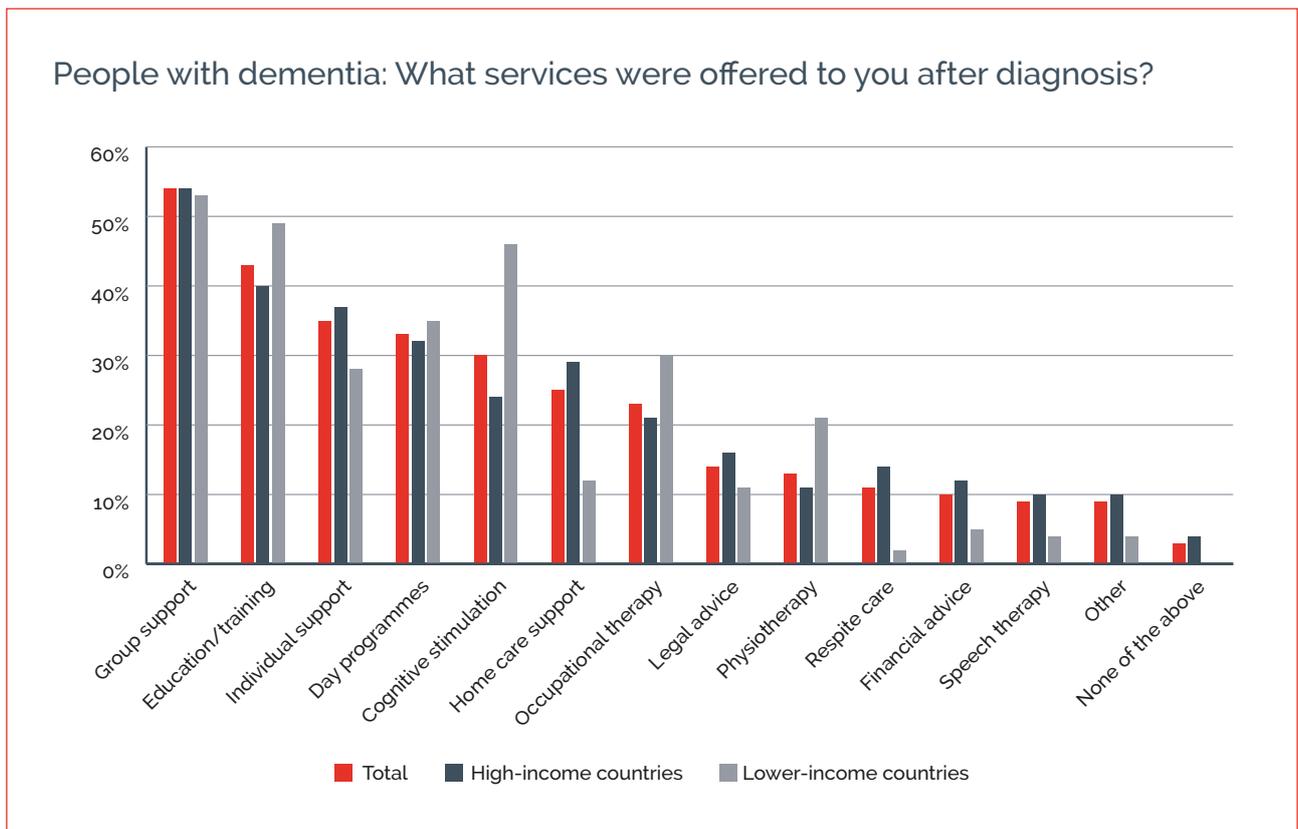
As the table below indicates, of the people living with dementia who had been offered support in both lower- and higher-income countries, the greater number of survey respondents reported being offered group support (29% and 34% respectively) and education/training (27% and 26% respectively). In lower-income countries, the third

most-offered type of support offered was cognitive stimulation therapy at 25%, whereas in higher-income countries it was individual support, at 23%.

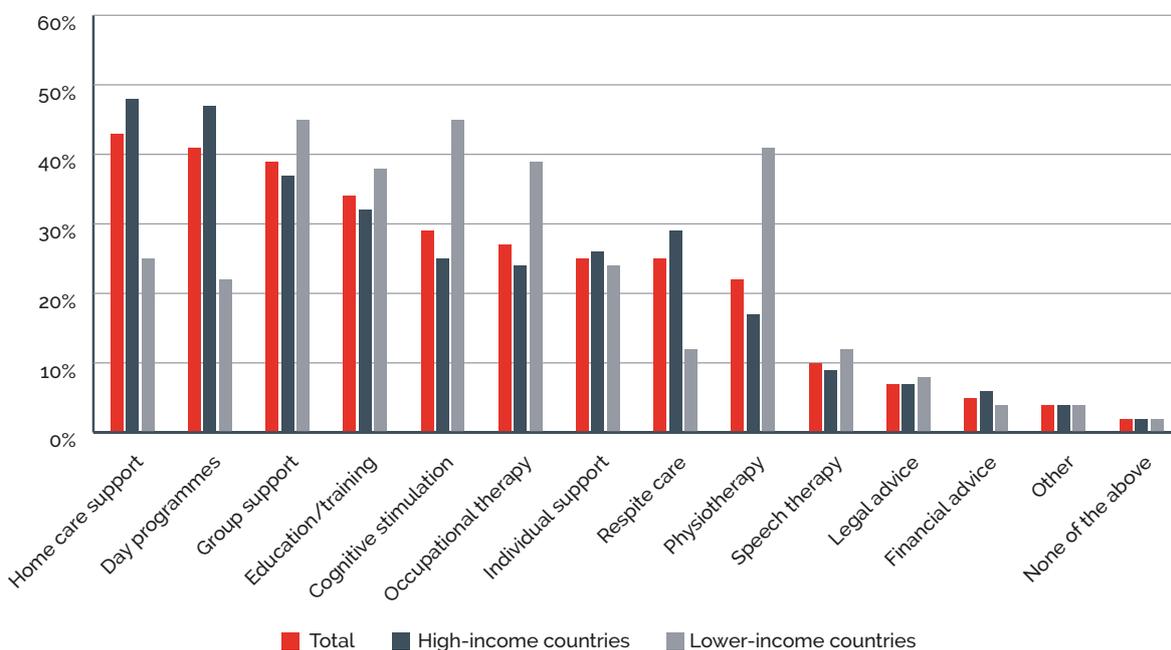
Sixty-two percent of informal carers from lower-income countries said that the person in their care had not been given access to post-diagnosis support, whereas 38% said that they had. In higher-income countries, the trend was reversed, with 64% saying they had been provided with post-diagnosis support and 36% indicating they had not.

Of the care that informal carers indicated was offered, in lower-income countries 45% respondents indicated the person they cared for was offered cognitive stimulation, while an equal percentage was offered group support. This was followed closely by physiotherapy at 41% and occupational therapy at 39%. In higher-income countries, 48% of respondents indicated they were offered home care support followed closely by access to day programmes at 47% and next by access to education/training at 38%.

Overall, 58% people living with dementia (64% of whom live in lower-income countries and 55% in higher-income countries) indicated they did not have access to a key worker or named professional who could advise and help them navigate dementia services after diagnosis. Interestingly, 58% of professional carers indicated that they are able to follow the same individual through their illness by case managing their care, whereas 35% said they were either required to discharge or unable to provide care to the same individual throughout their illness.



### Informal carers: Which services were offered to you and the person you care for at the time of diagnosis?



### Well trained healthcare and long-term care professionals

Seventy-nine percent of professional carers who responded to our survey indicated they had received specialist training to support people living with dementia, with 21% specifying they had not. This split was roughly the same in both lower- and higher-income countries. The top three areas of training were again aligned across lower- and higher-income countries, including Understanding dementia, Different types of dementia, and How dementia progresses/different stages of dementia and what to expect. It is worth noting that the results may be influenced by self-selection – health care professionals with a strong interest and/or training in dementia were more likely to have chosen to answer the survey.

### Person-centred, gender-sensitive and culturally appropriate care

Sixty-four percent of people living with dementia indicated they did not have a personalised care plan – a roadmap indicating how they would want to receive care throughout the progression of their condition– with 36% reporting they

had. This was pretty much consistent across lower- and higher-income countries. Of those who had a care plan, 47% of people living with dementia in lower-income countries said they had not been consulted or asked for their input or preferences when developing it, whereas 42% shared that they had been consulted. In higher-income countries, 71% of people living with dementia who had a care plan had been consulted on its development, while 12% had not. Overall, 15% said they did not know.

Seventy-seven percent of caregivers (82% in higher-income countries and 65% in lower-income countries) indicated they had been consulted and asked for input into their loved one's care plan, whereas 23% (18% in higher-income countries and 35% in lower-income countries) had not been consulted.

Similarly, 75% of professional (72% in higher-income countries and 82% in lower-income countries) indicated they regularly include either the carer and/or the person living with dementia in the development of the care plan. Twenty-one percent (23% in higher-income countries and 16% in lower-income countries) reported that they sometimes consult the carer and/or the person living with dementia, whereas around 4% do not consult at all.

## Stress and anxiety

The persons living with dementia answered a question about how often they feel stressed or anxious about their diagnosis of dementia after disclosure: 46% of them said they felt stressed or anxious "some of the time", while another 34% said either "often" or "all of the time".

Informal carers who responded to our survey indicated that stress was a very common factor while trying to cope with their caring responsibilities: 54% of them said they felt stress either often or all of the time, 39% said they felt stress some of the time, while only 8% of informal carers said they rarely or never felt stress.

Stress was also a common factor with paid health and long-term care professionals who responded to the questionnaire. Almost half (49%) said they felt stressed or under pressure some of the time while 37% said they felt stressed often or all of the time. Over half (54%) responded that they felt pressure impacts their ability to work some of the time, while 25% said it impacted their work often (20%) or all of the time (4%). When asked if they were given adequate time with their patients, 59% paid professional carers said they had not at all adequate (22%), or somewhat adequate (37%) time with each patient. Only 25% of professional carers felt they had adequate time. Finally, almost half (47%)

of paid professionals who responded said they did not feel they were adequately financially compensated for the work they provide.

## Respite services

Only 4% of people living with dementia and 8% of carers reported having access to respite services. The majority of informal carers – 70% – responded "no" when asked whether they had been offered professional support for themselves. There was a notable gap in answers between respondents from lower- and higher-income countries, with only 22% of informal carers in lower-income countries saying they had been offered professional support, compared to 33% in higher-income countries.

## Accessible information and training for informal carers

When asked if dementia education and training was important, 94% of informal carers indicated it was extremely important or important. Overall, 77% of carers have taken part in education and/or training, with training on understanding dementia, communicating with someone living with dementia, and understanding behavioural and psychological symptoms of dementia being listed as the most beneficial.

## Data availability

Parts of the survey findings are represented in clearly defined charts, figures, and statements throughout the report. Commentary and discussion points were provided by the McGill University team to frame and provide context

for the relevant figures in the respective chapters. The entire anonymised dataset can be made available as supplementary files through ADI upon request.

## References

1. Van Rossum G, Drake FL. Python 3 Reference Manual. Scotts Valley, CA: CreateSpace; 2009.
2. Anaconda Software Distribution. Anaconda Documentation. Anaconda Inc.; 2021. <https://docs.anaconda.com/>.
3. Global action plan on the public health response to dementia 2017–2025. Geneva: World Health Organization; 2017. Licence: CC BY-NC-SA 3.0 IGO.

We asked our survey respondents to describe their experience with dementia. Here are some of their answers, in their own words – the good, the bad, and everything in between.

"I've covered all my bases [...] but in the meantime, I suck the marrow out of life and live each God-given day to the max."

PERSON WITH DEMENTIA, 70  
Australia

"No day is alike; as a nurse, despite how difficult it can be for residents with dementia/Alzheimer's disease, it's worth fighting to give them the best care they deserve."

HEALTHCARE PROFESSIONAL, 58  
Bermuda

"It definitely opened our eyes to what really matters: human beings, your loved ones, the necessity to change our society, to show my kid what really matters."

INFORMAL CARER, 45  
Portugal

"Being independent and having dignity is very important to me, so I feel lucky and don't want too much doctor/hospital interference."

PERSON WITH DEMENTIA, 101  
United Kingdom

"My life is focused on taking care of my family member, which has not allowed me to develop my own life or fulfil my dreams."

INFORMAL CARER, 41  
Panama

"Early diagnosis and knowledge of the disease helps me to feel not too anxious, safe, calm, cared for, protected."

PERSON WITH DEMENTIA, 77  
El Salvador

"A sea of discovery that required plenty of time and effort to navigate."

INFORMAL CARER, 46  
Ireland

"Unfortunately, for more than 10 years, I have been the only doctor in the country who specialises in the treatment of dementia."

HEALTHCARE PROFESSIONAL, 49  
Kazakhstan

"It has been a humbling experience that has brought our family closer. It has given our family a different way to be attuned to our parent and with each other."

INFORMAL CARER, 34  
Malaysia

"It is very sad to live in mourning of oneself. Every forgetfulness, no matter how small, reminds me that dementia exists in me."

PERSON WITH DEMENTIA, 49  
Brazil

"I need to focus more on self-care to enable me to be able to give the best care possible."

INFORMAL CARER, 67  
South Africa

"Challenging but very rewarding - it's a privilege to work with people with dementia and their carers."

HEALTHCARE PROFESSIONAL, 66  
New Zealand

# Chapter 1

## Why and how do we stage dementia?

*Serge Gauthier, Pedro Rosa-Neto*

### Key points

- Staging is important in planning for the resources needed as dementia progresses.
- Some but not all people living with dementia inquire about their disease stage and their future. Anosognosia, lacking insight or awareness of their condition, is common.
- Most but not all carers inquire about disease stage and progression.
- Most clinicians are comfortable sharing information about the diagnosis of dementia, its current stage, and expected progression.
- Timely staging, as in preclinical or asymptomatic phases, offers hope for early treatments aimed at delaying progression to dementia.
- Staging can be useful in estimating the costs associated with post-diagnostic support.



## General background

### Early, middle, and late stages of dementia

When faced with a diagnosis of dementia, patients and family members invariably inquire about what to expect in the coming years. Information about clinical milestones in chronic progressive diseases is valuable to guide personal and family decisions. For physicians, information about clinical milestones informs prognosis and guides the choice of pharmacological and non-pharmacological interventions. Thus, more than an artificial descriptive construct, the concept of disease stages has practical relevance for patients, families, and healthcare professionals.

In dementia, there are the brain pathology staging and the clinical staging systems. While brain pathology staging informs about the magnitude of brain abnormalities associated with dementia, clinical staging informs about the functional decline expected over the years.

Carers usually want to know at what stage the person they accompany through their journey is, and what to expect in the future. We also expect that some people living with dementia would inquire about the stage of their condition in order to make advance planning about their care. Essays written by Roger Marple and Stéphanie Vallet explore these points in very poignant testimonies.

The perspective of David Knopman as a very experienced clinician is a natural complement to the discussion about clinical staging as a strategy to plan for optimal care.

Clinical needs change significantly between mild, moderate, and severe stages of dementia. The essay by Isabelle Gélinas clarifies functional changes over time, ranging from instrumental day-to-day tasks to basic care needs.

The concept of disease staging evolves as a function of scientific knowledge. For example, knowing that Alzheimer's disease starts in the brain many years before the onset of dementia, operational definitions of Alzheimer's disease incorporate both pre-dementia and dementia stages. The Global Deterioration Scale remains an influential clinical dementia seven-stage system (see subsequent section on the topic). The latest operational criteria of Alzheimer's disease proposed six clinical stages summarized in Figure 1. In the future, it is possible that disease stages will incorporate clinical tests.

For the purpose of this report, we decided to use a practical dementia staging system of "Early stage," "Middle stage," and "Late stage" in order to describe the changing needs over time for most people living with dementia (Chapters 7, 8, 9). Variations in the pattern of progression due to different causes of dementia do occur, as explained in Chapter 19, but we believe that the framework of early, middle, and late stages will resonate best for people interested in post-diagnostic care for dementia around the world.

### Stages of disease before dementia

The staging of primary degenerating conditions such as Alzheimer's disease has a long history: as summarized by Barry Reisberg in his essay, a framework of seven stages

called the Global Deterioration Scale was proposed in 1982 and has been used for many years, providing anchor points for clinicians and carers. A variation on this numerical staging has been proposed by the National Institute of Aging – Alzheimer Association (NIA-AA) working group in 2011<sup>[2,3]</sup>, using six stages (Figure 1). Of note, these staging systems encompass preclinical or asymptomatic and mild cognitive impairment stages, which precede dementia, the focus of our attention in this report.

Another perspective is biological: research involving hundreds of volunteers around the world has demonstrated that conditions leading to dementia have preclinical stages that can be studied and possibly lead to prevention

strategies to delay symptoms, or to disease-modifying therapies that slow clinical progression once symptoms are evident. The essay by Hampel et al. covers this strategy remarkably well. Risk reduction strategies are discussed in Chapter 24 and disease-modifying therapies in Chapter 18.

There are different costs associated with each stage of dementia, as explained by Anders Wimo. Delaying progression from one clinical stage to another can have cost savings, an important consideration for governments and agencies paying for care in planning long-term care. Equally important, delaying emergence and progression of symptoms will reduce burden.



Figure 1. NIA-AA numeric clinical staging, applicable to individuals in the Alzheimer's continuum. Top (1–3) illustrations represent pre-dementia, while the bottom (4–6) represent dementia stages. The pre-dementia stage has a silent phase of the disease, without symptoms (1). Subsequently, a second stage is characterised by the feeling of memory decline (2). The third pre-dementia stage is characterised by memory below normal levels, but forgetfulness imposes a mild impact on the person's daily living activities. This stage is called mild cognitive impairment. In the mild dementia stage (4), abnormal memory, attention, or language skills interfere with the person's ability to independently take care of their usual affairs (finances, shopping etc.). The moderate dementia stage (5) is characterised by the extensive functional impact on daily life with impairment in basic activities. The person is no longer independent and requires frequent assistance with daily life activities. Severe dementia (6) is characterised by complete dependency due to severe functional impact on daily life with impairment in basic activities, including self-care.

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## Expert essay

# Does the person with a diagnosis of dementia want to know about the disease stages?

Roger Marple

Alzheimer Society of Canada's advisory group, Canada

One thing I have learned over time about the general public's perceptions of dementia is that we all see this diagnosis from our own unique individual perspective. Most of us with a dementia diagnosis remember when a lot of friends, and sometimes even family members, went straight to a vision of the "end of life" phase when they first heard of our condition. But we know that those diagnosed with dementia in its early stage, or mild dementia, are functioning, contributing members of society. It's a complex subject and personal perceptions are complex. As I said, we see this from our own perspectives, which are mostly based on our unique lived experience. And it's pretty common for the general public to think "end of life" when they hear "dementia."

Although I feel the progression of the condition and its challenges is a reality, I still like to think I have plenty to contribute, challenges aside. To my point, my opinions stated here are from where I am with my form of dementia, from my own lived-experience perspective.

To the question: Does the person with a diagnosis of dementia want to know about the disease stages? From personal experience, I would give this a resounding yes. After all, these are our lives we are talking about. Without knowledge, how can we even fathom how to approach our situation? We all know there are different outcomes with forms of dementia; however, one thing I do know, in many cases (but not all) there is often a window of opportunity to live a meaningful life for some time to come, regardless of challenges we may experience. But we need to know, as best as possible, what to expect so we can adopt strategies to live a good life.

To this point, the million-dollar question for me is: How do I maximise my quality of life for my remaining days? We all have choices to make. We can approach this from a reactive point of view, fumbling our way through, or approach this proactively. Trust me when I say that being proactive and acquiring the necessary knowledge to understand where we are at, and will be, and most importantly, doing the necessary planning to achieve what we all want, is the best approach possible, but it can only happen if we have the knowledge

to live a meaningful life in the first place. We will need the tools to do so. And understanding the stages and what to expect is a vital step.

Since my diagnosis, I have leaned on our health services professionals to learn all I can about the stages of my condition. Often, I hang on every word they say, and their advice has improved my quality of life in so many ways. Another source I have reached out to is our Alzheimer's Society. I find they complement each other on approaches to credible information, strategies for living well, and advice.

I would like to discuss privilege for a minute. By privilege I mean that I live in a country where we have outstanding health services from coast to coast. I live in a country where I have the luxury of a doctor who specifically cares for my dementia needs and challenges. When I think of this, I am in a very wonderful position. Many others are not so fortunate. For this I am so grateful.

I try to think about the big picture as well from a world-wide perspective regarding dementia. I have had the privilege to work with Alzheimer's Disease International. It was an eye opener for me – not just seeing this from my perspective from my part of the world, but this wonderful opportunity to be versed on how things look from an international point of view.

I see countries where health services are not funded. Resources are far more limited with regard to dementia care. I have learned these challenges do not mean these countries are sitting on their hands but are advancing and doing their best to provide optimum dementia care.

A dear friend of mine, who is well versed in dementia care, once told me, "We do not have to reinvent the wheel regarding current, credible information in dementia care." Her point was that there already exist credible information and proven strategies out there for all to use. And that's exactly what I am seeing: many countries are taking advantage of this knowledge to expedite the care they give regardless of economic status or other challenges.

One of the very first comments I read after my diagnosis was, “Why should we do anything about dementia care? They are just going to die anyway.” I would like to point out that we all live with a terminal condition – it’s called life. In my world, it is all about the *quality* of life regardless of any challenges we live with.

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**“ We all live with a terminal condition – it’s called life. In my world, it is all about the *quality* of life regardless of any challenges we live with.**

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Comments like this left me in a dark place when I was first diagnosed – feeling lost in a sea of despair. But I had not yet researched the many ways our healthcare providers and

Alzheimer’s societies actively share information to improve the quality of life. If I had a nickel for every time my doctor pulled a rabbit out of her hat with practical advice and direction with my dementia, I would be a rich man.

The main point I would like to get across to those who are walking this journey is that people with a diagnosis, including the loved ones who support us, need to explore the great body of wonderful, practical information. Cherry pick and incorporate what works for you into your life. Listen carefully to your healthcare professional’s advice and direction, and act on it.

I am not going to sugar-coat living with a form of dementia. For me and others, it can be challenging as we feel the condition advancing, but then again, understanding the disease stages so we can prepare the best way we can to promote and live a good quality of life just makes good sense.

Before there is a cure, there is care; never forget that.

## Expert essay

# Does the care partner of a person recently diagnosed with dementia want to know the stages of the disease?

Stéphanie Vallet

Journalist and head of investigation unit, Devoir. Montreal, Canada

I'm a planner, the kind of person who makes to-do lists to stay in control and manage anxiety. I'm also a journalist, always trying to find answers and solutions to every problem that comes my way.

When my mom was diagnosed with Alzheimer's disease toward the end of the summer of 2015, I wanted to know it all. I started reading compulsively about the disease, asking millions of questions of the doctors and specialists I was introduced to during her evaluations. I made myself familiar with every stage of Alzheimer's disease, trying to plan what was going to be next to face it as best as I could. I wanted to make sure my mother was always going to be supported in the best way possible, every step of the way. For a while, this brought me some level of reassurance, although I was well aware that I had to brace for what was going to be a very long and emotional journey.

My mother was 65 when she was diagnosed. She sat there, peaceful, smiling, and beautiful, listening to the doctor as if he were speaking of another patient. I later tried to have a conversation with her about her diagnosis, trying to not only comfort her but also understand her fears and the rollercoaster of emotions she could have been going through. In the end, it turned out I was the one who needed most to be supported. She simply answered that the doctor didn't know what he was saying and that she wasn't sick. Seven years later, she is still in denial, even though she's reached stage 6, a stage that includes sub-steps that I stopped investigating in order to keep some faith and hold on to the little hope I had left.

Despite instinctively wanting to know every possible thing coming your way for each of the stages, you will never truly be prepared for what's coming next.

I'm fully aware that she has now reached an advanced stage of Alzheimer's disease. I remember reading a lot about this particular stage a few years back. Testimonies confirm that the most terrible times are still ahead. Despite all this, I keep hoping that she will be spared.

Knowing about the steps of the disease is one thing. Accepting and living through them is another story. Being a care partner of a person with dementia is a long journey, paved with pitfalls, hope, love, and deceptions. A long journey where every road, every curve, and every crossroad this disease forces us on, perhaps slowly at first and at rollercoaster speeds at times, is full of surprises and the unknown.

Some days are just a preview of what's coming next – like the days when she couldn't remember how to use the fork she was holding in her hand. It took a few months before she entirely forgot the purpose of this metal tool she now stares at for long minutes before setting it back on the table.

Alzheimer's disease also settles in stages in the minds and hearts for a care partner. No one warned me about that. These stages are like climbing a long staircase. We learn to tame the disease one crisis at a time. Even though you can imagine what will be next, you are not entirely prepared for it until you live it.

My dad lives with my mother and takes care of her, with the help of a professional carer for the last year and a half. They make a terrific duo whom I admire and try to support the best I can. Through the years, I saw the anger and the incomprehension gradually give away to acceptance and gentleness in the eyes of my father. His visceral reactions, asking her why she did this or that, turned into tender words filled with compassion.

At times, you're the one who forgets... forgets that your loved one is sick and that if she wants to keep her shoes on to sleep and argues with you because you want her to take them off, it's not because she chose to do so. For her, it doesn't make sense. Certain things simply no longer make sense to either one of us, in the same way that this disease doesn't make sense for the care partners who witness their loved one disappear and slowly fade away a little bit more every day.

I am still surprised to find comfort in one of the stages of the disease. What I could never have imagined being able to bear slowly becomes the new reality, and when we project ourselves for a few seconds toward the next stage, we try to hold on to the current one, hoping it will never end, hoping that the last one will never end.

As a care partner, the most important stage you will reach is the stage of letting go, admitting that you also need help, that someone can take better care of your loved one because you are running out of energy. This stage takes time to internalise.

Dementia is a disease that doctors sometimes manage to delay but cannot yet cure. Faced with this fatality, a feeling of defeat may settle in, and it is at times difficult to keep hope.

This said, does the care partner of a person recently diagnosed with dementia want to know the stages of the disease? Absolutely, especially at the moment of the diagnosis. Being well informed gave me a sense of control over Alzheimer's disease. I felt I could better plan for what was coming, such as hiring help to take good care of her when the time would come, finding new ways to make her feel safe and comfortable and dignified, despite her sometimes being aware of losing her abilities to do simple things independently.

What I can say with certainty, however, after several years of battling the disease by her side, is that all I wish for is to not think of what will be coming next. And so, for the last two years, I allowed myself to take it one day at the time. Because, in the end, even in knowing the stages, you still need a mountain of strength and resilience to adapt and power through every single day for yourself and your loved one.

In the end, knowing the stages also means you wish you could just forget them.



**Because, in the end, even in knowing the stages, you still need a mountain of strength and resilience to adapt and power through every single day for yourself and your loved one.**

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## Expert essay

# A clinical perspective on staging cognitive impairment

David Knopman

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“Where in the illness is she?” is a question invariably asked by family members after a diagnosis of mild cognitive impairment or dementia. Confronting the stage of illness is how people seek to understand the meaning of an acquired cognitive disorder. Knowledge of the stage of the illness provides the family and patient with a tool for setting expectations and judging current and short-term future needs.

Informal staging is ultimately grounded in more formal approaches. Staging schemes for cognitive disorders may range from one-dimensional scales[1] to multi-dimensional approaches[2]. See Rikkert et al[3]. for a review of several staging systems. A recent formulation of a one-dimensional scale intended for people specifically in the Alzheimer spectrum by an international workgroup[4], but easily extended to all-cause cognitive impairment, proposed a six-category scale of (1) not impaired, (2) subjective complaints only, (3) mild impairment with largely preserved daily functioning, and three stages (4, mild; 5, moderate; 6, severe) of cognitive impairment with impaired daily functioning of mild, moderate, or severe degree (dementia). At the lesser degrees of severity, there are no rigid rules for assigning a severity stage. That seems appropriate, in order to have the flexibility to assign severity according to the particular strengths and limitations of the person in question. The “severe” stage is widely defined by the loss of ability to carry out basic activities of daily living such as bathing, dressing, and personal hygiene without supervision or assistance.

Gathering the information to estimate a stage of illness does not require any technology; staging is a clinical judgment based on interactive discussions about the major symptoms and signs between the healthcare provider, the patient, and family informants. Time and expertise are the only two requirements. The major issues that go into a staging determination include short-term memory functioning, expressive and receptive language abilities, problem-solving and task completion abilities, geographic orientation abilities, ability to carry out activities such as driving safely, managing finances, preparing meals, managing one’s own medications, control of mood and behaviour, and proper conduct of interpersonal relationships. Depressed mood and the presence

of anxiety should be considered intrinsic to the staging of cognitive disorders, as both features have a powerful modulating effect on daily functioning.

There are other sources of complexity in staging that are not directly cognitive or behavioural in origin. Although motoric (for example, impaired gait and balance) or sensory impairments (for example, low vision or poor hearing) are not intrinsic parts of the definition of dementia, both may occur in older individuals concomitantly with cognitive impairment. And, to the extent that there are interactions between, say, impaired balance and the ability to dress oneself, it is entirely appropriate to consider an associated feature like poor balance into a determination of a dementia stage.

Family members have specific issues that a staging determination helps them with. They may wish confirmation about their own perceptions from the healthcare provider about their loved one’s level of functioning. They may also wish to understand the capabilities and limitations of the person with cognitive impairment and their care.

Sharing an estimate of stage of illness with the family of someone with cognitive impairment is critical and necessary if the healthcare provider determines that the person’s cognitive impairments have substantially interfered with their wellbeing in daily life. On the other hand, confronting a person with dementia who has impaired insight[5–7] with a statement about their disease stage may induce a dysfunctional emotional response that generates no appropriate compensatory behaviours or attitudes. In a person who lacks the mental capacity a) to recognise the nature of their own problems, b) to acknowledge their own limitations, and c) to grasp the consequences of those limitations, a frank discussion of stage of illness is not only unnecessary but counterproductive.

For healthcare providers, a judgment about degree of cognitive impairment and degree of functional impairment serves as a provisional estimate of stage. Such a cursory staging scheme may determine the appropriateness of a class of medication to be used or services to be recommended. Providing a stage estimate in a clinical note is a way to

communicate with other healthcare providers about the person living with cognitive impairment in order to coordinate care and services. Ultimately, however, a more detailed perspective on staging is almost always necessary.

The multiple dimensions of the symptoms that occur in cognitive impairment mean that a single staging label will often underestimate the heterogeneity of strengths and impairments of the person with cognitive impairment. Rather than considering the healthcare provider's stage estimate as final, it perhaps should be better seen as provisional and as the opening statement in a dialogue with the cognitively impaired person and their family about how well that estimate of stage captures the reality of daily life for them.

Discussing stage of illness is a useful way for a clinician to gain additional insight into the problems that the family and person living with cognitive impairment perceive as most important. While the clinician might feel that poor short-term memory is a major element of the person with dementia's severity, the patient's family might view behavioural issues such as irritability or paranoia as being much

more important in the quality of daily life. If a single stage label is a poor fit, the clinician should feel free to talk with the family about staging as multi-dimensional: with a "cognitive" stage and a "behavioural" stage and why the two diverge.

Agreement between family and healthcare providers on staging fosters a therapeutic partnership, as it indicates a shared sense of expectations. For example, agreement on a moderate severity of dementia in an individual can facilitate the decision to rescind driving privileges or to no longer have the person living alone. When the family and healthcare providers initially disagree on staging, resolution of the differences through further discussion will enhance collaboration moving forward.

Staging is a tool for use in the present and short-term, but stage of illness at any one point in time does not predict the tempo of progression. Stage of illness has very limited ability to predict what the patient will be like in two to three years. On the other hand, establishing a stage of illness can be very useful as an objective measure for judging change at future visits.

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## Expert essay

# A functional perspective on staging dementia

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Functional changes in the performance of daily living activities observed over the Alzheimer's disease continuum usually appear subtly and will decline slowly over several years. The trajectory of functional decline typically follows a continuous progressive course from cognitively normal aging to mild cognitive impairment to dementia. Evidence suggests that the changes observed in the performance of daily activities occurs in a characteristic hierarchical pattern[1]. Usually, decline in more complex activities such as work, demanding leisure, and instrumental activities of daily living (IADL), important for independent living and participation in community, will occur in the early stages of the disease while more basic self-care activities (BADL) such as dressing, bathing, and feeding will be affected in the later stages[2]. Individual variations are, however, noted in the sequence of activity loss and the time span over which this decline occurs for the different activities[3]. These functional changes are considered clinical milestones for the progression of Alzheimer's disease and are included in global assessment tools used for staging dementia severity based on clinical symptoms, such as the Clinical Dementia Rating (CDR) Scale[4] or the Global Deterioration Scale (GDS)[5]. Reisberg[6] also developed a functional staging tool based on the GDS, the Functional Assessment Staging (FAST).

The functional changes in activities of daily living observed over the course of Alzheimer's disease are strongly related to cognitive declines and particularly to executive functions[7]. These changes are also influenced by behaviour, motivation, social and physical environmental factors, and other comorbidities[8]. It was initially assumed that functional changes occur after the cognitive symptoms. However, more recent evidence indicates that changes in more complex activities of daily living may be present in preclinical stages of the disease prior to the appearance of clinical symptoms[9]. Subtle changes in functional abilities may also be observed when mild cognitive impairments are present[10]. The person will usually be able to perform activities of daily living independently but may experience difficulties in the performance of more complex activities requiring problem-solving and executive functions. These include preparing a meal, programming a phone, financial management (chequebook and bank-statement management, investment decisions), medication intake, use of transportation, or use of everyday technology. The observed difficulties may involve making

errors (for example, using the wrong ingredients while preparing a meal) or taking longer to complete the activity. Relying on compensatory strategies may be necessary to complete the activity. If the person is still working, meeting job demands may become more difficult, and some individuals may stop working if they are in highly demanding employments.

In the mild stages of the disease, the more complex activities of daily living, such as work, demanding hobbies, and IADL, become affected and the person may need sporadic assistance to remain independent. Notably, the ability to drive a motor vehicle may still be possible but needs to be monitored to detect any changes in fitness to drive. Other activities affected at this stage include managing finances (for example, remembering a PIN, doing financial transactions, or paying bills), performing domestic activities (for example, preparing meals safely, housekeeping, grocery shopping, and ensuring that food is not expired), or managing medication (for example, forgetting to take medication or taking it a second time). Changes in these activities have a significant impact on the person living with Alzheimer's disease and their relatives since they influence the ability to stay safely at home and participate in the community. Basic self-care activities are usually preserved at this stage. The impact of the disease on performance in activities of daily living is more important in the moderate stages. The person is no longer safe to drive. Mobility around the home becomes compromised because of increasing difficulties with orientation and with remembering one's address. In addition, there are more safety risks associated with decline in awareness of dangerous situations and the ability to react to emergencies. The basic self-care activities, which are more routine activities, become progressively affected. As a result, the person needs assistance and becomes dependent on others for these activities. Progressive decline is observed in bathing (preparing towel and soap, washing self completely), taking care of personal hygiene (brushing teeth or shaving in the right sequence), or in dressing (choosing appropriate clothing, dressing in the appropriate order). Eventually, the person may experience difficulties using the toilet and with feeding (for example, no longer remembering to feed oneself or how to use cutlery). In the severe stages of the disease, the person increasingly loses the ability to dress, bath, toilet, and feed, and is completely dependent for all activities of daily living.

Monitoring the trajectory of decline in functional abilities over the course of the disease, in addition to neurobiological or cognitive changes, is useful from a clinical perspective for several reasons. The changes in the ability to perform daily activities provide concrete and meaningful information to the person living with the disease and their family on the progression of the disease, since these impact directly on their daily life. The identification of day-to-day difficulties as well as preserved abilities allows healthcare providers to provide tailored interventions to the clients' needs and adjust the support needed (the right support at the right time). The person's ability to remain active and engaged for as long as possible in their activities can be facilitated. Knowledge about how the disease progression will affect the person's daily life over time can help families better prepare for what is to come and in decision-making with regards to financial or legal arrangements, or the need for placement in a long-term-care institution. This may help reduce the stress and burden experienced by families and in turn may improve their quality of life. Considering that impairments

in functional ability are related to higher care costs[11], understanding the progression of functional decline may assist managers and decision-makers in planning the human, physical, and financial resources needed to offer health-care services to support the person living with dementia and caregivers.

Considering that decline in complex activities of daily living may be a predictor of conversion to dementia[12], a functional evaluation should be part of the assessment battery used by clinical teams in the early stage of the disease to assist with the diagnosis process. These assessments, which usually include consultations with the person living with a dementia and family members, are easy to implement in clinical practice and more ecologically valid. The changes in the performance of daily activities should be monitored on an ongoing basis over the course of the disease. This would facilitate the implementation of timely interventions to support clients and their families in their daily life challenges over time.

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## Expert essay

# The Global Deterioration Scale (GDS)

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The Global Deterioration Scale (GDS) [1] was developed as a result of systematic observations of otherwise healthy people with what was originally termed “primary degenerative dementia.” [1] The GDS comprises seven stages.

**Stage 1: No Cognitive Decline:** Persons “appear normal” on a clinical evaluation, “have no complaints of memory deficit, and a clinical interview does not elicit evidence of memory deficit.” [1] We have recently demonstrated that a component of GDS stage 1 is a stage of psychometric cognitive decline [2] in which people begin to perform more poorly on psychometric tests.

**Stage 2: Subjective Cognitive Impairment:** People begin to complain of memory deficit. “Most frequently” people “complain of forgetting where familiar objects have been placed and of forgetting names they formerly knew well.” [1] “There is no objective evidence of memory deficit in the clinical interview and [there are] no objective deficits in employment or social situations. The individual displays appropriate concern about the symptoms.” [1] Our research has indicated that, in otherwise healthy people, the duration of this stage is approximately 15 years prior to the advent of the next stage[3].

**Stage 3: Mild Cognitive Impairment (MCI):** In which the earliest clinically manifest deficits appear. However, objective evidence of memory deficit is obtained only through an intensive interview. Concentration and calculation deficits may be evident on clinical testing. For example, a well-educated person may make more than two errors in endeavouring to mentally, without a paper or writing device, subtract sevens from 100, sequentially. Decreased facility in remembering the names of newly introduced people may also be evident on the clinical assessment. The person in this stage may read a passage in a book and retain relatively little material. In this MCI stage, decreased performance in demanding social and occupational activities is frequently noted by co-workers. Also, intimates may note the MCI person's difficulties in finding words and names. Furthermore, the MCI person may, seemingly for the first time, become lost when travelling to an unfamiliar location.

**Stage 4: Moderate Cognitive Decline (Mild Dementia):** In this stage, a clearly manifest deficit is apparent on a careful clinical interview. Concentration deficit is usually elicited if the person is required to subtract sevens serially from 100. The person may be unable to recall aspects of their personal history. Difficulties in management finances may become evident.

At this stage, people remain well oriented to their personal identity. They can distinguish familiar faces from strangers. Generally, the person with Mild Dementia can still travel independently to familiar locations. Numerous strategies for maintaining the independence of people with Mild Dementia are available. These include having the person wear an attractive gold- or silver-coloured bracelet with the person's name, address, telephone number, and the primary contact person's information.

Denial becomes an important defence mechanism at this stage. This is a mentally active process. The person recognises their deficits at some conscious level, but nevertheless denies the deficits. This denial is frequently accompanied by a decreased emotionality, technically termed a “flattening of affect,” and an emotional and physical withdrawal from challenging situations may be manifest.

**Stage 5: Moderately Severe Cognitive Decline (Moderate Dementia):** People at this stage can no longer independently survive in the community without assistance. Relevant aspects of the person's life may, or may not, be recalled. For example, the person may, or may not, recall their current address or telephone number. Similarly, the person may not recall their grandchildren's name(s). The person may, or may not, recall the name of the high school or college from which they graduated. The person at this stage is frequently somewhat disoriented as to the season, or the day of the week, or the date. At this stage, a well-educated person may make errors in endeavouring to consecutively subtract fours from 40, or twos from 20.

At this stage, people generally can recall their spouses' and children's names. The person at this stage frequently develops difficulties in their choice of clothing to wear in accordance with the weather conditions and the events of the day.

**Stage 6: Severe Cognitive Decline (Severe Dementia):** At this stage, cognitive decline accrues to the extent that the person with dementia may occasionally forget the name of their spouse, upon whom they are dependent for their survival. Persons are generally unaware of the year or the season. Often the person at this stage has difficulty counting backwards from 10 to one. Sometimes, the person with severe dementia may have difficulty counting forwards from one to 10. Some of the most dramatic changes which occur at this stage are in the performance of activities of daily living. In addition to not being able to select their clothing without assistance, early in this severe dementia stage, people

begin to have difficulties in putting on their clothing without assistance (stage 6a). At approximately the same time, or perhaps a bit later, the person with dementia develops difficulties in adjusting the shower temperature independently (stage 6b). Subsequently, as this stage progresses, people develop difficulties in negotiating the mechanics of toileting. Initially they may simply forget to flush the toilet (stage 6c). Later, as the sixth Alzheimer's disease stage progresses, people develop incontinence. Generally, urinary incontinence (stage 6d) precedes fecal incontinence (stage 6e).

Toward the end of this sixth stage of Alzheimer's disease, speech ability begins to break down in the person with Alzheimer's disease. Commonly, the person may develop verbigeration, an entity similar in some ways to stuttering. Irrespective of how speech ability breaks down, most intelligible speech is lost with the emergence of the seventh and final GDS stage.

**Table 1. Functional landmarks in normal human development and Alzheimer's disease\***

| Approximate age   |                  | Approximate duration in development                        | Acquired abilities | Lost abilities  | Alzheimer stage   | Approximate duration in AD                 | Developmental age of patient |                              |
|---|------------------|--|--------------------|---|---|--|------------------------------|------------------------------|
| Normal development (approximate total duration: 20 years) | Adolescence      | 13 – 19 yrs  | 7 yrs              | hold a job  | hold a job  | 3 (incipient)                              | 7 yrs                        | 19 – 13 yrs (adolescence)    |
|   | Late childhood   | 8 – 12 yrs   | 5 yrs              | handle simple finances  | handle simple finances  | 4 (mild)                                   | 2 yrs                        | 12 – 8 yrs (late childhood)  |
|   | Middle childhood | 5 – 7 yrs  | 2½ yrs             | select proper clothing  | select proper clothing  | 5 (moderate)                               | 1½ yrs                       | 7 – 5 yrs (middle childhood) |
|   | Early childhood  | 5 yrs<br>4 yrs<br>4 yrs<br>3 – 4½ yrs<br>2 – 3 yrs         | 4 yrs              | put on clothes unaided<br>shower unaided<br>toilet unaided<br>control urine<br>control bowels | put on clothes unaided<br>shower unaided<br>toilet unaided<br>control urine<br>control bowels | 6a (moderately severe)<br>b<br>c<br>d<br>e | 2½ yrs                       | 5 – 2 yrs (early childhood)  |
|   | Infancy          | 15 mo<br>1 yr<br>1 yr<br>6 – 10 mo<br>2 – 4 mo<br>1 – 3 mo | 1½ yrs             | speak 5 – 6 words<br>speak 1 word<br>walk<br>sit up<br>smile<br>hold up head                  | speak 5 – 6 words<br>speak 1 word<br>walk<br>sit up<br>smile<br>hold up head                  | 7a (severe)<br>b<br>c<br>d<br>e<br>f       | 7 yrs                        | 15 mo – birth (infancy)      |

Alzheimer's degeneration (approximate total duration: 20 years)

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As illustrated above, the order of functional losses in the course of Alzheimer's disease mirrors the order of acquisition of the same capacities in the course of normal human development. Interestingly, in sum, the temporal course of developmental functional acquisition is also mirrored by the temporal course of loss in the course of Alzheimer's disease.

**Stage 7: The Final Stage:** The GDS staging measure provides only limited information regarding the seventh stage, noting in part that over the course of this final stage all verbal abilities are lost and that the ability to ambulate

is also lost. More detailed information is available using an optimally concordant measure known as the FAST (Functional Assessment Staging)[4]; see Table 1.

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## Expert essay

# A biological perspective on staging: the evolving clinical-biological framework of Alzheimer's disease

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In 1984, the Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association (NINCDS-ADRDA) criteria were devised to systematise and structure the clinical approach to the Alzheimer's disease primary neurodegenerative dementia construct, characterised by a "progressive worsening of memory and other cognitive functions" [1,2].

Alongside this descriptive clinical syndromic phenotype-driven research approach, traditionally established neuropathological characteristics of the so-coined "dementia of the Alzheimer type" (DAT) and related putative pathophysiological hypotheses were conceptually amalgamated. Around that time, first observations emerged that regional brain atrophy co-localises with neocortical senile amyloid- $\beta$  plaque and widespread tau neurofibrillary tangle accumulation. Such findings were consistent between rare familial Alzheimer's disease cases (people with specific single-gene mutations) and sporadic individuals (around 98% of global cases)[3].

Large-scale epidemiological studies contributed to redefining the model behind the hypothetical natural disease history, that is, from the historical 1980's DAT concept to the early 1990's evidence-based sign and symptom-based model of amnesic Mild Cognitive Impairment (MCI) as a potential intermediate or "prodromal" clinical stage preceding the DAT construct[1,2].

After breakthrough technological advances in diagnostics, biomarkers, and genetics, clinical research in mid-late 1990s Alzheimer's disease neuroscience and neurology shifted to transformative conceptual adaptation. In particular, the integration and implementation of biology-guided clinical research and development as well as subsequently evolving medical practice originated from progress in basic sciences, systematic genomic/genetic studies, and biomarker-based

medicine. A biomarker is a "characteristic that is measured as an indicator of normal biological processes, pathogenic processes, or response to an exposure or intervention, including therapeutic interventions and that is not an assessment of how an individual feels, functions, or survives"[4].

Increasing multidisciplinary collaboration among healthcare providers, clinical researchers, and neuroscientists facilitated the development of molecular proxies for the in-vivo investigation of Alzheimer's disease pathological hallmarks. Moreover, scientists started to map out genetic risk factors for sporadic Alzheimer's. The consistent observation that patients with DAT and amnesic MCI individuals share common biomarker profiles – that is, pathological (and pathophysiological) changes and genetic variants/risk factors – ignited a progressive rejuvenation of the theoretical Alzheimer's disease model as a medical condition characterised by distinct underlying biological, and later in the disease process, associated clinical prodromes that are prequels of episodic memory impairment and progressive multi-domain cognitive decline, with consequent progressive reduction of activities of daily living with increasing dependency and overall functional autonomy[2].

In this vibrant scientific landscape, the 1984 diagnostic criteria were embedded and expanded into a broader clinical-biological research-oriented definition of Alzheimer's disease, providing a pathophysiological and topographical biomarker-based framework for Alzheimer's disease dementia and MCI (namely prodromal Alzheimer's or MCI due to Alzheimer's) stages. This conceptual and methodological evolution is currently facilitating more informative designs of biomarker-guided pharmacological trials targeting evidenced Alzheimer's-associated biochemical pathways and pathological hallmarks[2,5].

Moreover, the globally scaled effort to decipher the full range underlying Alzheimer's disease biology in space and time, coupled with the development of multi-modal biomarkers (bodily fluids and neuroimaging), led to studies in cognitively healthy older adults, thus consolidating the hypothesis that the natural Alzheimer's disease course is not dissimilar from other complex conditions, such as chronic, polygenic tumors or systemic endocrinological-immunological diseases (for example, diabetes and systemic lupus erythematosus) [3]. Albeit very different from a clinical and biological standpoint, all these chronic diseases share the high-level non-linear biological dynamic – complex pathophysiological changes that precede first symptoms often for decades [6]. Owing to a knowledge-driven transfertilisation of neuroscience, neurology, geriatric medicine, and psychiatry by established progressive intellectual paradigms in more advanced medical fields, such as oncology and immunology, the ongoing theoretical transformation increasingly achieves broader acceptance of a full Alzheimer's disease biological-clinical continuum model. A temporal staging dimension was reconstructed, with asymptomatic pre-clinical, followed by subtle, prodromal symptomatic, and finally late syndromic dementia stages that are constituted by the progressive biological and pathophysiological nature of Alzheimer's that begins to emerge, hidden to the neurologist's eye decades in the past [6]. In parallel, translational pharmacological study results, coupled with poor outcomes of clinical trials investigating putative disease-modifying compounds, indicated that intervening early in the Alzheimer's pre-clinical/prodromal disease course (when tissues and systems are not irreversibly damaged and brain homeostasis can still be preserved) is a pivotal research direction [6,7].

To operationalise the new era of expanded knowledge of the spectrum of neurodegenerative diseases including Alzheimer's, biological characterisation and staging, the current evidence-based, biomarker-guided hypothetical model of biological staging has been proposed and established by the "AT(N)" classification system – "A" stands for brain amyloid- $\beta$  overaccumulation, "T" indicates tau-composed neurofibrillary tangles, and "(N)" represents the progressive neuronal injury and cellular loss. This classification scheme is agnostic to the hypothesised temporal ordering of Alzheimer's disease pathophysiological dynamics; that is, amyloid- $\beta$  overaccumulation defines the presence of the Alzheimer's biological continuum and precedes the spreading of tau pathology that comes upstream to neural stress and cell loss (namely neurodegeneration). Since the AT(N) classification system is unbiased from the clinical syndromic label, it does not require any disease labels, and it shall not be considered a merely diagnostic tool; rather, it is a descriptive approach facilitating the categorisation of multi-domain biomarker findings [5]. Each score is represented in an "A $\pm$ /T $\pm$ /(N) $\pm$ " combination; thus, eight different

profiles can be generated, assisting manifold clinical and pharmacological challenges, such as risk stratification in cognitively healthy individuals, prognosis in MCI individuals, trials enrolment, target engagement, and theragnostic evaluation [5]. Currently approved biomarkers of Alzheimer's disease pathophysiology, reflecting in the AT(N) classification system, are represented by analytes measured in the cerebrospinal fluid (CSF) and/or imaging patterns obtained from molecular imaging [positron emission tomography, PET] scans. Although these tools allow the accurate in-vivo assessment of Alzheimer's disease biology, they are little suitable for pre-clinical individuals (invasiveness issue for CSF) or large-scale screening (time and cost-demanding issue for PET) [5].

To circumvent such multi-dimensional hurdles, minimally invasive, widely accessible, and scalable blood-based tools are on the horizon for Alzheimer's disease and other neurodegenerative diseases that exhibit pre-clinical, prodromal, and clinical stages. Currently emerging discovery and development stage blood-based biomarkers are expected to soon supply a primary care-scaled, cost-effective, and multi-tiered approach with a 90% negative predictive value, regardless of the positive predictive value [4]. A screening modality is urgently needed to implement good clinical practice for pathophysiology targeting biomarker-guided Alzheimer's disease-modifying therapies – as soon as they will be widely used. An effective screening campaign, inspired by evidence generation in oncology, will facilitate the accommodation of the increasingly enormous demand for prevention or treatment of Alzheimer's disease by high-to-medium risk asymptomatic or pauci-symptomatic individuals [4]. The exploitation of the blood matrix will help build up a pragmatic multi-stage diagnostic process, including an Alzheimer's disease liquid biopsy approach, and therefore structure and optimise the future clinical and biological management of Alzheimer's, ruling out who is unlikely to be biomarker "positive" if tested with second-level diagnostic and prognostic assessments (i.e., CSF analysis and PET imaging scans) [7].

In conclusion, the development of biomarkers charting the molecular pathophysiological dynamics in Alzheimer's disease, throughout its clinical and biological continuum, will supply actionable solutions for personalised and targeted treatments – in line with the mid-term medical strategy to deconstruct and transform the current fragmented neurology disease models into a holistic, integrative, and systems-based medicine framework. In the long run, early detection of incipient biological dynamics in asymptomatic subjects at genetic risk will promote brain resilience enhancement and disease prevention strategies [3,8], aligned with the precision medicine concept.

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Expert essay

# An economic perspective on staging dementia

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Dementia disorders have a huge impact on those affected and their families. The consequences of dementia also have a great economic impact worldwide. The World Health Organization (WHO) estimated the global societal cost of dementia in 2019 to be US\$1.3 trillion[1]. Furthermore, about 50% of this cost is due to the economic value of unpaid informal care.

There is also a very close relationship between costs of dementia and severity of dementia: the estimated annual cost per person with dementia is about US\$16,000 in mild dementia, about US\$27,000 in moderate dementia, and US\$36,000 in severe dementia (Figure 1)[1]. However, there are great differences between different income regions: In high-income countries, the annual costs are US\$30,000 in mild dementia, US\$52,000 in moderate dementia, and US\$66,000 in severe dementia, while for low- and middle-income countries it is US\$7,400 in mild dementia, US\$10,000 in moderate dementia, and US\$15,600 in severe dementia[1].

A key issue in health economics is to focus not only on costs. The viewpoint is broader and in the field of dementia, there is a strong relationship between severity of dementia and measures of burden, not only in terms of amounts of informal care, but also in terms of stress, coping, morbidity, etc. Thus, cost-effectiveness studies on interventions with effects on severity stages, should also include assessments on family members and not only the effects on the person with dementia.

Nevertheless, burden in terms of hours of informal care is an important factor. The hourly inputs from family members and other informal carers increase by severity. In a European study from three countries (France, Germany, UK), the daily amount of informal care was 2.7–3.7 hours in mild dementia, 4.4–6.3 hours in moderate dementia, and 8.5–10.5 hours in severe dementia[2]. A similar pattern was found in another European study[3]. Such data are crucial when support programs to families are developed. There is also a close relationship between severity

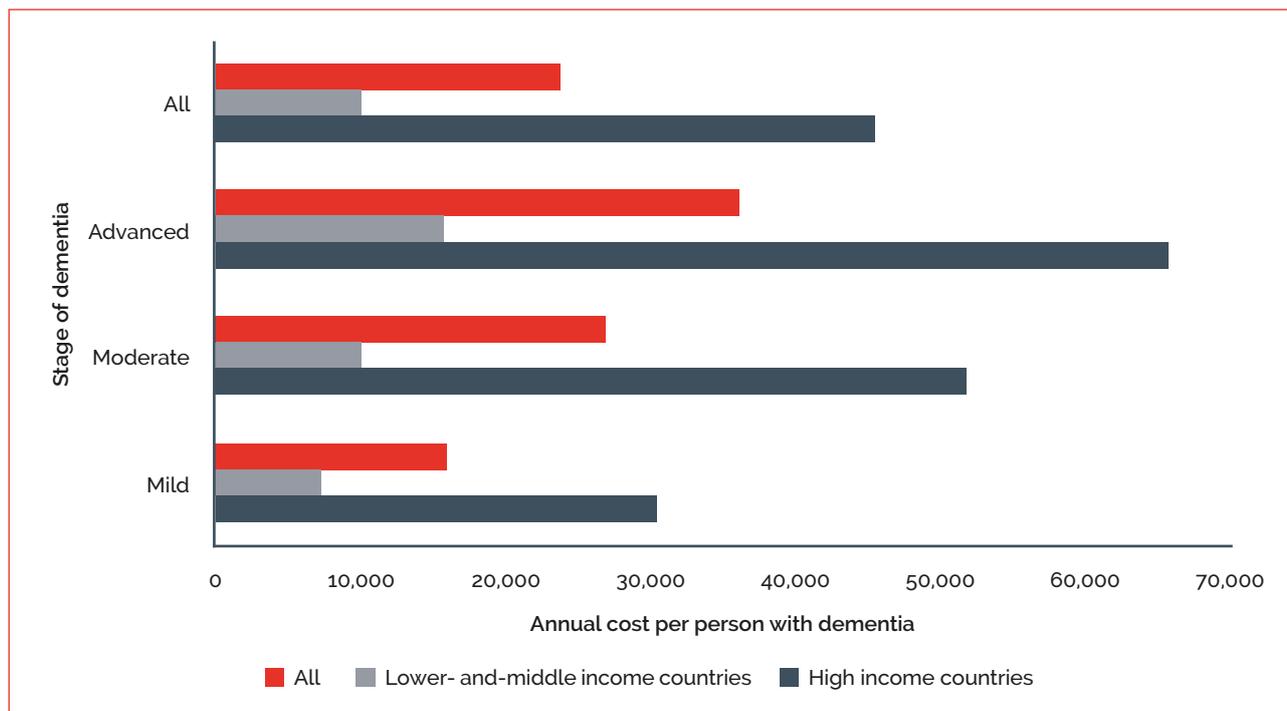


Figure 1. Annual costs per person with dementia by stage of dementia and World Bank income level. Source: Derived from Table 10b, chapter 3, Global societal cost of dementia in the WHO report "Global status report on the public health response to dementia."

of dementia and institutionalisation, although with some variations among countries. In a US study, about 40% of those with mild dementia, 62% of those with moderate, and 86% of those with severe dementia were institutionalised[4], in Germany 31%, 82%, and 87%[5], in Japan 43%, 67%, and 90%[6], and in Sweden 28%, 82%, and 91%[7]. Since institutional care is the heaviest cost driver from a budget impact viewpoint, data on the severity distribution of a dementia population are vital for any country's planning of long-term care resources. In 2019 WHO estimated that globally, there were 26.9 million people with mild dementia, 14.8 million with moderate dementia, and 13.4 million with severe dementia[1].

The impact on the severity distribution by an intervention (such as prevention and/or drug treatment) is crucial for its cost effectiveness. The duration of cognitive impairment from a lifetime viewpoint is long – usually decades, particularly if the pre-dementia stages (such as pre-clinical Alzheimer's disease, prodromal Alzheimer's disease, or mild cognitive impairment, MCI) are also taken into consideration. Because of the strong relationship between costs and level of cognitive impairment, any intervention that impacts the time in different severity stages has consequences for the costs in the long run; that is, prolonging time in early stages (such as MCI or mild dementia) is beneficial. One important question then is when to start treatment: very early, such as in pre-clinical stages (and then, for example, confirmed by Alzheimer's disease-specific biomarkers)? In prodromal stages such as in MCI or in established dementia? The potential target population for an intervention is of course much larger in pre-clinical stages[8], than in MCI or in established dementia, but on the other hand, the prevalence (such as percentages in different age-classes) from a population viewpoint is much lower. So there are trade-offs, and given the costs for case detection and the intervention costs, it is important to identify the optimal severity stage for case identification and initiation of

treatment. Starting in early stages may have small effects when the economic effects on the individual level are distributed to the initial target population, but since this target population is so big, the aggregated societal economic impact may nevertheless be great. Depending on how dementia care is financed and organised, this optimum may also vary among countries. The effects on mortality by an intervention are crucial. However, it must be clarified that cost-effectiveness is not the same as cost-savings. Even if an intervention might prolong the time in early stages, which is beneficial, another effect may be a prolonging survival versus no intervention. In the end, it may result in higher costs for the intervention. Thus, any cost-effectiveness study must also include effects on outcomes that are stage-related (such as positive effects on quality of life [9,10], longer time in early stages, longer time at home, etc). If the intervention is both cheaper and better than the comparison alternative, there is no problem. But if the intervention is better, but more expensive (a common result), the cost-effectiveness evaluation must be related to the societal willingness to pay for the intervention's results. Here the time-effects are problematic. There may be high costs for an intervention in early stages (if it is regarded as beneficial to start early with an intervention), but the costs of care also without the intervention are rather low in early stages. The beneficial effects in terms of a slower progression, such as lower institutionalisation risk and less need of other types of formal care and informal care may come later (years, decades), which highlights the need for a long time-horizon. Since trials are hardly run for decades, we need to rely on other types of studies, such as health economic modelling, registry studies, etc.

In conclusion, from a health economic viewpoint, staging of dementia is crucial for any cost-of-illness study and cost-effectiveness study. One challenge is that most data are derived from high-income countries, and we need much more studies from low- and middle-income countries.

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## Conclusion

We have consensus on the importance of staging dementia from the perspective of a person with lived experience, a carer, and experienced clinicians. That being said, the information shared with people living with dementia and their carers about current and future stages must be tailored to their needs at any given disease stage. Questions should be answered truthfully to the best of the clinician's knowledge about that individual, his/her social environment, and medical condition. A dialogue will be required over the course of many years.

In terms of stages of disease prior to dementia (asymptomatic with underlying silent pathology, mild cognitive impairment), research criteria have been proposed for Alzheimer's disease and are useful in designing randomised clinical trials aimed at delaying progression to dementia. Similar frameworks will be established for other causes of dementia as more and more biomarkers are validated for a given stage of disease. The potential economical savings of early diagnosis of conditions leading to dementia and planning for care are being studied.

# **Part I**

## Impact of diagnosis

# Chapter 2

## Impact of the diagnosis on people living with dementia

*Serge Gauthier, Claire Webster*

### Key points

- Post-diagnostic anxiety and depression are common in dementia but can be managed efficiently through many non-pharmacological approaches.
- Although most people living with dementia prefer to be accompanied by a family member or a friend at the time of disclosure of diagnosis, they have the right to be on their own.
- Accessing good support services, as well as having a sense of purpose after diagnosis, helps living to the best of one's abilities.



## General background

In the World Alzheimer Report 2021, a full chapter was dedicated to disclosure of the diagnosis of dementia (Chapter 15, pp 175–185), primarily from a clinician's perspective. Most clinicians who completed the survey felt at ease in disclosing the diagnosis and answering questions about it, however quite a few indicated that they talk only to family members.

As part of this year's World Alzheimer Report, 365 persons living with dementia answered a question about how often they feel stressed or anxious about their diagnosis of dementia after disclosure: 46% of them said they felt stressed or anxious "some of the time", while another 34% said either "often" or "all of the time".

The persons living with dementia who answered our survey also expressed their thoughts on their experience. Among the most frequent grievances were a lack of education or knowledge about dementia, as well as not being guided to any support services by their clinicians or other healthcare professionals. Many of them also expressed the fact that they had to be their own health advocates.

*"I am disappointed in both the lack of knowledge of dementia and ongoing support provided by the medical profession. I am self-directed with a background of working in health, so*

*am better equipped than so many others receiving a diagnosis. However, the whole process of diagnosis and ongoing care and support could have been made much more manageable if I hadn't had to find out everything and organise therapy and support for myself."*

*"Initially when diagnosed, I felt as if I had received the death sentence. No resources were offered to me. Now, I focus on what is significant in my life, what brings me joy, and spending as much time as possible with friends and family. It's been a long and valuable process. Life is good and I have quality of life."*

*"It's a roller coaster – other people's stigma reactions make it even harder. Keeping someone supported after a diagnosis the first year matters."*

The words most frequently used to describe the emotions felt by the persons living with dementia included: Enlightening, frightening, loss, challenging, roller coaster, uncertainty, unsettling, stormy, confusing, frustrating, difficult, daunting, anxious, long, and one day at a time.

*"Like a ride on a sailing boat through a storm – sometimes smooth water changing to very stormy, rough, scary sea that will make my dementia more difficult to accept."*

Having a sense of hope and purpose in life, being educated about the condition, receiving support services from the moment of diagnosis, participating in peer group sessions, as well as being met with patience and love from family members and friends were the most frequently mentioned cornerstones for persons who are managing to live their life to the fullest despite having dementia.

*"The best part of Alzheimer's is learning to live for today. Enjoying every moment and taking a hard look at what really matters. Fortunately, I found a peer-to-peer group with younger onset people like myself after a few years into diagnosis. This saved me, if not I may have sunk into depression or farther along with my Alzheimer's already."*

*"It took me a while to accept my diagnosis, but when I was finally able to stop ruminating on 'Why me?' and to focus instead on 'What's next?', life looked brighter. By focusing on my joys and blessings rather than on my losses and challenges, I was able to begin a new chapter and put my time and energies into helping others to do the same – to finding joy in this dementia journey."*

*"A challenging and fascinating journey from despair to a lifestyle with a great bunch of similarly affected friends focussed on enjoying life in general to the best of our ability and gaining satisfaction from helping each other along the way."*

*"Life doesn't end at diagnosis unless you let it."*

This chapter includes three essays written by resilient people living with dementia (Helen Rochford-Brennan, Keith Oliver, Emily Tan Tan Ong), who describe the importance of disclosure of the diagnosis to make informed decisions about their life, the need to be properly educated about their condition, and to have a person-centred care plan, as well as being spoken to in easy to understand "non-medical" language. With adequate post-diagnostic care, they are living to the best of their abilities and are helping many other people by sharing their personal experience. These essays were only lightly edited for clarity in order to preserve their voices.

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**“** Life doesn't end at diagnosis unless you let it. **”**

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As Helen Rochford-Brennan writes, "Disclosure has given me a happiness I did not realise was possible. It helped me to think about the future by planning ahead e.g. get a power of attorney, discuss any possible treatments and care I may require, participate in clinical trials and update my living will. It is especially important when giving this information that the language be understandable and not fully medical."

A common factor that was also highlighted throughout their testimonials is the importance of having a sense of hope and purpose in life – whether it be through volunteer or advocacy work, supportive family and friend relationships, leisure or recreational activities, etc. Keith Oliver outlines in his essay his "roles as an Alzheimer's Society Ambassador and Kent & Medway NHS & Social Care Partnership Trust Dementia Envoy, plus the resilience I derive from creative activities such as poetry and painting". "Alongside this, supportive friendships are crucial for my wellbeing. All this works just as well as the galantamine and memantine that are also in my survival kit," he adds.

This chapter also includes three experienced clinicians, a psychologist (Lisa Koski) and two old age psychiatrists (Johannes Pantel and Nori Graham), who share their experience in dealing with post-diagnostic anxiety and depressive symptoms using predominantly non-pharmacological approaches. According to Lisa Koski, "Symptoms of anxiety are reported in 70% of people living with Alzheimer's disease" and as it pertains to depression, Johannes Pantel writes, "40% of all people with dementia can be diagnosed with depression at some point during their illness".

In their essays, the clinicians offer practical advice about setting up as soon as possible after diagnosis a named person as point of contact as well as the benefits of peer-to-peer support groups and comprehensive practical and psychoeducation for carers.

Emily Tan Tan Ong's testimonial highlights the importance of these factors as she writes, "My anxiety post-diagnosis experience showed the lack of awareness and recognition of the psychosocial effect of dementia diagnosis on affected individuals. Prescription of SSRIs should not be the only solution to address the emotional distress experienced by people newly diagnosed with dementia. Psychosocial support must be made available upon a diagnosis of dementia and these interventions include grief counselling, dementia education for the person living with dementia, peer-to-peer support group, spiritual support, legal and financial advice support."

## Expert essay

# Responses to disclosure of the diagnosis of dementia

Helen Rochford-Brennan, Ireland

Receiving a diagnosis was a difficult and prolonged process for me. I was first told I may have Alzheimer's as I was experiencing memory difficulties. I continued with my life and subsequent meetings with clinicians until five years later I was finally diagnosed with Early Onset Alzheimer. Back then it was difficult to diagnose as I had a previous acquired brain injury. I had numerous tests including a lumbar puncture.



I received my disclosure by my clinician alone; that was my choice. I make my own decisions as is my right under the United Nations Convention on the Rights of People with disabilities (UNCPRD 2006). Yes, the journey home was long and emotional, but it was my choice. The clinician was very [clear] that there was no cure; all he could tell me was to get my affairs in order, which I already had done many years prior to this. There is no way I can describe the shock I felt the day I received my diagnosis.

The impact of disclosure is unimaginable, the sense of loss for a future I would never have, no plans, no strategies, no pathway of care. It was like a long black cloud that descended on my life and was there for good. Worst of all, there was no multidisciplinary team to help me through this grief.

Informing my family was very traumatic; my husband Sean and son Martin were devastated. We spoke about how in an undisclosed amount of time I may not remember them or recall all the memories we had banked along the way. I do not remember the conversation, but I can still feel the pain telling our only child, our son. There was, however, a degree of relief in getting the diagnosis, as I thought I was losing my mind. Also my husband and son were happy I had finally received a diagnosis as they too worried about my memory issues.

Disclosure is paramount; it's my basic right and my rights must be protected. Thankfully my rights were respected; by knowing something was wrong finally gave me an answer; it gave me an opportunity to come to terms with my deficit, it helped me to think about the future by planning ahead e.g., get a power of attorney, discuss any possible treatments and care I may require, participate in clinical trials and update my living will. I understand that in the event my capacity was diminished my husband or son could be informed primarily to ensure my safety.

The person receiving the disclosure should be given information about the illness the various forms of treatment and non-pharmacological intervention. It is especially important when giving this information that the language be understandable and not fully medical. I have the right to challenge if I do not understand the reasons and an appropriate [explanation] should be provided.

Looking back, I am happy to say the clinician gave me time to react and express my emotions. I have no doubt there was long silences as I was in shock. Its helps if we are not given too much information at once or too quickly as I needed time to overcome the shock of diagnosis. Luckily for me it was the same clinician for my follow-up appointments. When my husband joined me for the appointments the clinician always addressed me directly; my husband had expectations regarding the disclosure however the clinician allayed any fears he had. We both had lots of questions about the prognosis and consequences of daily life.

Whilst I was entitled to receive the diagnosis in private, for various reasons some people with dementia are accompanied by their significant other, supporters, or carers when they get their disclosure. This trusted person has an advantage as they are better able to understand how the person with dementia feels and remember what the person being diagnosed said.

I required someone to explain my options, to help me plan my new future – my Alzheimer's future – and to support me to tell my family (I still had to tell my eight siblings.) plus friends and my community which I was very involved in. Sharing my diagnosis mostly brought an incredibly positive

response; there were some people who had no idea how to engage with me. We all need family and friends whilst keeping autonomy is important.

Dementia is not a specific diagnosis: the type of dementia must be disclosed to the person receiving the disclosure. Currently the required diagnosis for Alzheimer's is a lumbar puncture (spinal tap) or for Lewy Body Dementia is a DaT Scan. The person must receive the appropriate tests to ensure a complete diagnosis.

Disclosure of the diagnosis of dementia is complicated; we can seek a second opinion, request further information and appropriate supports. We have the right to reject telling our family.

After a disclosure of dementia, we need appropriate support and information about how we stay involved and keep doing what we loved to do. We are the same people the day after diagnosis as we were the day before, except we have a confirmed memory impairment.

A new sense of hope is required; we can share our authentic voice to influence change in stigma, services, and policies. Involving people with dementia in policy making is crucial because that is how we ensure disclosure meets the needs of the newly diagnosed with a person-centred plan.

Disclosure also led me to research on diagnosis which gave me a voice for not just myself but all those with dementia. My involvement over the years has been a symbol of my acceptance of learning to live well with my diagnosis.

Yes, I had dreams, the positive disclosure assured me I could continue to contribute by having my voice heard. Having such a positive experience has allowed me to continue to develop my rose garden, and each new rose gives me great enjoyment and hope... hope that like the mystery of a new rose a cure for my illness will soon appear.

Disclosure has given me a happiness I did not realise was possible. It reminds me of this quote from author unknown:

*"Do not watch the petals fall from the rose with sadness; know that, like life, things sometimes must fade, before they can bloom again."*

I am glad my clinician told me Alzheimer's is not the end for me as I have been given the chance to bloom again through positive disclosure.

## Expert essay

# Living to the best of one's ability

Keith Oliver, United Kingdom

Supported by Lara Stenbridge, University of Kent student on placement with Kent & Medway NHS & Social Care Partnership Trust (KMPT)

Try as I will, the notion of “to the best of my ability” with dementia is both a target and a challenge which requires genuine person-centred support. In constructing this essay, I was fortunate to have the help of Lara, a placement student from the University of Kent, who this year is supporting my journey as I attempt to live with dementia to the best of my ability.



Although reticent to use the word journey, as it is an overused cliché, structured around David Denborough's “Journey of Life”[1], I am going to describe my dementia journey since being diagnosed 11 years ago aged 55.

When embarking on this journey, I did so with no knowledge, some fear, lots of misunderstandings, misapprehensions, and little or no support beyond that of my wife travelling by my side. Using my experience as a primary school headteacher/principal, I have always been a positive driven person, and I have continued with a sound moral compass, based on values, beliefs, and principles. I sought to read as much as I possibly could, using the maxim that information is power. Much that I read was not terribly positive, an exception being, *Dancing with Dementia* by Christine Bryden[2], which put a spring in my step as I moved forward. This has helped me when I reached crossroads along my journey and am unsure which way the pathway leads. Sometimes direction of travel is influenced by encroaching dark clouds or fog. I travel on foot as due to my dementia I no longer feel safe or stable on my much-loved bike and haven't driven for some time. My early diagnosis set me on this journey earlier than I wished but may well have helped me in developing my coping strategies to enable me to travel as safely as possible. Some days when the metaphoric sun shines, travelling is easier. There are days when I am able to engage with activities and people from whom I feel I take more than I

give. Other days the road seems to climb a steep gradient, and that one hilltop merely leads to another, tantalisingly stretching before me.

What would have helped me starting the journey would have been a clear map or a care plan to support my efforts to live to the best of one's ability. My care plan took me four years to achieve and 15 minutes to write in a consultation appointment with my consultant psychiatrist, who as it happens I taught for two years in primary school. I cared for him on his journey, now he cares for me on mine. Using the metaphor of milestones and favourite places on the journey, my care plan identifies what activities I find most helpful, amongst which are my roles as an Alzheimer's Society Ambassador and Kent & Medway NHS & Social Care Partnership Trust (KMPT) Dementia Envoy, plus the resilience I derive from creative activities such as poetry and painting. Alongside this, supportive friendships are crucial for my wellbeing. All this works just as well as the galantamine and memantine that are also in my survival kit.

Support from friends or professionals is not always available as I march on ahead, and I have difficult days when the only person alongside me is my wife, and she clearly sees the real impact dementia has upon me when words evade me; when I cannot judge the safe two-metre spacing; when what she has told me a number of times has failed to register; when the TV programme we both watched and enjoyed has left my memory so we cannot share a conversation about it; or when the roses which enhance our route are scented to her, but lack scent to me. But dementia will always fail to damage our love and what we seek to achieve together. A small number of onlookers, ignorant of what living with dementia is like for me, stand along the wayside, questioning my journey. There is no one-size-fits-all and there is no one typical person with dementia. Each person travelling with dementia is unique. Understanding this helps us all as we continue along the pathway.

Sometimes living positively requires recognising and responding to triggers which bring fog descending or the sun to shine; these can be seen as obstacles to overcome or rivers

and bridges to cross. I need to be busy but am vulnerable to overload. I need companionship but can be inclined to feel lonely and isolated. I need to lead but sometimes to follow.

I gain a lot from walking, and most when walking with someone so that we can talk as we walk. If walking alone, I do so with some travelling songs playing on my iPod. That then becomes my journeying companion.

One former placement student described me as “once a teacher always a teacher” and this means a lot to me because I hope that I can share some of my journey of life experiences with dementia to the benefit of others, either affected by dementia or professionals and students seeking to support us along this dementia journey. Some of the gifts that I hope to be able to share are around insight, empathy, compassion, and maybe even an element of wisdom. When this works, the survival kit is much easier to access.

I have never been a fan of tattoos, but if I had one on my journey, it would illustrate what Tom Kitwood described as the main psychological needs of people with dementia which he portrayed as a flower[3]; indeed I carry it with me every day in my diary.

Within the petals, he refers to identity, occupation, inclusion, attachment, comfort, and at the centre of the flower, love as it should be, at the centre of life. If I am to live, or if anyone with or without dementia is to live to the best of their abilities, this is by far more achievable if lived with these six elements in mind.



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## Expert essay

# Anxiety post-diagnosis – perspective of a person living with dementia

Emily Tan Tan Ong

Dementia Alliance International, Singapore

I might not remember much of what was said in the consultation room, but I can remember the numb, cold feelings I experienced in August 2017. My mind went blank, and not sure what I had just heard was that I might have young-onset Alzheimer's. At 50? My late mother-in-law and my childhood friend's mum developed Alzheimer's in their 70s. The diagnosis was too much to take in and process. I left the consultation room with my elder daughter beside me, feeling like I had just received a death sentence.



I did not have a good experience and impression of dementia because I watched helplessly how my late mother-in-law progressively declined. She was a conversationalist and an independent woman, but Alzheimer's turned her into someone who became completely dependent on others and lost her ability to speak and recognise family members.

A diagnosis like dementia – which is terminal and progressive, and one might potentially die from and has no cure – can be devastating. From personal experience and individuals that I have supported or come to know, it is common for both men and women to find themselves spiralling deep down into the valley of helplessness or hopelessness. While it is normal for newly diagnosed individuals to experience a range of emotional distress, anxiety is often the first symptom of diagnosis aftershock[1].

I spent the majority of my initial two years post-diagnostic phase in a state of a constant panic attack. Almost every other day, I would experience palpitations, cold sweat, uncontrolled clenching of the teeth and contractions of jaw muscles, hand tremors, nausea, the unexplained piercing pain in my head which was unlike the typical migraine or headache I experienced, and avoidance of going to crowded places, common signs and symptoms of anxiety[2]. The

neurologist prescribed Fluoxetine, a class of medications known as Selective Serotonin Reuptake Inhibitors (SSRIs), to help me cope with the anxiety symptoms that were beginning to interfere and affect my day-to-day living. Over the course of three years or so, my anxiety issue improved remarkably with Fluoxetine and I often found myself saying, "I am as cool as a cucumber." Unfortunately, I paid an expensive price because I was not able to have tears and cry even when I was in bereavement grief and lost a very caring stepbrother. In addition, I started to have more frequent headaches and severe migraine during those few years while on Fluoxetine.

My anxiety post-diagnosis experience showed the lack of awareness and recognition of the psychosocial effect of dementia diagnosis on affected individuals. There is mention of emotions like sadness, denial, and anger, but not anxiety, which is an irony itself because when it comes to cancer, there is a recognition of fear and anxiety experienced by persons with cancer. A diagnosis of dementia affects the physical functioning, social wellbeing, emotional and mental health, and spiritual parts of life. The emotional distress and psychological impact that come along with a dementia diagnosis must be recognised, accepted, and supported before any other interventions like cognitive stimulations and reminiscing therapy. Prescription of SSRIs should not be the only solution to address the emotional distress experienced by people newly diagnosed with dementia. Psychosocial support must be made available upon a diagnosis of dementia and these interventions include grief counselling, dementia education for the person living with dementia, peer-to-peer support group, spiritual support, legal and financial advice support.

In 2021, I asked to be taken off Fluoxetine because I believe that I am the expert of my dementia condition after living with it since 2017. I have learned to be in control of my life with dementia and I hardly experience the anxiety symptoms and have become a much more resilient person. With anxiety out of the way, my ability to function overall improved, have a more positive outlook on life despite setbacks and decline, and be more open and confident to address limitations caused by dementia.

How can psychosocial support help to reduce anxiety post-diagnosis?

## Peer-to-peer support

Before one can accept a diagnosis, the person needs to hear from others who have been living with dementia. It offers first-hand information on how life will be and what can be put in place to make life with dementia much more comfortable and manageable. These are real-life experiences sharing that provide the first spark of hope that may be “I too can do it just like they continue to have a life.” Peer-to-peer support can also serve as an informal group counselling where individuals feel safe to grieve and share.

I remember that sense of relief and comfort when for the first time since my diagnosis, I got the chance to meet others diagnosed with dementia through the Voices for Hope program provided by Dementia Singapore and the online peer-to-peer support group by Dementia Alliance International (DAI), the pioneer of online P2P service.

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## Dementia education

Even though the person diagnosed with dementia is the one who is living with progressive cognitive impairment and experiences activity limitations and participation restrictions, they are not included in dementia education programmes. People living with the condition need to know and understand as much as possible about dementia so that they can make sense of what is happening to them. With that understanding, it will also help them to be more open to accepting support and understand how to maintain their functioning and independence for as long as possible.

The post-diagnosis anxiety that I experienced has become the driving force in my advocacy work to improve the quality of life for people newly diagnosed with dementia and calls for psychosocial support included in the Post-Diagnostic Support. There is a need for research to investigate the association of post-diagnosis anxiety and health-related quality of life for people living with dementia.

## Expert essay

# Anxiety post diagnosis – a psychologist's perspective

Lisa Koski

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Symptoms of anxiety are often reported in people living with Alzheimer's disease. What exactly do we mean when we say someone is anxious or has anxiety? Anxiety is a feeling of worry, nervousness, or unease, typically about an upcoming event or something with an uncertain outcome. In fact, anxiety is a part of our normal human experience.

Anxious feelings go along with various physical changes in the body's physiology when faced with a threat. Those changes help us fight back against a dangerous adversary, to freeze in place so as to avoid being detected by the threatening force, or to flee from the situation entirely. So, anxiety serves the useful purpose of motivating us to behave in ways that will keep us safe in a dangerous situation.

When does anxiety become a problem? When it interferes with a person's ability to function in everyday life. In generalised anxiety disorder, a person feels in a state of constantly present anxiety. In panic attack disorder, the mere thought of a feared situation triggers responses from the mind and body that are as much a problem as the actual threat.

## Anxiety in Alzheimer's dementia

Anxiety disorders are seen in 14% of people living with dementia, although they are less common (5%) in the Alzheimer's type of dementia[1]. Anxiety is most common in the earliest stages of Alzheimer's, when cognitive impairment is mild and dementia is not yet obvious[2]. Indeed, sometimes anxiety is the earliest sign of an underlying problem that only later is diagnosed as Alzheimer's. Many people with Alzheimer's dementia lack insight into their difficulties, meaning they forget or are unaware of the extent of their memory problems. It is not surprising that people who retain awareness of their condition are more likely to report anxious symptoms than those without insight.

In later stages of dementia, anxiety may be expressed differently as effective communication becomes more difficult. Anxiety in later stages of dementia may be difficult to distinguish from other forms of mental distress such as depression or agitation, which tend to go along with increasing cognitive impairment.

## Causes of anxiety

What causes anxiety in people with Alzheimer's disease? Diverse explanations could, together or separately, account for increased anxiety[2]. Neuroimaging studies have shown direct links between anxiety and the amount and location of Alzheimer's pathology in the brain. Alzheimer's plaques and tangles disrupt brain areas that are essential for filtering out unimportant sensory information and for interpreting and controlling emotions. In other words, the disease affects parts of the brain important for regulating anxiety.

Psychological factors can also play a role in the development of anxiety. Alzheimer's disease is one of the most-feared medical diagnoses in the world. In this context, anxiety can be seen as a perfectly normal response to the fear that one's memory problems are caused by dementia. Anxiety can lead one to postpone seeking a diagnosis when Alzheimer's is suspected. Yet surprisingly, research shows us that anxiety may actually *decrease* once a diagnosis of dementia is made[3]. It seems that uncertainty and fear of the unknown helps to drive anxiety disorders, whereas knowledge is power: Knowing what it is that must be faced can be the first step towards planning for the future to ensure the best possible quality of life.

Cognitive impairment associated with Alzheimer's can also contribute to anxiety. For example, memory decline can make it more challenging to complete tasks that once seemed easy, such as getting to a doctor's appointment on time. The extra effort needed to achieve these goals creates added stress for the person living with Alzheimer's disease. In later stages of the disease, language problems can make it harder to communicate one's needs to carers. Frustration and anxiety rise as others struggle to understand how to support the person in need.

## Effects of anxiety

For some people living with Alzheimer's disease, anxiety might motivate positive lifestyle changes to improve quality of life. For others, anxiety can be so overwhelming that quality of life is affected. High levels of anxiety interfere with the ability to use remaining mental abilities effectively.

For example, we know that older adults with generalised anxiety disorder perform worse on tests of memory and problem-solving than those without anxiety. More importantly, test performance improves when anxiety declines. Therefore, it is important to recognise and treat anxiety when it begins to interfere with health and wellbeing[4].

## Treating anxiety

Anxiety symptoms can be treated by taking medications that work by shutting down the body's physiological response to a perceived threat. Yet these medications can have side effects on concentration, memory, and other thinking abilities. This makes them less than ideal for use by people who are already coping with cognitive challenges. They also add to the burden of medications that must be managed by the older person living with dementia.

Psychotherapy is an alternative approach that targets the mental as well as the physical components of the experience of anxiety. Psychotherapy is effective at treating anxiety disorders in older adults[5]. The most studied type of psychotherapy for anxiety is cognitive behaviour therapy (CBT). CBT works by acting on people's thoughts and beliefs about their symptoms, and by training people in relaxation techniques to minimise physical symptoms of anxiety. Mindfulness training and practice is another effective approach to treating anxiety without medication.

Some people might think that CBT cannot work for people living with dementia because psychotherapy involves learning and remembering new skills. On the contrary, research shows that psychotherapy is effective at treating anxiety in people who are living with mild to moderate dementia[6]. Some adaptations to standard CBT are recommended[7]. These could include shorter therapy sessions and the use of memory aids. For people with moderate dementia, the therapist should offer more support for understanding CBT concepts, and more repetition of concepts. Family carers can also be taught to support the person in applying and practising therapeutic skills in everyday life.

Cognitive training and rehabilitation interventions to improve cognitive function in people with dementia can also reduce symptoms of anxiety[8]. Emerging research shows that magnetic brain stimulation may also be effective at treating both anxiety symptoms and cognitive decline in people living with Alzheimer's disease[9].

Last but not least, anxiety can be lessened by making changes to the environment of the person living with dementia. This can include setting up systems of support that reduce the cognitive demands involved in everyday tasks, such as keeping appointments, preparing meals, and managing medication. It can also include psychoeducation for carers to develop their skills at recognising and responding effectively to symptoms of anxiety while meeting the needs of the person living with dementia.

## Cultural moderators of anxiety in dementia

Work to understand the role of cultural factors in determining a person's psychological response to a diagnosis of dementia is only just beginning. How we understand dementia is affected by cultural beliefs. While Alzheimer's is a disease of the brain, depending on the cultural context it may be viewed by some people as a curse, a punishment for past sins, or simply a normal part of ageing. The meaning we give to dementia is likely to have an important impact on anxiety. The systems of caregiving support vary enormously across different countries, cultures, and segments of society, in ways that are predicted to significantly affect the experience and expression of anxiety in people living with dementia.

## Conclusion

In summary, anxiety is a normal human emotion that can sometimes escalate to a point where it interferes with a person's cognitive functioning and mental wellbeing. Fortunately, a wide range of approaches exists for treating anxiety and these are known to be effective in people living with dementia. Recognising and treating anxiety symptoms when they arise will contribute to optimum cognitive functioning and mental wellbeing in people living with dementia.

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## Expert essay

# How do you detect depression in someone with dementia?

Johannes Pantel

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Depression is very common in the general population. About 16–20% of all people suffer from any form of depression at some point in their lives[1]. The main symptoms of the major form of depression, called major depression, are persistent depressed mood, joylessness (anhedonia), and lack of drive. If one talks to depressed people, they often express very negative views of themselves, their environment, and their future. This is also known as the cognitive triad of depression. Depressed individuals are constantly brooding over these negative perceptions. Ultimately, this is a distorted perception of reality. While most people have to cope with great burdens and problems at times, depressed people are no longer able to perceive the positive aspects in their lives and to draw hope from their own strength (the glass is always half empty and never half full).

The good news, however, is that depression can be treated very effectively and can often be cured if it is recognised as such. The established therapies include antidepressant drug treatment as well as psychosocial and psychotherapeutic support. In particular, psychological therapy is effective for people with dementia[2], who suffer from depression even more frequently than people in the general population: 40% of all people with dementia can be diagnosed with depression at some point during their illness. In fact, depressive syndromes can occur at any stage of dementia: In a meta-analysis of all available studies on this topic, the frequencies for the mild, moderate, and severe stages of dementia were given as 38%, 41%, and 37%, respectively[3].

Depression and depressive symptoms are usually subsumed under the so-called *behavioural and psychological symptoms of dementia* (BPSD). This is based on the idea that the neurodegenerative brain changes in dementia may have a direct impact on emotional perception and mood and thereby directly cause depression. On the other hand, the diagnosis of dementia and the associated fears, worries, and real losses represent an enormous psychological and emotional burden for those affected. The gradual loss of cognitive or intellectual abilities is perceived as a massive threat to personal integrity and identity, especially in the initial phase of the disease – but often also

during the following course. If the individual cannot cope with these stresses on its own, hopelessness and depression can develop as a psychological reaction.

In this respect, it can even be seen as a psychological protection that some people with dementia are in denial of their progressive deficits throughout all stages of their disease or are sometimes even unable to recognise them at all. This lack of self-awareness can partly be explained by pathological brain changes in dementia and is also referred to as *anosognosia*[4]. In my more than 20 years of experience as a clinical physician, I have met only a few patients who suffered from anosognosia for their cognitive deficits and were depressed at the same time. This suggests that anosognosia does in fact provide some protection against development of depression in dementia[5]. Conversely, those patients who are very conscious of their cognitive deficits (and this includes a large number of patients immediately after disclosure of diagnosis) need a lot of understanding and emotional support from their family and friends. This helps them to better bear the burden of the diagnosis and the illness, which can prevent development of depression.

In addition to the main symptoms of depression mentioned above (depressed mood, anhedonia, and lack of drive), depressive disorders can also be characterised by numerous secondary symptoms: these include appetite disorders and weight loss, sleep disorders in the form of insomnia or hypersomnia, or somatoform complaints. The latter are symptoms experienced somatically (such as dizziness, chronic pain, digestive problems, or fatigue), but for which no physical causes can be found. In older depressed people, these secondary symptoms stand sometimes even in the foreground and can mask the main symptoms. In these so-called *sub-syndromal forms of depression*, it is particularly important to always ask about the main symptoms in order not to make a misdiagnosis.

In people with dementia, the correct diagnosis can also be complicated by the fact that some symptoms of depression overlap with some symptoms of dementia: these include, for example, social withdrawal and the loss of previous interests as well as slowing down of thinking and poorer

concentration. *Apathy* is also a very common accompanying symptom of dementia and can be easily confused with lack of drive in depression. In contrast to lack of drive and social withdrawal in depression, however, apathy is rather accompanied by emotional indifference than by hopelessness and despair.

The reduced capacity for self-disclosure and self-reflection in some people with dementia can also stand in the way of diagnosing depression in people with dementia. Therefore, if depression is suspected, it makes sense to ask about the presence of the typical symptoms specifically and explicitly. The use of publicly available and easy-to-use paper-and-pencil instruments and scales is therefore recommended, especially in dementia. The *Geriatric Depression Scale (GDS)* [6], which was developed for depression in old age, can still provide valid results if the ability for self-reflection is retained in the early stages of dementia. However, as the dementia progresses, the validity of the GDS decreases. Recommended scales specifically designed to assess depression in dementia are the *Dementia Mood Assessment Scale (DMAS)* [7], which is based on both patient self-report and behavioural

observation, and the *Cornell Scale for Depression in Dementia (CSDD)* [8], which is predominantly based on behavioural observations, for example, by caregiving relatives or nursing staff. The questions and behavioural observations relate to the presence of sadness, anxiety, lack of interest, and depressive thought content. However, irritability, agitation, and motor activity as well as physical symptoms such as sleep and appetite disorders are also recorded. Filling out both scales takes about 20 minutes. Further, the *Apathy Evaluation Scale (AES)* [9] can be used to differentiate between depression and apathy.

Recognising depression provides important clues for further treatment and psychosocial intervention, especially since psychosocial support is also effective in people with dementia [10]. Left untreated, depression in people with dementia can not only severely reduce the quality of life, but also further aggravate the social withdrawal and loss of everyday skills caused by dementia. In the worst case, they can lead to suicidal thoughts and behaviour, which is why diagnosis and treatment of depression in dementia are always necessary.

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## Expert essay

# The need for accessible, positive, and stigma-free services: a personal view

Nori Graham

Honorary Vice President of Alzheimer's Disease International (ADI), United Kingdom

In 1981, I was appointed to a National Health Service consultant post at the Royal Free Hospital in north London. At the time I was appointed, there was no service in the area for older people with mental illness. Over the next decade, I was fortunate enough to be able to create a service that was indeed accessible, positive, and free of stigma. I had beds in the general hospital and a separate unit for longer-stay patients in a highly desirable location nearby. The service was multidisciplinary and community orientated. It was able to respond rapidly to demands made upon it by general practitioners and others who referred patients to it. About half the work related to patients living with dementia. No patient I saw was in any doubt after they had been seen how to contact me or any member of my multidisciplinary team. It gives people great confidence when they know whom to contact when difficulties arise.

In 1987, I was elected chairman of the Alzheimer's Society early in its history. Our main aim, our top priority, was to provide easily accessible information and encourage the development of support groups. From 1996, I was chairman of Alzheimer's Disease International. Early on, under my chairmanship, our World Alzheimer's Day Bulletin headline in 1999 was "Carers need greater support as dementia figures grow." In 2001, the headline was "Diagnosing Dementia: the first step to help" emphasising the importance of the provision of diagnosis and support services as priorities for new national organisations.

Currently I am adviser to Care UK, a large care home provider. These days, on an almost weekly basis I give interactive talks on understanding dementia to members of the general public in the neighbourhood of one of our care homes. Thus, I hear what carers of people with dementia, people with dementia themselves, and stakeholders feel is missing from the provision available to them. Their main complaint is their inability to access relevant information and obtain support. Every week I hear this complaint. It exists countrywide. There are, of course, numerous schemes that aim to fill this gap. The people who come to my sessions report that they have no idea how to get in touch with them. Why is it still so difficult in a high-income country to know where to go for information?

Of course, some progress has been made. In some high-income countries there is a multitude of support services, training courses; dementia has become big business. But the information and support services are fragmented. The concept of collaboration/teamwork and continuity is no longer in evidence. We do hear the voice of people living with dementia. These are mainly from relatively young and highly articulate people. The voice of the carers, often very elderly themselves, seem to be drowned out. Yet their needs are great, too. We urgently need to hear the voices of both people with dementia *and* their carers. It is through Alzheimer Associations that their voices can best be heard.

Good services can only be provided for people with dementia if they have first been assessed and given a diagnosis. But people need more than a diagnostic label. Services need tailoring to the individual needs of people with dementia and their carers. For this to happen, there needs to be information on their capacities, what they can and cannot do, and the social setting in which they are living. Obviously, people living alone need very different care from those with family members around them; people who cannot feed or dress themselves will require much greater help than those who are so far independent. A diagnosis alone is not enough.

There is an important and sometimes neglected connection between diagnosis and post-diagnostic services. Reluctance to refer for a diagnosis is often related to feelings that diagnosis is pointless. If there is nothing to offer people after they have been given a diagnosis, what is the point in assessing them? By contrast, if there are well-established, effective post-diagnostic services available, then clinicians carrying out assessments will have a real sense of purpose and will communicate their belief that there is much that can be done to help both people with dementia and their carers. Further, as my personal experience confirms, the stigma associated with a diagnosis of dementia that so often makes people hesitant to ask for a diagnosis will be much reduced if such services exist and are well-publicised.

My experience leads me to regard the following as key elements of good support services:

## Information

Following diagnosis, the person living with dementia and their family members should automatically be put in touch with the local or national Alzheimer association, whose contact details should be given to all carers and people with dementia immediately after diagnosis. It is not a simple matter to provide information to people with dementia and their carers about the condition. There is great variation in the severity of the condition, the speed of progression, and the presence of associated problems. But in most countries, Alzheimer associations can provide a wealth of information ranging from newsletters, fact sheets, and telephone inquiry lines to carer training courses.

## Psychological and personal support

Following the receipt of a diagnosis, both people with dementia and their carers will normally experience severe anxiety about what the future will bring. Often, they will be depressed and confused. There will be just too much uncertainty for them to bear. There are two main ways in which they can be given psychological support to reduce their emotional turmoil.

First, they need one point of contact, a named person who is available to them to listen to them, to answer their questions, and to help them to identify and negotiate what may be a multiplicity of services that may be available to meet different healthcare and social needs as well as to help them apply for financial benefits to which they may be entitled. I put this into practice myself years ago when I worked in the National Health Service.

Second, they need to be able to join a support group so that they can share experiences with others and learn from them. Time and again, people with dementia and their carers have reported how they find such support groups to be incredibly helpful.

## Regular medical reviews

The responsibility for the medical care of people with dementia and the support of the carers needs to lie with primary medical services. In many countries, these are the only health services available. Where secondary services exist, their use should be reserved for complex problems. Regular medical reviews of the person living with dementia together with their main carers, carried out by a member of the primary or, where it exists, the secondary care team, are essential. They should include reviews of the current symptoms and concerns and an assessment of the mental and physical state and the general social situation. Regular review of all medications is key for people living with dementia to ensure they are receiving as little medication as possible. These reviews also need to ensure that the person with dementia is kept as fit as possible, with daily walks and healthy eating habits, that eyes, ears, feet, and teeth are regularly checked, and that the person is engaged in social activities appropriately.

## Practical help

There are numerous practical issues for which people whose lives are touched by dementia need help. Often this is signposted by members of the primary healthcare team to social services. These may include, for example, ways of making necessary adaptations to the home, advice on diet, help with incontinence problems, help with housework, how to find professional carers if family members cannot cope, how to access financial benefits to which the family may be eligible, the availability of day care and residential care, and there are many others.

Let me repeat because clearly 40 years of pushing the same messages has not been enough: the availability of good joined-up services reduces or even removes stigma.

## Conclusion

While individual circumstances vary, the three essays written by the people living with dementia and the three health professionals for this chapter confirm that there is often a feeling of shock at the time of disclosure and the rest of the information is a blur; the presence of a family member greatly helps right from the start; anxiety post-diagnosis can last months but improves with psychotherapy and adapting work and home routines to the decline in memory and other cognitive symptoms. Getting papers in order such as advance medical directives, power of attorney, and legal will gives confidence that one will be safe and satisfaction that one's choices are on record.

Another dimension of the early management of post-diagnostic care can be added: hope for the future. Participation in observatory and/or therapeutic research may be a way to channel the desire to keep control of one's life. For many people living with dementia, their motivation is to help create new knowledge that will help their children and grandchildren even more than themselves.

As Nori Graham states in her essay, "There is an important and sometimes neglected connection between diagnosis and post-diagnostic services. Reluctance to refer for a diagnosis is often related to feelings that diagnosis is pointless. If there is nothing to offer people after they have been given a diagnosis, what is the point in assessing them? By contrast, if there are well-established, effective post-diagnostic services available, then clinicians carrying out assessments will have a real sense of purpose and will communicate their belief there is much that can be done to help both people with dementia and to their carers."

# Chapter 3

## Impact of the diagnosis on carers

*Claire Webster, Serge Gauthier*

### Key points

- Stigma associated with dementia is often based on traditional, cultural, or societal beliefs that can affect people's pursuit of a diagnosis or access to much needed support.
- Upon diagnosis, informal carers expect to be provided with information from the clinician about the disease, potential medications to manage symptoms, as well as resources that can provide support to both the person they are caring for as well as for themselves.
- Participation in decision-making by the person with dementia is viewed as essential to the delivery of individualised and person-centred dementia care with the concept of shared decision-making becoming a well-established model for clinical practice.
- Carers feel burdened when they are not provided with the information, resources, and time required to support their caregiving efforts. Understanding how the diagnosis will affect their own life and learning how to ask for help is of significant importance.
- Carers are more likely to have positive experiences when they can access a supportive network that recognises their contributions, internalise a sense of mastery of their role, and maintain a satisfying relational dynamic with their family member/friend.
- Anticipatory grief is common in dementia as it is the process of beginning to grieve as early as when a person and their family members receive a diagnosis and will likely last until that person dies.



## General background

In addition to the impact that a diagnosis of dementia has on the person, there needs to be an equal amount of attention placed on the roles and responsibilities of the carers and the challenges that they face while navigating the caregiving journey. There are a significant number of contributions throughout this chapter written by health-care professionals, as well as the heartfelt voices of carers with lived experience from around the world who have shared their personal stories, which all have a common thread – the education, information, guidance, and support that was not provided to them and how that lack of information had an impact not only on the quality of care of the person who was diagnosed, but on the wellbeing of themselves, the carers.

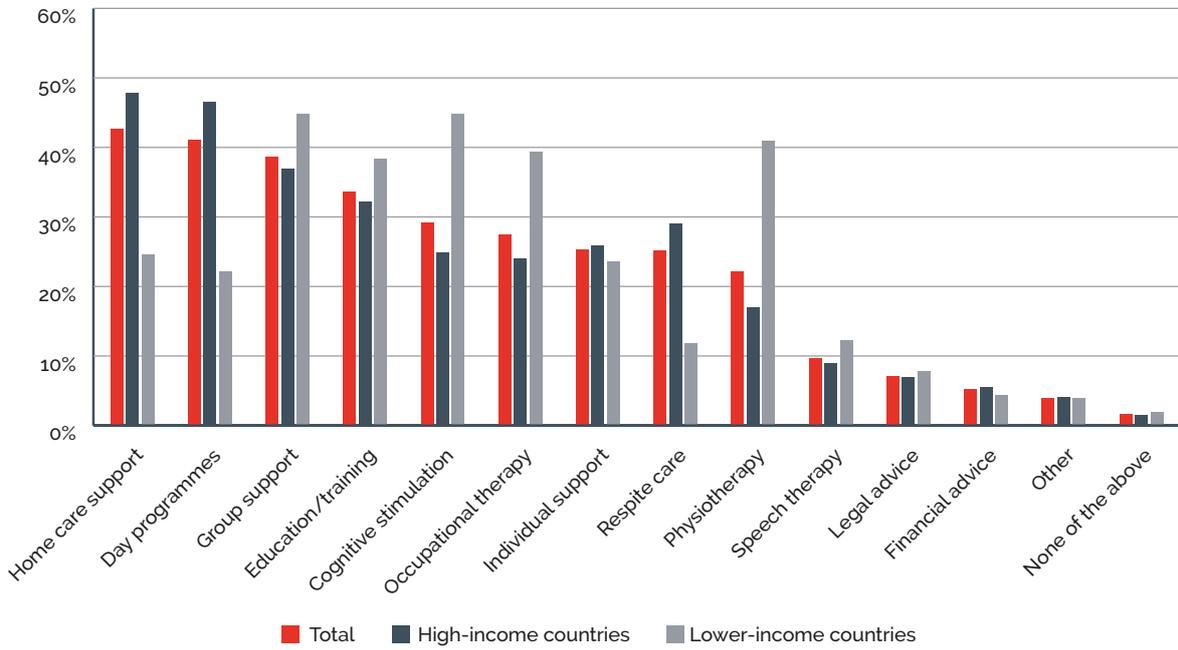
A quote from Carmel Geohegan's personal essay about caring for her late mother represents the common theme that is consistently expressed by carers from around the world. *"Life changes very dramatically when dementia comes to visit, so if you are not prepared or have no means of accessing information, supports, or medical advice, life becomes a vicious circle of staying upright on the hamster wheel. Life would have been so much easier if at the point of diagnosis we were given some information and support to help us understand the meaning of the diagnosis. What we need to do to support our loved ones live the best life possible."*

As compared to other diagnosed diseases, the family is rarely presented with a "prescription of care" or "road map" of how to navigate the challenges that are associated with managing and living with this disease. The medical community does not automatically educate individuals and refer them to the available support services as documented in the survey conducted this year among 1,669 carers: Our survey shows uneven referral to services between lower- and higher-income countries, as well as generalised low access to certain services that, as this report will explore in depth in coming chapters, can play a crucial role in making the dementia journey easier to travel.

When asked about how often they feel stress in trying to cope with their caring responsibilities, 54% of carers indicated they feel stressed "often" or "all the time," whereas only 8% said "rarely" or "never."

Another reality that many carers must face is that of stigma which may prevent the person from seeking a medical diagnosis as well as the carer reaching out for support. Elizabeth Mutunga discusses how dementia is viewed in certain cultural communities in Kenya, while Julien Rougerie outlines the challenges of caregiving faced by the LGBTQ+ community.

Informal carers: Which services were offered to you and the person you care for at the time of diagnosis?



The important topic of advanced care planning and shared decision making is also highlighted in this chapter by Dr Karen Harrison-Dening, who states, "Historically, people with dementia have been rendered powerless, with decisions being made 'for' them by professionals rather than 'by' them or 'with' them. Participation in decision-making is now viewed as essential to the delivery of individualised and person-centred dementia care with the concept of shared decision-making (SDM) becoming a well-established model for clinical practice."

Anticipatory grief is a big part of dementia that can affect the person who is diagnosed but has a more lingering impact on the carer as they witness the ever-evolving cognitive and physical changes that take place over the course of many years. As Corrie Sirota highlights in her essay, "the process of grieving typically begins as early as when a person and their family members receive a diagnosis and will likely last until that person dies."

Tamara Sussman and Jack Lawrence provide a more optimistic profile of care as they state, "While the journey of caring for a family member/friend with dementia is marked with unavoidable tribulations, it is also embedded with many rich positive experiences. Carers must adjust to the challenging behavioural changes linked to dementia, navigate complex healthcare systems, and simultaneously juggle life's other responsibilities – but they often feel a sense of purpose, pride, and gratification in fulfilling their important roles."

To quote Sussman and Lawrence, "Carers are more likely to have positive experiences when they can access a supportive network that recognises their contributions, internalise a sense of mastery of their role, and maintain a satisfying relational dynamic with their family member/friend."

## Expert essay

# A wife's journey of love, devotion, and care challenges

Linda Grossman

Former carer to her husband Dr S. William (Mickey) Grossman, Engagement of People with Lived Experience of Dementia (EPLD) advisory group member, Toronto, Canada.

My husband, Mickey, was a very bright, talented, professional, and considerate individual. There came a time in our lives, however, when our children kept telling me that “Dad is forgetting things, Dad is sometimes acting in a strange manner, Dad seems different.” I assured them that nothing was wrong, saying that it was a condition of getting older. I did not know how to respond when my family talked about what they felt were changes in his attitudes and behaviour. In my mind, it was impossible to think that there was a problem with Mickey’s cognitive abilities. We, as a couple, never discussed the “What-ifs,” because neither one of us had ever thought about dying any other way than old age. It just wasn’t an option! After giving their insinuations some serious thought, I decided to approach the matter in a different way. Looking back now, it was here that I made my first mistake. I told Mickey that I noticed that we were both forgetting things and that I felt we should seek some medical advice and perhaps receive a “pill” from a physician to help us with our weakness in memory. I, therefore, “tricked” him into getting an opinion re OUR memory problems, saying, WE should go to seek advice.

In 2006 we went to a large hospital in downtown Toronto where Mickey was seen by an expert in dementia. Mickey went through a series of tests and at the conclusion of the appointment, the physician blandly announced his diagnosis: he said that Mickey had mild cognitive impairment which most probably would end in Alzheimer’s disease. He continued to say, “Take steps to end your dental practice immediately. I am removing your right to drive today. See my social worker on your way out.” Of course, there was more to this conversation, but the wallop that was delivered to us in this diagnosis was completely unexpected and totally demoralizing. There was very little respect or communication, and a complete lack of compassion. His attitude indicated that there was nothing he could do about it. He had delivered his learned medical opinion, and, for this doctor, that was the end of the business.

Because Mickey’s right to drive had been removed, I drove home from the appointment; we didn’t say a word. Mickey was very, very angry and I was frustrated and annoyed at my ignorance. We could have talked about the diagnosis, but unfortunately, we did not!



Shortly after the diagnosis, Mickey retook his driver’s licence test, and without any difficulty, he had his driver’s licence reinstated. What was I to think? To me, obviously, the physician made a horrible mistake. There was no further discussion and we tried to carry on our lives as best we could in as normal a fashion as possible, even knowing the results of that medical appointment. Even then, although so many things were changing in our lives, we still did not take the opportunity to discuss the “What-ifs.”

I was totally unprepared when I was thrust into the role of carer. I had no education in the subject of dementia or being a carer. What were my options? Mickey and I never had discussed what either one of us would want in this situation. What would happen to the lives we had built together? What was the role of carer going to mean to me? Who would help us?

As the primary carer, I just took over. I started to worry and think about what may happen if I wanted to go out without him, so I began to ask a family member to come and be with Mickey or one of his friends to take him out to help occupy his time. This annoyed him to no end, and he reiterated on several occasions that he did not require a “Babysitter!” While I was able and while Mickey was able, I investigated programs that I thought he might enjoy, that

would keep him busy, allow him to be with others and at the same time, allow me some much-needed free time. Of course, there are programs available for people with Alzheimer's, but Mickey did not want to attend. How do you make someone participate if they are adamant that they do not want to go? *What do you say when your husband turns to you while you are encouraging him to join in the activities and says, "I never would have done this to you; why are you doing this to me?"*

**“ What do you say when your husband turns to you while you are encouraging him to join in the activities and says, “I never would have done this to you; why are you doing this to me?”**

I sought the advice and help of physicians, programs, and services, but nothing was helping. And so, my life completely changed. Because I was desperate for help, I spoke with my family physician who recommended me for a special carer's course at a hospital in my city. This was to allow me the opportunity to speak my mind and to learn how to deal with my problems. I joined and quickly realised I was not alone caring for someone with dementia – or trying anything to get help with it. That week after my lesson, Mickey and I were going out for dinner. I had placed all the clothes for him on the bed, that is, everything except his socks. While I was occupied on the other side of the room, I asked him to get a pair of black socks out of the sock drawer. He went to the drawer and within seconds he had pulled all the socks out of the drawer and dropped them on the floor. I saw this and immediately started to scream, “What are you doing? Who do you think is going to pick up those socks?” I was very angry, and I didn't stop to consider for one minute that he did not do this on purpose. I only thought, “Who do you think is going to clean up this mess?” He looked at me in bewilderment. Neither of us knew what was happening or how to deal with it. All my lessons from the well-intended course instructors went out the window. There is no “role playing” when something such as this occurs, no pretending, only reality and the situation becomes worse day by day. Who was there but me to clean up this mess?

Things became increasingly worse. My life as I knew it completely changed and I accepted the fact that I could not manage alone. The assistance that I received from the support workers provided by the health system was not working. I found in many cases that the services were inefficient and unreliable. I realised that people providing home care are not well paid; they take two or three jobs just to get by, and the work is demanding and often thankless: even though many of their clients are living with dementia, they, unfortunately,

are not properly educated or trained in the field of dementia or Alzheimer's. The home-care system was not set up to give us the help we needed.

I got desperate; my role as carer was overwhelming and when I realised I was running out of options, I borrowed money from the bank and hired a full-time carer. My family noticed, even with this new addition to our household, that things were getting worse, and they encouraged me to seek other means of support for Mickey. It was obvious to them that one of us was going to go. I was despondent, at the end of my rope, and to be perfectly honest, if you think that I did not consider suicide several times, you would be quite incorrect; then my husband would be someone else's problem, not mine! I was constantly frustrated and angry. I was beginning to forget what my husband was like before Alzheimer's struck; I forgot what I was like before. It was another life that I had shared with him! Family, support workers, and different care providers came and went, but I felt completely alone.

Eventually, I was forced to consider long-term-care facilities. How sad it was that I was considering this. I wished I had taken the opportunity to ask Mickey what he would have wanted. I investigated 12 long-term-care facilities and found something wrong with all of them. But, after continuous searching, at last, I found a place that I thought would properly care for my husband. Unfortunately, there were problems but by the time I realised this, it was too late; Mickey had been there for a while. What was I to do? I couldn't bring him home and I knew of no other better facility in which to place him. I was disillusioned and desperate even before COVID-19 hit, but for me, for Mickey, the pandemic was the end!

Because Mickey was a senior and because he was living with Alzheimer's, was it right for him to be placed on a shelf, by himself, waiting to die? Where was the respect and dignity that he gave so freely to others? Why was it acceptable that he remained in isolation in his room, nobody allowed in to be with him, nobody to oversee his real needs, nobody to offer him love, to show him that people cared about him? Did he think we had abandoned him? Wouldn't it be better if the government had a program to support, educate, provide guidance to carers like me in the art of taking care of people with dementia so that they could spend the balance of their lives in their own homes? Long-term care has and continues to be underfunded, ignored, and left unchecked for far too long.

Without doubt, I wanted the best for my husband, a man who always gave his best to those around him. I regret many moments in my journey as primary carer. I will forever regret that I could not find a way to keep him at home, with me, instead of sending him to long-term care. I wish I had been able to do better in caring for Mickey. **I wish there had been the supports in place to help us both.**

## Expert essay

# How can care partners empower a person living with dementia?

Maikutlo Palesa Mabile

Maikutlo Mabile Alzheimer's Foundation (MMAZ), Botswana

**D**ementia is one of the worst things that could happen to an individual as not only does it rob them of their abilities to continue living their lives on their terms and in control of their self-reliance, but it also slowly strips them of their normalcies, as it sends them into oblivion. None of us who are without the disease could ever comprehend the terrifying experience a person living with dementia is subjected to throughout the trajectory of the illness.

The effects of dementia also extend to people close to the one diagnosed with the disease, such as care partners and/or families. From the point of diagnosis, in most cases the experience has a detrimental psychological impact on these people, who often draw different coping mechanisms, some of which are destructive and may result in negative consequences for all involved. Such reactions are usually susceptible to the children of the person living with dementia or on some occasions, their spouse. Denial is usually the root cause of negative reactions, with a lack of knowledge and understanding of dementia as a close second. In my opinion, the aforementioned are prime causes that lead to stigma and taboo attached to dementia, especially in societies such as mine in Botswana. A person who suffers from dementia is quick to be categorised as a witch or mentally deranged, by virtue of them displaying unusual behaviour deemed inappropriate in society.

Case in point: It was only after my mother's diagnosis in 2017 when I learned Alzheimer's was genetic in my family. It was only after the fact when I also learned my grandmother had succumbed to the disease after a 10-year battle. My aunt, who is my mother's elder sister, had been diagnosed with the same disease a year earlier than my mother but all this information was kept a secret from the rest of the family, which I believe was a decision made in accordance with how Black communities generally deem mental illness. Even after my mother had been diagnosed, I still had no full understanding of what the disease is and what to expect from it. Without much information to empower us, there was a lot of fear of the unknown, but nothing could ever have prepared me and my siblings for the trauma that would befall us as our mother's Alzheimer's rapidly progressed.



We were never prepared to consider aspects of all the care our mother would need, mainly due to her late diagnosis. We could not consult her about what was best for her and who would be the primary carer and we could not find common ground either, which caused a major conflict in our family. As the sibling who was most proactive and “brave” in dealing with our mother's diagnosis and care, I was met with a lot of resistance and resentment from my siblings, none of whom had processed the reality of the diagnosis and the colossal changes that came with it. I abandoned my life and sacrificed my and my child's wellbeing to give full-time care to my mother while others continued with their lives as if nothing had happened, or at least at that time, that is the conclusion which made sense best to me. Which I now realise was how they were coping with the diagnosis.

A loss of contact with people who were a support structure at some point is also a reality most carers face because we give so much of ourselves and time to the person we give care to. We turn to neglect or rather fail to balance time with our circles of support, such as friends and relatives because we are so consumed by our responsibility. We

give up socialising and engaging in leisure activities which bring us joy and unintentionally isolate ourselves, denying ourselves the support we desperately need. Discussions are seldom had to dissect what transpires during these times, so even people we expect help from do not know our sentiments or how they could help us; this leaves us with abandonment issues and anger.

A negative financial impact is usually also expected from a point of diagnosis and often sacrifices are made along the way to cater to and care for one who suffers from dementia. A lot of carers in our society are usually informal, in a form of a family member or a friend. These people usually give up their lives and dreams to dedicate their lives to providing care to a person diagnosed with dementia, giving up their financial independence with no prospects of financial support either. Their needs do not cease to exist, despite their decision or predicament. In some instances, they are the breadwinners, or the diagnosed person is the breadwinner, and in this case, there is a serious jeopardy to their livelihood. Providing care in dementia is an expensive exercise since there is no end to the disease and the trajectory is usually elusive, meanwhile basic welfare needs and almost all aspects of care which require finances continue.



**Support from government has never been more imperative than now for people living with dementia and their care partners.**

Support from government has never been more imperative than now for people living with dementia and their care partners. The adoption of the Global Action Plan on the public health response to dementia could be the essential tool to ensure health ministries in governments include dementia and dementia care as a priority, at the same level as some non-communicable diseases, such as diabetes and hypertension. This especially applies to low- to middle-income countries such as Botswana, where there are no plans or support in place for people living with dementia and dementia care at present. With a policy in place, education of the public about dementia would be prioritised, and symptoms of the disease would be spotted early thus availing a chance at early diagnosis, which is instrumental in managing prevention of the disease or at least offers a fighting chance to delay progression of the disease.

## Expert essay

# The impact of care in the LGBTQ+ communities

Julien Rougerie

Program Manager at Fondation Émergence, with the help of Dr Shari Brotman, Canada

When a loved one is diagnosed with dementia, or any other debilitating illness, LGBTQ+ carers experience the same realities as any other care provider. However, being part of sexual and gender diversity can expose care partners to additional challenges.

Many people who identify as a Lesbian, Gay, Bisexual, Trans, Queer and/or other sexual or gender minority (LGBTQ+) individual have experienced many forms of rejection, exclusion, and discrimination over their life course. This is especially true for people who live in environments that are not LGBTQ+ friendly, such as may be the case for those who are part of communities that are rooted in conservative and/or traditional religious beliefs. This is also true for a majority of LGBTQ+ older adults who spent most of their lives in societies where sexual and gender diversity was considered a crime, a mental disease, or a sin, which was the case for most LGBTQ+ people prior to the development of political liberation movements, particularly in Western countries.

Even in Canada, one of the most progressive countries in terms of recognition for LGBTQ+ communities, rights and protections were granted to these communities only recently. As a result, older LGBTQ+ people had to hide their sexual orientation or gender identity over the course of their lives in order to avoid arrest and incarceration, unwanted medical or psychiatric treatments, and discrimination and rejection by their families, co-workers, or society in general. This life experience results in a fear of disclosing their sexual orientation or gender identity that may persist, even today, especially when they have to navigate through environments or services that aren't inclusive. In seniors' residences for example, most LGBTQ+ residents tend to stay or go back "in the closet" to avoid the risk of exposure to discriminatory acts, isolation, harassment, mistreatment, ridicule, etc.

According to several studies on LGBTQ+ seniors, victimization, prejudice, loneliness, and the constant stress of having to disclose or hide their sexual orientation or gender identity weakens their mental and physical health, in addition to affecting their ability to access health and social services[1].

When LGBTQ+ older adults fear discrimination in health and social care services, it constitutes an additional burden on themselves and their carers. Indeed, carers, in seeking to avoid exposing the care recipient to the risk of discrimination, may have to avoid external services, be present more often and for longer periods, and provide education to service providers to ensure an LGBTQ+ friendly environment and service provision and to negotiate conflicts and concerns as they arise. LGBTQ+ carers experience the need to protect the care recipient from the risk of discrimination, on the one hand, and, on the other hand, they are often more frequently solicited for support by older LGBTQ+ family and friends since older adults may be reluctant to use external services. In addition, LGBTQ+ carers may feel more isolated and invisible because they receive little help as carers from the health and social care system, and also because they care for LGBTQ+ seniors who tend to be isolated and invisible themselves. It is important to note that they also tend not to identify as unpaid carers or be recognized as such [2] within care partner support organizations.

Lack of identification and recognition as carers can be explained by the fact that most representations of unpaid carers continue to emphasize traditional family norms or structures (that is, heterosexual spouses and the adult children of these), whereas LGBTQ+ carers, in addition to assisting members of their families of origin, also assist their friends and partners. Many members of LGBTQ+ communities rely on their friends because they might have faced rejection from their families of origin or had to distance themselves from them because families were not fully accepting of their sexual orientation or gender identity. Also, some LGBTQ+ unpaid carers feel automatically designated by their family as carers because they tend to be single more often and without children and so are assumed to be available to care for parents, for example. When LGBTQ+ people are in a situation where they are not openly LGBTQ+, or when this aspect of their identity is not fully accepted, it may result in an increased risk of burnout or psychological distress in these types of situations[3].

Some LGBTQ+ community-based organizations address the realities and needs of LGBTQ+ older adults and their carers in Canada. Among them, Fondation Émergence, based in Montreal, is committed to providing education and policy advocacy through two specific programs:

- Aging Gayfully, dedicated to raising awareness about sexual and gender diversity in seniors' settings, as well as in health and social services. Through that program created in 2009, Fondation Émergence offers dedicated awareness material and training sessions to help professionals provide a more inclusive approach.

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- Chosen Family, a program dedicated to supporting and informing LGBTQ+ unpaid carers since 2019.

Fondation Émergence also participated in recent policy development in Quebec, especially on the new law about unpaid carers in which it has been made clearer, in the legal definition of unpaid carer, that the relationship between the carer and the recipient could be family related or not. The action plan following the law also mentioned Fondation Émergence as a partner to raise awareness and help professionals better include sexual and gender diversity in their practices. For more information: [fondationemergence.org](https://fondationemergence.org).

## Expert essay

# What information are carers looking for or should they be seeking?

Carmel Geoghegan

Dementia Ireland Empowering Communities, Ireland

As a former primary carer for a loved one who received a very late diagnosis for vascular dementia and frontotemporal dementia, I can give a lived experience of the wider impact the diagnosis has on not just the person but the care partner/supporter and the wider circle of contact.

The late diagnosis robbed my beautiful mother of many years of a productive, meaningful life, where she could have made decisions as to what her preferences were around her care when her dementia advanced. Unfortunately for my mum, once the diagnosis was received her wishes were ignored and she was basically a non-identity in her community; some of her family and the clinicians in general dismissed it as the ageing process. Instead of having more control over her life, she and I lived in a glass bowl for over three years with constant fears, anger, and confusion, feeling isolated and ignored.

The difficulties began with the question “*What was wrong with my mother?*” Over a number of years there had been a change in her personality, but nobody understood what was happening. Finally, a gerontologist referred her to a neurologist, and we got an answer after scans showed that vascular dementia and frontotemporal dementia were present in Mum’s brain. We left his office with that information but no explanations, referrals, or signposting to any supports that were available.

We were happy we now had a name for what was happening but no idea of what it meant or what would manifest each day going forward. In Ireland, in 2011 there were no dedicated clinics where it was possible to go for a diagnosis. If you were living outside the main urban areas, you were completely isolated and left to work out for yourself how life would progress. Homecare was impossible to secure; it was not person-centred [1] and had no dementia-specific care plan. It was a person care plan not a social care plan, which is what is required. Care/support should give the person with dementia the opportunity to maintain dignity and autonomy, not reduce their self-worth and confidence.



Life changes very dramatically when dementia comes to visit, so if you are not prepared or have no means of accessing information, supports, or medical advice, life becomes a vicious circle of staying upright on the hamster wheel. In our case, I was lucky to have been involved in various community projects and therefore self-education was not new to me. I began my own journey of exploring life with dementia and how best to deal with the day-to-day challenges.

Life would have been so much easier if at the point of diagnosis, we had been given some information and support to help us understand the meaning [2] of the diagnosis and what we need to do to support our loved ones to live the best life possible. The sensory challenges were something we struggled with, but now thanks to Agnes Houston[3], these have been highlighted. The sensory issues can affect all of the senses or just a few, depending on the individual, touch – taste – smell – hearing – sight.

Other issues that can manifest, such as delirium[4], are very disturbing both for the person with dementia and the carer/supporter, but if they have prior knowledge of the possibility of this occurring and how it is manageable, that will lessen anxiety. The importance of a good balanced nutritional diet [5] for the brain to nourish is vital, as documented in the report by ADI in 2014. This applies to both the person living with the diagnosis and the carer.

There was a stigma around the diagnosis of dementia in Ireland (Nolan et al., 2006) for many years and still is to some extent. Even after the awareness-building campaign that has been in place since the National Dementia Strategy 2014[6], for some there has been little to no change. For others, it must be stated that they are experiencing more fulfilled lives; the awareness programme is taking the mystery out of dementia and the public in general have a more educated understanding of the diagnosis. They also see that getting a diagnosis as early as possible leads to a better quality of life.

Becoming an advocate [7] for those less vocal is something that is a powerful way of getting involved and now putting the person with the diagnosis at the centre of Public Patient Involvement[8], and their voice has become so strong that they are now deciding on the research projects.

Building awareness is being achieved and has become very evident in recent years, but following on from the success of the awareness campaign, there has been an increase in the demand for services that are not available. This is where we must put the resources on the ground by supporting those who wish to remain independent, to remain in their place of work, their home, and their community. For those who need some extra support and may need full time care, they have to be given the choice of remaining in their own homes or, if they wish, to go to a residential care facility. A value-based healthcare [9] model is the most effective and one where the patient is centre stage.

The supporter/carer involvement in awareness campaigns can be a very powerful way of connecting with the outside world, meeting your counterparts and exchanging vital

information. Sometimes it is as simple as having human contact with someone who understands where you are at in your life journey.

During the COVID-19 pandemic, while social and rural isolation were extreme for many, it also brought the virtual world to those of us with access to internet and technology. We connected on a global scale on a daily basis; it was a very positive experience, and one project that was a privilege to be involved in was My Support Study[10]. End of life is a conversation that is not always broached but it is inevitable and needs to be prioritised. There are a number of elements entangled in end-of-life care [11] including physical comfort, mental and emotional needs, spiritual needs, and practical tasks.

Now I advocate for supports such as a link worker [12] being allocated at point of diagnosis to signpost the various services and supports. Social prescribing [13] is an important part of our good mental healthcare; in a country where rural and social isolation are very prevalent, more emphasis needs to be put on this, as medication is not always the answer. If a loved one has to go to residential care, be it respite or long stay, they are entitled to their material citizenship[14]. We all have human rights and need very basic things like having a cup of tea when you feel like it and not only when it is offered during teatime at the care home.

While the whole experience of living with a loved one who had very little knowledge of what had happened to her over a number of years, we both came through the experience on a completely different course of life. Mum went her way – experiencing a beautiful pain-free, at-peace death. I continue to advocate for her voice and my own so that in time no one will experience the isolation, loneliness, fear, and abandonment we felt.

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## Expert essay

# Supporting positive carer experiences

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While the journey of being a care partner for a family member/friend with dementia is marked with unavoidable tribulations, it is also embedded with many rich positive experiences. Carers must adjust to the challenging behavioural changes linked to dementia, navigate complex healthcare systems, and simultaneously juggle life's other responsibilities – but they often feel a sense of purpose, pride, and gratification in fulfilling their important roles[1]. A small but growing body of scholarship has affirmed that positive caregiving experiences like these are a critical component of the wellbeing of carers' and people living with dementia[2,3].

**“ Carers must adjust to the challenging behavioural changes linked to dementia, navigate complex healthcare systems, and simultaneously juggle life's other responsibilities – but they often feel a sense of purpose, pride, and gratification in fulfilling their important roles.**

Carers are more likely to have positive experiences when they can access a supportive network that recognises their contributions, internalise a sense of mastery of their role, and maintain a satisfying relational dynamic with their family member/friend[4]. Thus, service providers can foster positive experiences by celebrating carers' important contributions to care and highlighting ways to maintain meaningful bonds throughout the trajectory of a person's dementia.

## Viewing dementia through a biomedical lens has negative implications for carers

Dementia has traditionally been viewed through a narrow biomedical lens, which frames the condition as one that leads to cognitive and physical deterioration and inevitable loss of self[5–7]. Relying solely on such a framework to understand dementia can result in stigmatisation and disregard the

reality that people with dementia are whole people, capable of participating in meaningful social connections[7]. When people with dementia are framed as incapable and deficient, carers can be robbed of the opportunity to have empowering positive relationships with their family members/friends[8].

Perhaps as a consequence of the dominant biomedical perspective of dementia, much of the care literature has exclusively focused on carer burden and other negative experiences[2]. While such research is important, it does little to highlight carers' important contributions to the care of someone living with dementia and potentially undermines the establishment of meaningful connections between carers and people with dementia.

## Alternative dementia narratives can support alternate caregiving narratives

*My mother would certainly fail a pop quiz about my name, but she lights up when she sees me. She is eager to talk, and tries to speak, but words often elude her, and sentences get distracted and wander off in unanticipated directions. The difficulties of talking don't seem to bother her terribly, though. There is pleasure in it still[8].*

When people with dementia are seen as whole people who, despite limitations, may still socially connect and thrive, it creates a space for carers to participate in a gratifying relational dynamic. Such a dynamic can foster positive experiences for carers and their family members/friends with dementia[1–3].

Consider a parent with dementia who, as their condition progresses, evolves from having a closed-off and uncommunicative demeanour to one that is emotionally expressive and loving. Where the biomedical perspective may argue that this behavioural change reflects dementia-related disinhibition, it could instead reflect the parent's evolving self[5].

Dementia frameworks such as personhood[6] and citizenship[7] offer lenses that explicitly recognise, embrace, and celebrate such changes. However, these frameworks have only recently begun to influence the healthcare systems that support people with dementia and their carers. As a result, caring for a family member/friend with dementia is often still cast in a negative light.

## Next steps

Carers feel burdened when they are not provided with the resources and time required to support their efforts and have positive experiences. Their burden is exacerbated by dominant narratives that position dementia solely as a biomedical condition that results in inevitable deterioration without also considering the ways in which people with dementia can grow, thrive, and engage in meaningful connections with carers.

There are some programs and practices that aim to overcome these constraining narratives and help carers connect with their family members/friends, even at the end-stages

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of dementia when communication is severely compromised. Namaste Care[9] and paramedical elder-clowning[10] are evidence-based interventions that can stimulate communication and connection between people with dementia and their carers.

It is time to disrupt the dominant narrative that positions people with dementia as lost to a disease with no known cure. Failing to do so perpetuates the stigma associated with the condition and constrains carers' capacities to experience growth amid loss and joy amid pain.

## Expert essay

# What do carers expect at the time of disclosure of mild dementia diagnosis?

Elizabeth K. Mutunga

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In Kenya, dementia is poorly understood, and we are in the early stages of raising awareness of dementia as a medical condition. A lot of stigma associated with the condition is based on traditional cultural beliefs[1]. It is believed that if someone has dementia, they must have done something wrong to the gods and they are being punished. Others think one has been bewitched and thus stigma is rife when dealing with people living with dementia. As a result, most people do not seek medical assistance, as belief in witchcraft and spiritual intervention can further isolate people with dementia and their families from the community, compounded by limited access to a diagnosis and low prioritization by governments experienced across the region[2].

Most carers are informal caregivers. This means that they are either a relative or a friend giving care voluntarily. Most of them are not prepared for what to expect as a carer and thus the need to support them. There is a need to sit with them when they get a diagnosis of dementia so that they can understand what is expected of them and also have their queries addressed[3].

## Understanding dementia

As stated earlier, dementia is a condition that is not understood in Kenya and there is a need to demystify the condition. Carers go to the hospital when they notice the change in their loved ones, and they want to get all the evidence they can on the condition. One thing they want to know is if there are medications they can access for their loved one for the condition. Symptoms of the conditions, both physical and mental, are also an area of interest. Resources they can access are also of importance to them. This is important as they can know what they can do when they face an emergency during the development of the illness[4].

Most carers need to know if other people are going through the same issue and how they can connect with them. Introductions of support groups are very key at this time. This is where they can learn from others how to care for their loved ones. There is a need for a report from the doctor that would assist in ensuring that financial and legal affairs are put in order and issues of power of attorney are dealt with.

Carers also have a concern about what is expected of them as they care for a loved one with dementia. Understanding how the illness will affect them is a great concern, too[5].

## Personal self-care

Carers need to understand the importance of self-care. The physical and emotional demands of caring can have a toll on them. As the care demands increase, the energy and the time burdens are higher, too. Burnout is thus experienced and there is a need to be educated on the importance of taking time off for oneself. If carers do not have time for self-care, then they will face emotional issues such as guilt, grief, loss, or anger. This is due to the frustration of caring for a loved one living with dementia. Feelings of abandonment by family and friends are experienced as most people do not understand the condition and thus stay away[6].

Carer burnout involves physical, emotional, and mental fatigue. A carer may experience depression and anxiety while caring for a loved one. There have been instances where one's attitude to caring will change due to these factors. It can impact the way one gives care to one's loved one living with dementia. Carers may realize that they have less patience and perhaps demand lots more from their loved ones. It is therefore important that as a carer, when you notice changes in yourself towards a person living with dementia, you must take a moment to assess yourself. Dealing with one's feelings efficiently is key to giving good care. Identifying signs of carer stress and understanding how to relieve these emotions will help one maintain the best health[7]. The carer should be encouraged to continue with activities that give them pleasure. If they do not take time for themselves, it will be harder to become great care partners. Asking for help is something carers must learn as this makes the burden less tiring. Carer burnout must be avoided at all cost[8].

## Post-diagnosis care

Post-diagnosis care is important for the carer to know as this helps them understand what is expected to be done. Issues of having one's own schedule while caring for the person living with dementia come to the forefront at this

time. Ensuring that the loved one is on a proper diet is key to ensuring that other diseases are kept at bay. Physical activities need to be incorporated daily to ensure good health is maintained. Engaging the mind is key for people living with dementia. Activities such as filling out the crossword or playing Sudoku will help keep the mind active of the person living with dementia[9].

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## Expert essay

# Involving care partners to plan for the future

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**D**ementia is a progressive, terminal illness and as it advances, a person's ability to make decisions and plan for their future deteriorates. In the UK, clinical guidelines have called for improvement in the palliative and end-of-life care for people with dementia[1], with momentum growing considerably since the launch of the White Paper on palliative care recommendations for dementia[2]. It has been proposed that all people should be encouraged to identify their needs, priorities, and preferences for end-of-life care through the process of "advance care planning" (ACP)[3].

## Advance care planning

ACP is an important part of palliative care and has been present in the clinical literature since the latter half of the 20th century[4]. ACP is defined as a process of discussing and recording of wishes, values, and preferences for future care and treatment held between individual, family members, and their care provider(s)[5] that takes effect when the person loses capacity[6]. Research on ACP has peaked and troughed over the last two and a half decades with varying attention given to elements such as the numbers of people with dementia who have advance care plans, who is the best placed professional to facilitate them, and exploring the various barriers to their implementation[7]. Advance care planning has become a ubiquitous term used to describe many different elements of decision-making; however, it is estimated that only between 3% and 39% of people with dementia undertake ACP worldwide[8].

## Shared decision-making

Autonomy in decision-making depends upon consciousness of our past and future thoughts and actions, much in the same way we are conscious of our present thoughts and actions[9]. As dementia progresses, in particular, the ability to consider future thoughts and actions becomes compromised and this affects the capacity to make decisions[9–10]. Historically, people with dementia have been rendered powerless, with decisions being made "for" them by professionals rather than "by" them or "with" them[7]. Participation in decision-making is now viewed as essential to the delivery of individualised and person-centred dementia care[11], with the concept of shared decision-making (SDM) becoming a

well-established model for clinical practice. While there is no common definition of SDM, Daly et al [11] suggest SDM is an approach that involves patients in making medical decisions with their clinician. However, best practice in SDM should incorporate the values and preferences of the person with dementia and support them to make decisions about their own care in collaboration with family members and clinicians [12] with family carers' involvement increasing as the person with dementia's abilities to make decisions decline.

## Family carers' preparedness for proxy decision-making

Family carers are often expected to act as proxy decision makers for the person with dementia, but what preparation do they have? Expectations on them to make difficult and emotionally challenging decisions can be too demanding of them, especially in circumstances where there is significant carer distress and "anticipatory" or "pre-death" grief[13]. Feelings of guilt and failure, together with insufficient information about the course of the disease, often leave family carers unprepared to make end-of-life decisions on behalf of their relative[14].

In the absence of any ACP discussions led by or involving a person with dementia, many family members may be unclear about what the wishes and preferences of the person with dementia for future care and treatment are. The carer's own preferences may be articulated within the context of their caring experience, often one that was negative and influenced by the nature and quality of the relationship with the person with dementia[14,15]. Harrison Dening et al[14] found that when thinking about advance care planning for the person with dementia for whom they cared, family carers reflected on what their own future might hold based upon their perceptions of what it was like for their relative to have dementia, in a care system where carer support was inadequate.

## What information and resources do people need?

People with dementia and family carers need, first of all, a diagnosis. At the time of diagnosis, they should also be presented with information about some of the key decisions

that they may have to face – for example, managing their finances and driving[16]. It is also an opportunity to start thinking about an ACP and consider their wishes and preferences for future care and treatment. There is a tension between the volume of information to take in and at the same time absorbing the impact of the diagnosis and, importantly, its prognosis and what they may need to plan and mitigate for in the future as their condition deteriorates. But, of course, the earlier people with dementia start to make decisions about the future, the more likely they are to have the capacity to do so.

Ideally, the support to discuss these complicated and often emotion-laden topics should be delivered and ideally over a period of time and with suitable professional support, such as an Admiral Nurse (specialists in dementia care)[17].

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## Expert essay

# Anticipatory grief – what is it and how do you cope?

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**Y**ou or your loved one has just been diagnosed with an illness – Alzheimer's, Parkinson's, cancer, or any number of degenerative conditions. You start experiencing a range of emotions – shock, denial, sadness, anger. In fact, it feels like you may be grieving, but wait, no one has died. You may even begin to worry that there is something psychologically wrong with you or wonder what kind of person grieves a death before it has actually occurred. Welcome to Anticipatory Grief.

To understand anticipatory grief, one must explore the definition of grief. Grief is that feeling or emotion that is traditionally experienced when an unwelcome change occurs or someone we love dies. **Anticipatory grief** is the process associated with grieving the loss of someone before the person dies. Some refer to these emotions by utilizing other synonyms such as premature grief, pre-bereavement reaction, anticipatory mourning, pre-loss grief, and pre-death grief.

## How does anticipatory grief differ from grief?

Anticipatory grief can be distinguished from grief in a number of ways. To begin with, unlike grief, anticipatory grief can be experienced by both the person who is diagnosed with an illness and their loved ones. Additionally, the process of grieving typically begins as early as when a person and their family members receive a diagnosis and will likely last until that person dies.

## How does it manifest itself?

Anticipatory grief can manifest in many different ways, including physically, emotionally, cognitively, and spiritually, as grief is a holistic response to change and as such it is not limited to feelings. The diagnosis can also pose a threat to the stability of the person's life and/or the lives of those around them. These feelings of uncertainty can be experienced at various stages throughout this illness from the onset of diagnosis through middle stages culminating with the death of the person.

## What makes anticipatory grief unique?

- Anticipatory grief can affect the person who has been diagnosed with an illness as well as their family and friends.
- As previously stated, anticipatory grief will be experienced upon receiving a diagnosis and will end as the loved one dies, whereas post death may last indefinitely.
- The emotional intensity of anticipatory grief increases as death approaches whereas emotional intensity of grief after a death may diminish over time.
- Anticipatory grief helps provide time for the person with the diagnosis and their loved ones to prepare for their deterioration and subsequent death and make necessary adjustments around the impending loss.
- It also gives loved ones the opportunity to develop coping skills for the life changes that will take place after the death and attend to unfinished business/ have important discussions that may have not been previously addressed.
- Anticipatory grief can also serve as an ideal time to make the most of the time the person who has received the diagnosis and their loved ones have together.

## What is the experience for an individual living with terminal illness?

For the individual living with a diagnosis, they may experience multiple losses and numerous stressors concurrently. These include but are not mutually exclusive to physical losses, cognitive losses, loss of their perspective on life, loss of hopes and dreams, and loss of the future with their loved ones. They may also experience multiple feelings such as denial, shock, disbelief, anger, depression, bargaining, and potentially acceptance (as identified by Elisabeth Kübler-Ross, 1960). Further to that, they may experience distressing thoughts about their loss of functioning and eventual death, which include unexplained symptoms and uncertainty regarding treatments.

## What is the experience for loved ones supporting the individual living with a terminal illness?

The loved ones of someone diagnosed with an illness may also experience multiple losses and numerous stressors such as loss of hopes and dreams, and loss of the future with the terminally ill person. They may also be impacted physically, emotionally, cognitively, and spiritually by the anticipatory grief they are experiencing. Furthermore, they may experience a significant amount of uncertainty about their future as they navigate the imminent death of their loved one.

### Now what? How to navigate anticipatory grief:

While there is no one-size-fits-all model of how to help someone navigate anticipatory grief, the following are a list of suggestions to consider:

**Remember that anticipatory grief is normal.** Many individuals may think that these feelings are wrong and harbour guilt about thinking this way. It is important to acknowledge these losses as part of your lived experience and lean into these thoughts and feelings rather than avoid them.

**Anticipatory grief shared may be anticipatory grief diminished.** Try to connect with others who may be experiencing these types of losses. Consider joining a support group in your area that will help you bond with other like-minded people. If you are not a “group person,” please consider seeking some sort of social emotional counselling that can offer much-needed support and validation.

**Experiencing anticipatory grief doesn't mean you are giving up.** You can grieve the changing circumstances and still support the person with the diagnosis.

**Make the most of the remaining time.** The silver lining in knowing that someone has a limited time provides you with the opportunity to cherish that time and make the most of it. Communication is integral for both the person with the diagnosis and the loved ones. Don't leave anything left unsaid.

**Self-care is not being selfish.** For those who become caregivers to the person with an illness, it is essential that you remember to find some time for yourself. This includes creating and accessing the support systems that are available to you.

**Anticipatory grief does not diminish grief.** Just because you mourned your loved one when they were ill, that does not mean you will not have strong feelings of grief when they die. The type of grief changes it does not disappear.

Essentially, it is imperative that you recognise that anticipatory grief is a very real emotion when someone is diagnosed with an illness and for their loved ones. While it is painful, there may also be some positive aspects to it, in that you are able to make some arrangements, and share feelings and emotions that you would not have when someone dies of a sudden death. Always keep in mind that support is available and that no one must experience this alone. Acknowledging anticipatory grief allows all those who experience these feelings to plan the best possible quality of life for the remaining time they have as well as a dignified death.

## Conclusion

This chapter highlights the significant role that family and other informal carers play in the post-diagnosis journey from the very moment that a person is diagnosed with dementia. They are an essential part of the care plan and must be properly educated and informed about all aspects of the illness, as well as know how to access the necessary resources required to support the person they are caring for – without which, a lack of proper education and resources will have a negative impact on the quality of care and safety of the person living with dementia as well as having a ripple effect on the health and wellbeing of the carer.

Cultural beliefs, stigma, and a lack of public awareness about the signs and symptoms of dementia are also contributing factors that may prevent carers from seeking out support for themselves or result in the inability to be able to understand how to navigate the care of a person living with dementia. The lack of public awareness, education, and access to timely support services for informal carers looking after a person living with dementia is a significant global issue despite the attempts of many countries to introduce national dementia strategies. As the majority of people living with dementia across the world are cared for at home, clinicians and healthcare professionals who are responsible for assessing and diagnosing patients must ensure that family and other informal carers are empowered with the information and resources they need to provide this care.

# Chapter 4

## Impact of the diagnosis on siblings and children

*Pedro Rosa-Neto, José A. Morais*

### Key points

- Information about genetic risk of developing dementia should be part of post-diagnosis care for siblings and children of people living with dementia as their risk of developing dementia is higher.
- Genetic forms of Alzheimer's disease affect entire families and can impact not only their medical care, but also their psychological and social well-being.
- Genetic counselling has the goal of providing individuals and families with information on the nature, inheritance, and implications of genetic disorders to help them make informed medical and personal decisions.
- Clinicians should always encourage risk reduction, independent of family history of dementia.



## General background

Siblings and children of people living with dementia often inquire about their chances of developing dementia. Although it is well established that having a parent or sibling with dementia increases the risk of developing the same condition, its genetic risk depends on the underlying cause of dementia. For example, children of people who have Alzheimer's disease are 1.73 times more likely to develop the same condition. When two first-degree relatives are involved, dementia risk increases nearly four times. By contrast, in truly genetic cases this risk reaches 50%.

It is important to emphasize to relatives of dementia patients that having a parent diagnosed with dementia does not mean that a person will acquire the same condition. Independently from family history, the nature and stigma of dementia symptoms impose a significant psychological burden on the family that should be considered in the prescription of care. Such a burden seems amplified in families of patients affected by young onset or with a high load of dementia cases, whose uncertainty and fear have implications on the mental health of people coping with a family member's possible diagnosis of dementia [1][2][3].

The fear of developing an inherited condition is further exacerbated by medical, personal, and social implications associated with the diagnosis of dementia. For example, insufficient information concerning a parent's prognosis and their underlying pathology of dementia affects the ability to plan for the demands of future functional decline, adding to families' stress, anxiety, and uncertainty. In this regard, the healthcare team must provide support to family members as well as inform and provide educational materials to advise on the risk of developing and preventing dementia [4].

Genetic causes of dementia are frequently discussed in diagnostic disclosure visits. When concerns regarding a possible genetic cause of dementia arises in a visit to a healthcare provider, formal consultation with a genetic counsellor should be considered for families meeting clinical criteria for familial disease. More and more, asymptomatic family members require risk assessment visits to clarify results obtained from direct-to-consumer genetic testing. In certain cases, it is important to inform the limitations of results derived from these tests, given their widespread accessibility [5].

The search for genetic causes of dementias should be conducted at specialized clinics with the support of a multidisciplinary team and target many genes. The genetic diagnosis involves several steps, is guided by the clinical characteristic of the person living with dementia and includes various genes including those associated with Alzheimer's disease and frontotemporal dementias.

Several genes increase the risk of developing Alzheimer's disease. Novel diagnostic tests called polygenic risk scores are under development to assess the overall risk of developing dementia based on the assessment of various genes simultaneously. The apolipoprotein E epsilon 4 (Apo-ε4), located in chromosome 19, is the most frequent risk factor for Alzheimer's. The APOE ε4 risk allele frequency varies across ethnic groups and geographic regions, ranging from 7 to 40%. Carriers of one Apo-ε4 copy have nearly double the risk of developing dementia. In contrast, carriers of two

copies have conferred approximately eight times the risk. However, none of these tests have diagnostic validity in clinical practice [5][6]. More information on genetic testing is available in the World Alzheimer Report 2021.

The two essays in this chapter contemplate the issue of fear of developing dementia in siblings and children of people living with dementia. Laura Rob introduces us to genetic testing of individuals with early onset dementia (also called young onset dementia), considering the reasons and possible consequences around pursuing such tests with people living with dementia and their family members.

The essay by Alexandre de Mendonça reflects on the impact of genetic testing in clinical care and highlights the need for prevention, irrespective of the presence of specific genetic risk factors.

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## Expert essay

# Special issues with relatives of a person diagnosed with familial Alzheimer's disease

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Many questions arise when a clear hereditary form of Alzheimer's disease is found in a family. While the issues brought up with such a diagnosis are undeniably challenging to think about, it is valuable for the relatives of a person with this type of Alzheimer's disease to understand the condition and the available options for their affected family member and for themselves.

Although strongly hereditary forms of Alzheimer's disease are quite rare, some clues that this may be a diagnosis to consider include a person who presents with the condition at a younger than expected age (generally below 65 years old) and the presence of more than one person with younger onset Alzheimer's disease over more than one generation. In some families and in some countries, it is possible to identify a specific genetic cause for the early onset familial Alzheimer's disease (EOFAD; also known as young onset Alzheimer's disease) and, if such a cause is found in the affected family member, genetic testing becomes an option for relatives to consider. The result of genetic testing for relatives will clarify if they have inherited or not this same genetic factor and therefore have a predisposition for EOFAD themselves. Even if genetic testing is not available in all healthcare systems, the diagnosis of a suspected hereditary form of Alzheimer's disease will still confirm a risk of this same condition in other family members.

Genetic conditions affect entire families and can impact not only their medical care, but also their psychological and social well-being [1]. This type of early onset Alzheimer's disease affects relatives in different ways, as they might be the unaffected parent of an affected person, their partner, their sibling, their child, or someone more distantly connected. Because of the shared nature of genetic information within a family, the impact of a diagnosis of EOFAD can reverberate through numerous generations.

## Questions that may arise for a relative caring for a person with EOFAD:

- How will my relative's diagnosis affect me and my family, personally and in the community?

- Do I and the rest of my family wish to move forward with genetic testing for the person with Alzheimer's disease?
- How would I react if this testing confirmed a clear hereditary cause for the Alzheimer's disease?
- Who would I speak with in the family to communicate our relative's diagnosis and genetic result?
- If I am not ready to move forward with genetic testing for my affected relative, would DNA banking be an option to consider, in order to leave the option of testing open in the future?
- If I am a blood relative, what would a genetic diagnosis mean for my own health?

## Questions that may arise for relatives, if a clear genetic cause is identified in their affected family member:

- Do I want to know if I myself have the genetic factor found in my family or not?
- If no, will I make lifestyle changes, who will I tell or not tell about my family history, would I consider research participation?
- If yes, when would I test (for example: before or after having a family, when choosing or changing careers, etc), will I make lifestyle changes, who will I tell or not tell about my genetic result and family history, would I consider research participation?

Perhaps the most important first question is: How do I obtain information about my relative's condition? Healthcare providers are in an ideal position to inform and to refer relatives of a person with EOFAD to a professional to best answer their questions. Genetic counselling has the goal of "providing individuals and families with information on the nature, inheritance, and implications of genetic disorders to help them make informed medical and personal decisions" [2]. Once a specific genetic cause for a neurological condition, such as EOFAD, has been identified, testing for other family members (known as presymptomatic or predictive

testing) can be offered. The main goals of predictive genetic counselling are to facilitate decision making and provide an opportunity for reflection regarding self-management [3]. Some of the reasons that relatives may consider genetic testing for EOFAD include managing uncertainty, life planning, deliberating family planning options and weighing participation in research [4]. Factors influencing the choice of whether to test or not for hereditary neurological conditions are very individual ones, ranging from stage of life,

ability to cope, experience of living with an affected loved one, attitude of the family, social visibility to personality and temperament [5]. Many studies evaluating the psychosocial impact of predictive genetic testing have shown that the knowledge about the presence or absence of the familial genetic factor can stimulate feelings of distress, guilt, anger, relief, and empowerment, as well as change how individuals feel about themselves, how they believe others may be judging them and can alter their perception of their future

## Personal motivations for genetic testing

- Presence of symptoms
- Find out about personal risk
- Find out risks for other family members
- Reduce worry
- Help with general planning for future
- Find out about possible medical, prevention or treatment interventions
- Aid research
- Advice from physician
- Advice from family or friend



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Brain et al. (2000) J Natl Cancer Inst. 2000 Aug 16; 92(16):1345-51  
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## Reasons for declining genetic testing

- emotional impact on self or family members (fear, anxiety, depression, influence on life decisions or plans)
- can emotionally cope with having increased risk without testing
- prefers to postpone (ie. until after childbearing, children grown)
- too preoccupied with other psychosocial problems
- time constraints
- unclear benefits of risk assessment and of genetic testing
- concerns about insurance discrimination
- cost of the test



Metcalfe et al. (2000) J Med Genet. 2000 Nov; 37(11):866-74.  
Brain et al. (2000) J Natl Cancer Inst. 2000 Aug 16; 92(16):1345-51  
Van Asperen et al. (2002) J Med Genet. 2002 Jun; 39(6):410-4.  
Power et Robinson, Can Fam Phys 52:1425-31, 2006  
Ott et al., (2016) Alz Dement 2(1):23-29

[6][7]. Predictive counselling with a multidisciplinary team of experienced healthcare providers, such as neurologists, psychiatrists, psychologists, and genetic counsellors, can provide appropriate information and support when considering genetic evaluations [3][4]. When a genetic cause for dementia is suspected or identified in a family, it is important that relatives are aware of the implications and various alternatives in order to assess how they would like to proceed, based on their own values, beliefs, and preferences.

Various ethical issues, as well as barriers to accessing both genetic counselling and testing, can complicate the consideration of genetic testing. The balance of benefit and harm comes into play when considering choices about proceeding with testing for any individual. Testing for an affected person with cognitive decline may present ethical challenges due to questions about their decision-making capacity, decisions free from coercion, informed consent, and ability to comprehend test results [9]. Issues of confidentiality might present when the genetic testing of one person can reveal the genetic status of another family member. The value of the privacy of one family member may come in direct conflict

with a healthcare professional's duty to inform other family members of their own risks. While participation in research may provide relatives with an opportunity to contribute to knowledge about EOFAD and give them a sense of hope, some studies may require that a person knows their genetic status to participate. Barriers to predictive testing and genetic testing in various jurisdictions may include access to appropriate care, information and support, travel distance and time, cost, insurance concerns, as well as legal obstacles [8][9]. Knowledge of both the facts and the issues surrounding EOFAD will assist a relative in reflecting on the options and making decisions.

Genetic evaluation in families with EOFAD will bring up many questions for both individuals and their healthcare providers. The relatives of a person with this condition should be encouraged to seek out information and to obtain referrals to specialized centres, when appropriate. Family members who understand the underlying causes for EOFAD and the implications for others in the family will be empowered to make medical and lifestyle choices which are the right ones for themselves.

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## Expert essay

# In the absence of known genetic risks, what do we tell concerned siblings and children?

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When a person is recently diagnosed with dementia, the asymptomatic siblings and children commonly ask about their own risk for dementia. If other members of the family have been previously affected by dementia in a pattern suggestive of an autosomal dominant disease, or a particular phenotype is present, the asymptomatic relative should be referred to a specialised team able to manage the medical, ethical, and social complexities associated with genetic testing [1]. However, in the majority of cases, no family history of concern is present, so that the asymptomatic relative may be reassured. Even though, they must realize that the risk of any person developing dementia in the future is substantial, provided he or she lives a sufficiently long life. It is estimated that as many as one third of dementia-free 70-year-old people will develop dementia before they die [2]. Furthermore, the risk of developing dementia if a first-degree relative had the condition is somewhat higher than if no first-degree relative was affected [3].

A positive aspect is that the concern conveyed by the asymptomatic relative may represent an opportunity for the clinician to recommend changes in the person's lifestyle that might reduce the risk of developing dementia in the future. In fact, these recommendations are general and applicable to any person, independently of having a relative affected with dementia or not, and certainly aligned with the global dementia action plan promoted by the World Health Organization (WHO) [4] on controlling behavioural risk factors, non-communicable disorders and other risk factors associated to dementia.

It must be recognized that large part of the present knowledge about the preventive factors and risk factors for dementia was obtained with data from epidemiological studies. These studies recruit large cohorts of people and follow them for several years to find out what baseline characteristics are associated with development of dementia. However, in these observational studies it is difficult to be sure whether variables associated to the risk of developing dementia in the future are themselves important, or just linked to other variables that might determine the risk. To overcome this limitation and find out whether a particular factor or combination of factors are really protective,

interventional randomised controlled studies are necessary [5]. However, these studies are costly, long lasting, difficult to accomplish and have been unfrequently performed.

A Lancet commission paper extensively reviewed the available evidence and estimated that as much 40% of dementia is attributable to a combination of twelve risk factors, namely low education, midlife hypertension, midlife obesity, hearing loss, late life depression, diabetes, physical inactivity, smoking, social isolation, excessive alcohol consumption, traumatic brain injury and air pollution [6]. The control of these risk factors would play an important role in the prevention of dementia. In the same line, the WHO issued specific recommendations on risk reduction of cognitive decline and dementia [7]. While the quality of evidence and the strength of the recommendation varied according to the specific interventions, treatment of hypertension, diabetes mellitus, high cholesterol, overweight/obesity, and depression are recommended. Interventions aimed at reducing or ceasing hazardous and harmful drinking and tobacco cessation are also mentioned. Physical activity, as well as cognitive activity, should be promoted. The management of hearing loss is advisable. Social participation and social support are desirable since they are connected to good health and well-being. The preventive effect of a healthy diet is also emphasised in the WHO guidelines, the Mediterranean-like diet may be counselled to adults with normal cognition and mild cognitive impairment to reduce the risk of cognitive decline and/or dementia, and more generally, a healthy, balanced diet should be recommended to all adults [8]. It is interesting to mention that several studies have reported recent stable or declining prevalence and incidence of dementia across different countries, that have been attributed to modifications of risk and protection factors related to living conditions, lifestyle, education attainment and availability of healthcare [9].

In conclusion, even in the absence of a positive family history of dementia, the clinician might have the opportunity to let the asymptomatic concerned relative know about interventions that might reduce the risk of developing dementia in the future.

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## Conclusion

Healthcare providers should be prepared to inform care partners and relatives of people living with dementia about their risk of developing the condition. Although siblings and children of affected individuals have higher chances of developing dementia, current genetic analysis fails to precisely define the risk of developing dementia or have any role on the management of these individuals.

However, concerns about possible genetic predispositions can provide an opportunity for physicians to inform concerned relatives of interventions that might reduce the risk of developing dementia in the future.

PART I

PART II

PART III

PART IV

PART V

PART VI

PART VII

PART VIII

# Chapter 5

## Cultural implications for people living with dementia and their families

*Claire Webster, José A. Morais, Wendy Weidner*

### Key points

- Stigma continues to be a barrier, with many countries reporting lack of knowledge, awareness, and understanding as an obstacle to accessing post-diagnostic care.
- Families, particularly female relatives, provide the bulk of post-diagnostic care across lower- and middle-income countries.
- Whole-of-society and person-centred approaches yield positive results at both the societal and individual levels when it comes to the wellbeing of people living with dementia and their carers.
- There is a critical need for culturally appropriate approaches to post-diagnosis care that consider complex socio-cultural and traditional practices.
- Technology may have an increasingly important role in helping people access support.
- There is an urgent need for more national dementia plans to provide a framework for post-diagnostic care and support.



## General background

The global population is aging rapidly and by 2050, 80% of older people will live in lower- and middle-income countries (LMICs)[1]. By the same year, the number of people living with dementia is expected to rise to 139 million, the majority of whom will also be living in LMICs[1] where access to diagnosis and post-diagnostic support can be challenging and, in many places, limited. Indeed, there remain key barriers to progress in dementia diagnosis, treatment, care, and support across the globe. In its Global status report on the public health response to dementia[1], the WHO indicates that limited financial resources, urban vs. rural inequities, lack of care coordination, stigma, and lack of dementia awareness are major stumbling blocks.

The following essays are thoughtful reflections about dementia care in 13 different countries, many located in the Global South. The essays lay bare the distinct challenges faced by each country, but also provide ways forward – an emphasis on possible solutions that can bring about policy change and improve access to care and outcomes for people living with dementia and their families.

Stigma remains pervasive and is threaded through each of the essays as a consistent barrier to accessing diagnosis and care, contributing to misinformation, isolation, shame, and even abuse and neglect. But innovative responses are

being developed and Musyimi et al. share how the “anti-stigma” toolkit developed as part of the Strengthening responses to dementia in developing countries (STRiDE) project in Kenya is raising awareness, increasing knowledge, and changing attitudes.

Most post-diagnosis care takes place in the home and is often considered a “family issue,” with the bulk of responsibility placed upon female relatives. Jacob & Schneider’s essay on South Africa demonstrates the critical role of family in decision-making and how care interventions need to consider this to improve outcomes. From Nigeria, Ogunniyi explores the role of extended family in caring for the person with dementia and how this impacts carer well-being. In Mexico, Lopez-Ortega et al take a closer look at the impact of the carer role on women and call for a comprehensive national care system to support families. From Indonesia, Turana outlines how governments can plan community long-term care services to support families caring for loved ones at home.

Socio-cultural complexities are a key consideration, with Dudley et al from New Zealand and Australia emphasising the importance of ensuring dementia care takes different cultural and perspectives into account – developing a framework that recognises diverse principles and

understanding about health and wellbeing. Equally, in their essay on Indigenous communities in North America, Lewis and Jacklin state that services need to be "grounded first in Indigenous knowledge and second supported by biomedical advancements". From Madagascar, Rason-Andriamaro explores what connects us to society, discussing Malagasy notions of "Valim-babena" (what we owe to the parents who raised us) and "Fihavanana" (mutual help and solidarity) – connections that are core principles of life in Madagascar. Finally, Alladi et al explore the rich and complex socio-cultural landscape of India, emphasizing the need to develop dementia intervention programs that are integrated into the collectivistic system within the country.

Access to care is another major theme of the essays in this chapter, with Oliveira et al in Brazil, Huang in China, Govia et al in Jamaica, and Pearson et al in Scotland sharing specific challenges experienced in their countries and how technology can enable greater access for people living in rural or hard-to-reach areas and how learning from the COVID-19 pandemic is helping some countries explore telemedicine and tele-support models for upskilling carers.

Finally, almost all essays emphasize the need for government policy to legislate and fund dementia care through the development of national dementia plans. National dementia plans provide a policy framework and are the best strategic planning tool to help governments focus on diagnosis, post-diagnostic support, and care pathways for people living with dementia and their carers.

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## Expert essay

# Post-diagnostic support for people living with dementia and their family carers in Brazil

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## Dementia and support services in Brazil

**B**razil is an upper-middle-income country with 214 million people[1,2]. In 2019, people aged 60 years or older represented 16% of the population, and the majority were women (57%)[3]. Brazil is the fifth largest country globally (8,000 km<sup>2</sup>) in territorial extension[2], with a huge diversity in terms of culture, socio-economic profiles, and service provision across its five geographical regions (North, South, East, West, and Midwest). It has been estimated that, in 2019, 1.8 million people were living with dementia in Brazil[4], and this number is increasing[5].

Brazil has a National Health System (SUS) that is state-funded, universal, and free of charge at the point of use to the whole population. The Unified Social Assistance System (SUAS) is state-funded and provides care at home and other long-term care services (such as day care centres), though very limited in number and mostly means-tested. Private health and social care services are also available through out-of-pocket payments and through insurance companies. People living with dementia are eligible (as much as any other person in Brazil) to receive healthcare from primary care units, home-based care, and specialized services. However, in general, the number of specialised health professionals and services is higher in larger urban centres, and in wealthier areas. The wealthier and those with higher levels of education are more likely to benefit from such services, which contributes to inequities in access to care.

## Challenges and barriers to the provision of specialised post-diagnostic support in dementia

Brazil has many challenges that hinder the provision of specialised post-diagnostic support for people living with dementia and their family carers. We currently do not have a national dementia plan, nor is dementia included as a health and social priority within other policy areas (for example,

disability, mental health, older people) at any country level (federation, state, municipality). The public mainstream health and social care systems are not prepared to adequately identify, diagnose, treat, and support people living with dementia. Rates of dementia underdiagnosis in Brazil reach nearly 80%[6] and most people living with dementia who receive a diagnosis do so at a later stage of the condition. Integrated dementia-specific care pathways are practically non-existent, and so people with dementia and their family carers struggle to obtain any post-diagnostic support.

It is possible that structural stigma toward older people and people living with dementia plays an important role in the non-prioritization of dementia in the allocation of funding schemes, capacity development, and service provision, for example. This stigma is often expressed through, or informed by, negative views and beliefs such as seeing older people as a burden to society, thinking that dementia is a natural part of ageing, and that “nothing can be done” to support people living with dementia to live meaningful lives, for example[7]. In addition, the care needs of people living with dementia or other disabling conditions affecting older people are still considered to be a “family issue,” rather than a societal responsibility in Brazil. This prevents care from being socially and politically construed as a right, at both policy and service delivery levels, and is reflected in the clear expectation that exists from governments and service providers that families (mostly women) should take care of their family members experiencing care needs, regardless of the costs to their health, wellbeing, or financial situation.

Moreover, Brazil still faces several other pressing public health and social development needs, such as high rates of poverty and violence, as well as high prevalence of infectious diseases (for example, dengue and tuberculosis). Together with other structural problems such as corruption and further forms of poor management of public resources, these other priorities often come at the centre of policymakers and service providers' attention, and dementia is kept hidden away as “another issue to deal with.”

## Innovation and technologies for post-diagnostic support

In Brazil, dementia disproportionately affects more women both as carers (wives, daughters, and daughters-in-law) and as people living with dementia. Care tasks are most often combined with household tasks, role captivity, loneliness, and financial strain. Local governments and private corporations could support internet access as part of their social responsibility toward female carers to help reduce carer burden. However, as with many other Latin American countries, most Brazilians still face multiple challenges in basic telecommunication infrastructure, especially in rural areas, and women have less access to technology that could help in care activities. Digital resources might be a major help for carers from rural areas and distant or larger cities in a large country such as Brazil because broadband internet could connect them to hospitals, clinics, online existing peer-to-peer support groups, and online social groups for carers. Telephone counselling is a promising intervention that can be more exploited in Brazil and in other lower- and

middle-income countries (LMICs). This approach was developed rapidly with the COVID-19 pandemic and should be encouraged[8–11].

Brazil has made progress in many aspects of public health that benefit people with dementia, but it needs to assess how current service provision and family support are meeting the needs of people with dementia and their carers, and plan services that will meet the needs of a rapidly ageing population and increasing numbers of people with dementia. In the long-term, Brazil needs to consider the implementation of healthcare strategies for people living with dementia that provide easier access to care (especially community and primary care services) including long-term support, outreach care, and the management of the needs of people living with dementia at home or in residential care. It is important to increase the population literacy for the use of computers and mobile phones, as well as access to these devices as this can increase access to interventions that can benefit people with dementia and their families.

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## Expert essay

# Post-diagnostic care for people living with dementia in China

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Over the past decade, the ageing population has increased by 6.5% in China[1]. Accordingly, there is a surge in the number of people living with dementia nationwide[2]. Therefore, providing optimal care for people living with dementia has been prioritised in the national healthy ageing and mental healthcare agenda. For example, the national dementia strategic plan urges provision of post-diagnostic dementia care for people living with dementia, including cognitive rehabilitation, psychosocial intervention, and family carer support[3,4].

## Whole-of-society approach

Due to limited resources for care provision, a whole-of-society approach has been proposed in the national dementia care strategic plan[5]. Maintaining daily function and improving the quality of life of people living with dementia is the core of the whole-of-society framework. To achieve the goal, support for families, maximising functions of communities, and coordination of societal efforts remain equally important.

Dementia care is not a single service but a concept of the continuum of person-centred support[5]. Although individuals diagnosed with dementia have easy access to anti-dementia medications in memory clinics, their personhood needs to be cared for beyond medical institutions. Therefore, post-diagnostic care becomes one of the major components of the continuum of dementia care. It complements clinical care by valuing personal needs, improving autonomy, respecting personal perspective, and increasing social engagement for people living with dementia[5].

Social workers, mental healthcare workers, and volunteers are primary service providers for post-diagnostic care in China. The typical service includes hosting group programs for cognitive enhancement, managing behavioural symptoms, supporting carers and family members, and assisting with daily living activities. In addition, as mental healthcare workers have been extensively involved in the service framework of national psychosocial care for older adults, they tend to lead psychosocial intervention for families of dementia.

Previously, most post-diagnostic dementia care services were fragmented. However, in recent years, with the implementation of the national dementia strategic plan, memory specialists, social workers, and mental healthcare workers have started to formulate collaborative teams, aiming to provide more efficient service care.

Non-pharmacological support is the first-line option for people with psychological and behavioural symptoms as explicitly specified by the consensus on the clinical management of neuropsychiatric symptoms[6]. However, the resources for psychosocial intervention for people living with dementia are minimal, even in long-term care settings[7]. Therefore, in collaboration with dementia carers, the Chinese experts reached a consensus on the indicators of psychosocial interventions for people living with dementia. The proposed 20 indicators are classified into five domains: assessing people living with dementia and their carers, conveying the message of diagnosis, developing and implementing the person-centred psychosocial intervention, training carers and improving care capacity, and managing multidisciplinary teams[5,8]. These indicators are tailored to local culture and are appropriate for dementia care practice in China.

In China, most people living with dementia are cared for at home. During the long journey of caring for people living with dementia, family members have a higher risk of stress, depression, and anxiety[9]. However, family members seldom seek mental healthcare for two primary reasons: lack of insight into their mental health problems and stigma against mental healthcare. Therefore, there is a great demand for developing seamless psychosocial support for family caregivers[10]. In the past two decades, caregiver support groups, that is, memory cafés, either run by memory specialists or social workers, have become mainstream services during post-diagnostic care[5].

*Social workers take people living with dementia as the centre, valuing personal dignity and maximising their competence. We follow the ecosystem theory, focus on the community, family environment, and personal*

resilience, adhere to the person-centred care principles, and apply multi-dimensional intervention[s]. With such a practical strategy, we aim to improve the person's quality of life and reduce caregivers' stress.

### ***A social worker, also an instructor of social prescribing***

In terms of long-term care for moderate and severe dementia, developing individualised and feasible care plans, having well-functioning organization and implementation, and receiving external support from dementia specialists may facilitate implementing person-centred care. By contrast, poor physical health of people living with dementia and limited caregiver service capacity may constitute two major barriers to implementing person-centred dementia care[11].

## Future development

Reduced social connectedness is associated with the risk of dementia and cognitive impairment. Recently, social prescribing, which focuses on interlinking medical and social care, has been shown to improve social connectedness and thus benefit the cognitive outcome among older adults[12]. In China, the National Center for Mental Health recently

initiated a project to improve community-based dementia care. The implementation of social prescribing is expected to improve the quality of post-diagnostic care.

New technology development helped supplement online services during the COVID-19 pandemic[13]. If provided with the right resources and used broadly, this new technology could help increase access to services, including in previously underserved areas, and improve service coordination between sectors. For example, the national mental healthcare action plan encourages setting up community outreach programs to improve access to post-diagnostic care for dementia. Such a strategy will encourage memory specialists using remote or mobile support to connect community healthcare with memory clinics.

The involvement of charity foundations is increasing over the years. Their work might supplement the mainstream service providers. In addition, as the government budget invested in post-diagnostic care is limited, charity funds may cover part of post-diagnostic care costs through interlinking with different administrative sectors and service care providers.

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## Expert essay

# Indigenous communities of Australia and New Zealand

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Elders and older people are central to the culture, health, and wellbeing of many Indigenous communities, and this is true for Māori people of Aotearoa/New Zealand as well as for Aboriginal and Torres Strait Islander peoples of Australia. As such, rising rates of dementia in these communities are concerning and increasingly at the forefront of Indigenous health priorities. Although there have not been any national prevalence studies in Australia or New Zealand, localised studies in both countries indicate higher prevalence and incidence of dementia among Aboriginal and Torres Strait Islander peoples and Māori people compared to other Australians and other New Zealanders, respectively. In Australia, these disparities are similar across remote, rural, and urban settings. Life expectancy for Aboriginal, Torres Strait, and Māori peoples is increasing and with projected large increases in the number of older people in coming years, a much higher burden of dementia is predicted across all communities. These health disparities are understood in the context of colonisation, systemic racism, and intergenerational trauma and social disadvantage, and further disadvantage is experienced due to the lack of culturally appropriate care in dementia services that contributes to poorer outcomes.

Māori, as well as Aboriginal and Torres Strait Islander populations, tend to experience earlier ages of dementia onset, eight to 10 years younger, which has been associated with a range of risk factors. These include many of the well-established and potentially modifiable dementia risk factors (for example, high prevalence of diabetes, hypertension, depression, obesity, and traumatic brain injury), but risk factors may also differ in nature or degree from non-Indigenous populations[1,2]. However, rarely are these data presented in a context of colonisation and therefore help to perpetuate the myth that these medical conditions are inherent in Indigenous peoples due to genetic or cultural differences. The pathways that have contributed to these health disparities, such as differential access to the determinants of health or exposures leading to differences in disease incidence, differential access to healthcare, and differences in the quality of care received, are therefore disguised. Adopting a life

course approach to dementia prevention and targeting the structural barriers to health and ageing well for Indigenous peoples are crucial for delaying dementia onset and achieving equitable ageing outcomes.

Diagnostic tools such as the Kimberley Indigenous Cognitive Assessment (KICA)[3] and the Māori Assessment of Neuropsychological Abilities (MANA)[4] have been developed to aid in the detection of cognitive impairment and dementia in the Indigenous peoples of Australia and New Zealand. However, in practice, dementia remains largely under-diagnosed or is diagnosed at more severe stages, when opportunities for secondary prevention and adequate planning are limited. Low awareness of dementia likely contributes to this, as well as the fear of receiving a diagnosis and becoming a burden on family. Adequate skills and systems to support dementia diagnosis and care across primary health settings are urgently needed[5]. This may include, for instance, adapting and promoting the use/uptake of government-funded health check programs (for example, the comprehensive “45+ assessment” in Australia) to address population health needs in relation to dementia risk reduction and diagnosis. We also need to consider implementing routine dementia screening in chronic care services where Indigenous peoples are over-represented, such as renal clinics. A wider range of culturally safe cognitive assessment and other diagnostic tools is needed to address current gaps and enable more flexibility in practice, to respond to the diversity of individual, socio-cultural, and service contexts.

The Indigenous peoples of Australia and New Zealand are significantly underrepresented in residential aged care which equates to substantial disparity in government-aided social care funding[6,7]. While limited access of these services is partially due to traditional cultural practices and preferences around providing care at home by family, there are also systemic barriers in both countries that perpetuate a Western medical model that is generally difficult for Indigenous people to navigate. In Australia, there are positive examples of the ways that diverse Aboriginal and Torres Strait Islander communities and community-controlled organisations are

creating their own flexible and integrated care models to meet the needs of local Elders and older people[8]. Similarly in New Zealand, Māori models of dementia healthcare such as Whare Tapa Wha[9] have been operationalised[10] to provide a framework for a holistic approach to dementia care which privileges Māori principles and understandings of health and wellbeing. Further investment in this area is needed, particularly to support community-controlled health services to transition to a greater role in delivering community and residential aged care that meets the cultural needs of Indigenous people.

Accessing specialist services and post-diagnostic care (for example, allied health) can be especially difficult, for many reasons, and cultural safety of services critical. There could also be opportunities to form community partnerships and foster Indigenous-led strategies to better understand the role of brain health and dementia-related medical technologies (for example, genetic, blood, and brain scans) with

Aboriginal, Torres Strait Islander, and Māori peoples, to enhance access to medical care. While these services are important, we also need more “whole of community” and “healing-centred” models, and localised models responding to diversity (for example, art centres/programs, intergenerational programs, and peer mentoring), which may help to break down the stigma of accessing dementia care and promote earlier diagnosis and engagement with support services. Finally, it is vital to recognise the important leadership and cultural custodianship/teaching roles of Elders which are “threatened” by dementia and to focus on ways to support/re-enable these roles to foster wellbeing and quality of life. Overall, the Indigenous peoples of Aotearoa/New Zealand and Australia share similar dementia disparities and the ensuing need for culturally appropriate approaches to risk reduction, cognitive assessment and diagnosis, supporting family carers, and delivering high-quality aged care through to the end of life.

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## Expert essay

# Providing optimal dementia support to Indigenous people in North America

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## Introduction

Rates of Alzheimer's disease and dementias have been increasing in Indigenous populations in North America for the last 20 years. A slow response from policy officials, researchers, and providers has exacerbated already gross inequities in access to appropriate diagnosis and care. This dementia disparity results from multiple systemic factors that elevate the risk of dementia, including a history of colonialism and government policies contributing to poorer health status and biological risk factors such as high rates of multiple cardiovascular and metabolic health conditions occurring at younger ages. Indigenous communities have also been severely impacted by social and economic policies aimed at assimilation and disconnection from the cultural and healing systems that supported healthy ageing and ageing in place for thousands of years[1].

## The need for culturally safe and fair dementia care

A significant challenge in accessing appropriate care is the cultural incongruency that exists for an illness for which there is a distinct Indigenous explanatory model. For some Indigenous worldviews in North America, symptoms of dementia are not necessarily viewed as a disease but rather considered part of the natural course of the individual's circle of life. Indigenous worldviews in North America include an understanding of the lifecycle where a person returns to the place of childhood as they age and eventually to the intersection of the place of birth and death at the time of one's end of life transition. This is viewed as a spiritual journey that requires respect. As a result, individuals who exhibit symptoms of dementia consistent with this transition time (for example, inhibition, hallucinations, younger memories) may not seek services or a diagnosis, and their carers may not be overly concerned by such symptoms. These misalignments between Indigenous and Western understandings of

dementia result in Indigenous people having reduced access to education and services appropriate to their culture and context and can impede engagement with healthcare systems altogether.

Improving access to culturally appropriate post-diagnosis care for Indigenous populations is an urgent need. However, access to an accurate diagnosis of dementia remains a significant barrier for Indigenous people. Culturally appropriate assessment tools are only just being developed and have not yet been systematically implemented into health systems[2]. Having access to a medical diagnosis is crucial to accessing supportive care and early interventions in both Canada and United States health systems. Without it, appropriate home care, outpatient care, and long-term care resources are not available to support the person with dementia or their caregivers. Lack of a timely or accurate diagnosis contributes to increased stress for family carers who struggle to understand the illness and its progression and a gross health inequity for Indigenous people with dementia who cannot access dementia care.

## Resources and solutions

Our research and others have demonstrated that Indigenous people find mainstream resources and services irrelevant to their contexts. We advocate that Indigenous cultural knowledge of dementia is valid and must be incorporated into resources and care. Dismissal of, or lack of attention to, Indigenous cultural knowledge concerning dementia by healthcare providers runs the risk of alienating people living with dementia and their carers from the health systems meant to support them. We encourage providers to pursue culturally safe care practices, engage in critical self-reflection, as well as engage in an open dialogue on the appropriateness of Western biomedical approaches for Indigenous populations. Engaging in this dialogue often uncovers culturally relevant approaches to care that better

support Indigenous families living with a diagnosis of dementia. For example, natural helping systems exist in many Indigenous communities and can be a valuable resource for families, including extended families, fictive kin, natural helpers, community carers, neighbours, and friends. Many of these resources remain in place and active in Indigenous communities despite centuries of assimilation practices.

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**“ We encourage providers to pursue culturally safe care practices, engage in critical self-reflection, as well as engage in an open dialogue on the appropriateness of Western biomedical approaches for Indigenous populations.**

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Similarly, Indigenous values of respect and reciprocity act to maintain a strong commitment to elders in Indigenous communities and are important factors in decisions to care for people with dementia at home for as long as possible. It is important for family members to care for those who cared for them and in many cases, while difficult, it is considered a gift. Within Indigenous communities, respect for, and seeking guidance from, knowledgeable Elders is a centrepiece of the culture. In Western science, this aligns with the concept of generativity, which is the later-life desire to contribute to the well-being of younger generations[3]. Enhancing feelings of generativity is relevant to Indigenous caregivers to ensure their continued

feelings of usefulness and involvement in valued personal, family, and community activities, as well as their sustained ability to engage in healthy behaviours and provide care for those with dementia.

Current estimates suggest that dementia will continue to rise quickly in Indigenous populations in the coming years. We must work with Indigenous communities and organisations to develop appropriate interventions and support systems to avoid an even larger dementia equity gap. Solutions resulting from academic-community partnerships are beginning to emerge to address the need for culturally fair clinical assessments[2] and culturally appropriate educational resources[4,5], but Indigenous populations remain underrepresented in Alzheimer's disease and dementia research and investments are disproportionate to the need.

Research carried out in partnership with Indigenous communities to date suggests that addressing the dementia equity gap for Indigenous populations requires a focus on the development of programmes and services grounded first in Indigenous knowledge and secondly supported by biomedical advancements. We advocate for a strength-based approach to research and program development as an effective lens to identify and build upon cultural and community strengths that are appropriately aligned with cultural knowledge and values. Support for community and family caring models and a strong tradition of aging in place are good examples. Despite the challenges faced by Indigenous communities, they are developing innovative and culturally responsive dementia programs to support Indigenous people with dementia and their carers that support ageing in place and may serve as models for other under-represented populations.

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## Expert essay

# Impact of diagnosis: cultural implications in Indonesia

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The global challenge of increasing dementia prevalence is well recognised. It is the reality that it will be most pronounced in lower- and middle-income nations due to growing population ageing. As with other nations, Indonesia is expected to see a substantial increase in the number of people living with dementia (PLWD), from 1.2 million in 2015 to 1.9 million in 2030, and 3.9 million in 2050. If not foreseen, the large number of PLWD will have significant healthcare and social consequences. [1,2]

Various promotive and preventive activities have been carried out, including the importance of early detection of dementia. Indonesia launched a national dementia action plan in 2016[3], followed by the regulation of the Minister of Health, November 4, 2019, concerning essential services for the elderly, which includes screening for cognitive examinations. However, these policies have not worked as expected and have not been implemented. There are many reasons the screening process has not run entirely to plan.

The availability of accessible management and support after receiving a diagnosis is essential to ensure that people living with dementia and their carers can continue to live well after a diagnosis. Therefore, it will also indirectly influence people's interest to undergo screening and diagnosis, and this is urgently needed. After getting a diagnosis, a person with dementia and their family should be given accurate information and support to understand the illness and what it means for them, such as managing symptoms, planning for future care and support, navigating the care pathway, and accessing peer support networks[4]. The factor of the stigma of dementia will undoubtedly affect the various phases before and after the diagnosis is made.

## Stigma: forgetting is a normal symptom of normal ageing

Research conducted in Yogyakarta shows that more than 90% of caregivers who care for the elderly with dementia consider that memory impairment is a part of normal

aging[5]. It is interesting to see the data from the 2019 World Alzheimer Report survey involving 70,000 respondents from 155 countries, in which 62% of healthcare practitioners think dementia is a normal part of aging[6]. This belief will result in a lack of early detection and treatment awareness. When forgetfulness is considered a normal condition, it may result in the carer, who is not ready to care for the person, taking an inappropriate approach to the person living with dementia and will result in treatment being carried out only when the disease condition is more severe and there are more complex symptoms.

## Competency of health workers

The stigma connected with dementia will affect patients and their families and health workers. Studies conducted by Taufik et al. also show that nursing students still have a high stigma (59%) against people with mental disorders[7]. Research in Indonesia conducted by Sani et al. found that healthcare practitioners feel inadequate in their knowledge and competence in managing dementia, as the subject is not discussed during their training[8]. Indonesian data in the World Alzheimer Report 2019 shows that just under 70% of the general public thinks there are adequate competent physicians for diagnosing and treating dementia. However, essential data on service quality show that around 40% of the general public think doctors and nurses ignore people with dementia[6].

## Culture of dementia care

Women tend to take care of their families rather than focus on their careers and earning a living, likewise, in the context of dementia care. There are more women caregivers than men. The study of Theresia et al. showed that the carers experienced several obstacles, such as difficulty finding a balance between work and taking care of their family members who live with dementia. One of them ended up resigning from her job as a kindergarten teacher and reported that the responsibility of caring for her mother full time led to no social life[9].

The same study also shows how misconceptions about the symptoms being attributed to spiritual or supernatural causes further adds to the distress and confusion of the carers[9], so that a dementia education approach is needed for traditional healers.

The 2019 World Alzheimer Report data also show a high proportion of Indonesian respondents (74.2%) among the general public who believe that people living with dementia are impulsive and unpredictable. Likewise, consensus among the general public in Indonesia that people with dementia are perceived as dangerous (44.1%), quite higher than India at 24.3%, Australia at 11%, and the Philippines at 10.3%[6].

Although most of the Indonesian respondents thought that those living with dementia were dangerous and tended to be impulsive and unpredictable, Indonesian respondents showed that less than 6% agreed with institutionalised care for older people/elderly parents, much lower than in neighbouring countries (for example, Malaysia indicated more than 10%, whereas in higher-income countries more than 20% agreed to nursing care)[6]. This is also supported by a culture that shows that parents are the source of wisdom in the family.

This means most people tend to care for their older family members at home. This will undoubtedly affect the long-term-care (LTC) system model for dementia care. This can reduce the government's expense of building LTC facilities, and thus the government can focus on strategic programs to strengthen community based LTC.

## Reducing stigma in national policies

Efforts to remove stigma through general education alone are insufficient; a higher-quality, more equitable service system and strong national policies are required. Indonesia established a National Strategy on Alzheimer and Other Dementia Diseases Towards Healthy and Productive Older Persons in 2016, which essentially covers the seven action areas identified in the WHO's Global Action Plan on Dementia Public Health Response 2017–2025[3,10]. Although the policy has been developed to support this national plan, there has been no systematic evaluation of the strategy's execution so far. This complicates determining the success of this national policy.

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## Expert essay

# Post-diagnostic support in Jamaica

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## Challenges

The limited understanding of dementia in the Jamaican context, even among general practitioners (GPs), is exemplified by the use of the term Alzheimer's to describe all types of dementias. Similar to many other contexts in which the workforce is not adequately trained to conduct diagnostic assessments and to differentiate between sub-types[1], in Jamaica, there is a lack of specialists such as geriatricians, gerontologists, neurologists, neuropsychologists, neuropsychiatrists, or others with dementia-specific training. GPs often find it challenging to differentiate depression from dementia in older people and require additional training in how to conduct thorough history-taking to clarify warning signs for cognitive deterioration and dementia. In addition, given the few specialists in the workforce, and the reality that these services are more readily accessible in the private sector than in the public healthcare system and in the corporate centres of the country, standard neuropsychological assessments and neuroimaging tend to be accessed only by those with financial means and/or geographical proximity to afford and reach these services. Patients tend to be referred for neuroimaging by their GPs or sent to psychiatrists who in turn refer them for neuroimaging, typically for MRIs to identify potentially treatable causes for cognitive impairment or to clarify where there are structural changes. PET imaging is even less frequently used for diagnosis of Alzheimer's disease; fluid and genetic biomarkers have not been used to date in Jamaica. Even when neuroimaging investigations are conducted, there is little follow up with the patient and his/her care network to clarify the implications of the investigations or additional tests needed; there is also little continuity of care, as patients and their families often see different specialists for different needs. Diagnosis, in the cases when it is initiated, is often incomplete. Most times, it is based on the use of a screener such as the mini-mental state examination (MMSE) or the Montreal Cognitive Assessment (MoCA) and a clinical exam by a psychiatrist.

In the context of these challenges to obtain a diagnosis, which are embedded in a wider societal context of limited awareness and high stigma about dementia, the journey for families experiencing dementia is confusing, costly and

until recently, largely one borne in silence, leaving families feeling adrift. Consistent with other countries, support is mostly pharmacological for symptomatic treatment and this pharmacological support is quite unaffordable to most: the minimum wage in Jamaica is JMD\$9,000 per week (around USD\$59 or £49); the average monthly cost of anti-dementia medication in Jamaica, which is not subsidized, ranges between JMD\$8,691.90 and \$51,950.00. Less than 20% of Jamaicans are insured either privately or publicly. While government has tabled a national insurance plan to increase coverage, it has been in limbo for the past 50 years. Among those who are insured, there are no long-term-care insurance products, and no social protection grants targeting long-term carers. Families are therefore forced to make complex decisions around paying for care – whether those costs are out of pocket or indirect costs such as reduced working time[2]. Carers are typically women who are often juggling caring for other family members and/or paid work and are also managing their own co-morbidities in addition to those of the person with dementia.

The option of placing family members into a care home is out of reach for many, as the average cost is over 90% of the typical household income. Even for those who can afford it, over 80% of care homes are unregulated, with just a handful able to accommodate dementia patients. For families in the lowest income bracket, abandoning their family member with dementia at a public hospital may seem to them the most affordable and manageable solution to long-term care[3].

## Solutions

For Jamaican families, the general practitioner (private or public sector) is usually the first point of contact, and that person may sometimes refer to a medical specialist such as a psychiatrist or neuropsychiatrist. In most cases, though, general practitioners identify dementia late into the progression and therefore not early enough for referring to a specialist to optimise support as the condition progresses. As in many other LMICs, where low dementia awareness and stigma is a barrier to detection and timely diagnosis, families often require urgent help with managing behavioural symptoms

when they've finally arrived at a doctor's office with a concern about memory or "not being themselves" in terms of their family member's thinking or general functioning. General practitioners and psychiatrists provide pharmacological support by prescribing sleep regulation or psychosis management medication. Follow-up care or support is largely medicalised, revolving around medication prescription and management. There has been marked progress over the past decade in the public health system in terms of psychiatric support in the form of mental health clinics, with at least one assigned psychiatrist now operating in all but one of the 14 administrative areas or parishes (with the Greater Kingston corporate area having even more); before this, the ratio was one psychiatrist for every 3–4 parishes. In cases where the person with dementia is a long-time patient of the general practitioner managing their care, that GP might help to manage family conflict or distress, reduce medication costs, or even get them early access to a medical specialist in a public hospital.

Psychosocial, rehabilitative, and social care support from social workers, allied health professionals such as occupational therapists, or geriatric nurses are rarely recommended by GPs, who are often the gateway to post-diagnostic care. These options are only explored by a fraction of those who screen positively for suspected dementia or who receive a diagnosis.

Support in homes is typically provided by domestic workers, also called helpers in Jamaica[3,4]. Untrained for such care responsibilities, their activities typically revolve around meal preparation and provision, and assistance with some activities of daily living. Jamaica, like many island economies, has a high proportion of transnational families. Some older Jamaicans who emigrated to the US or UK decades ago and develop dementia are relocated back to Jamaica where a family member, typically a child, can provide care. While care resources are sparser in Jamaica, the strength of their strong foreign dollar pension, for example, can go a longer way in providing preferred at-home care typically provided by an untrained, sometimes experienced helper. For older people whose children all live abroad, a distant relative who is unemployed might be designated to provide unpaid care in the home in exchange for accommodation and meals. In other cases, a female relative (such as a daughter) might leave her job and move into their parents' home to provide care, becoming dependent on their parent's income, the financial support of relatives, or the remittances of relatives living abroad.

These family caregivers attempt to assume control for the financial matters and bills payments for the person living with dementia. This is often a struggle as the person with dementia may be in denial of his/her condition and not accept help with even medication management – let alone their finances. Carers turn their attention to helping the person with dementia be the most comfortable and they employ a range of non-pharmacological approaches for risk reduction. These include adjusting the family member's diet to reduce salt and fat, while increasing their intake of root vegetables and other healthier foods. They also administer

coconut oil as a regular treatment and use herbal supplements and teas. Many carers also then turn to risk reduction for themselves, attempting to improve their own diet and exercise. Some carers also incorporate cognitive stimulation such as playing music, especially from religious programmes aired on the television or radio.

## Innovations

In 2018, Jamaica's involvement in the STRiDE Dementia Project (Strengthening responses to dementia in developing countries) allowed the first large scale national convening of groups of potential collaborators for targeting national and regional gaps in care provision. This facilitated a diversifying of stakeholders who function as gatekeepers for dementia care conversations and actions. Confronted by the realities shared in that initial meeting and subsequent data collections about the lack of care pathways to send patients on, in partnership with local traditional and social media and partner non-governmental organisations, the STRiDE Jamaica team embarked on a public sensitisation campaign which has been instrumental in linking personnel and amplifying resources, and which raised awareness among GPs and other health and social care practitioners about their need for dementia-specific training for healthcare workers. Working collaboratively with these partners, the STRiDE team continues to respond to these needs by co-developing opportunities for education and exposure. This in turn will help GPs and other health and social care practitioners to improve referral and diagnostic rates and to build out the health and social care system with trained staffing for multi-disciplinary dementia care. Regional health departments and non-governmental organisations can invest in similar evidence-informed interventions to increase awareness and reduce stigma.

The STRiDE Jamaica team has also offered fully subsidised care management consultations. These services have facilitated psychosocial support for carers by equipping them with knowledge about what is likely happening with their family member, what to expect in terms of disease progression, and how to best prepare – emotionally, financially, and logistically. The service has been instrumental in linking informal carers to other support and services and encouraging them to ensure effective investigation for and management of co-morbidities. With the end of the funding for the STRiDE project in March 2022, it is clear that training and services such as these need to continue and that they can in fact be built further. This can happen both as part of the primary care reform currently underway and as extended service offerings in a network of non-governmental organisations, with designated dementia/brain health clinics with multi-disciplinary teams that are partly subsidized.

In the absence of a formal long-term-care system, places of worship and voluntary service organisations such as Kiwanis International and Rotary International Community offer companionship and in some cases meal provision and care packages. This type of activity can, as well, seek

more formal and steady means of support, with, for example, financial assistance for carers via vouchers for respite care or care supplies.

Through its National Advisory Group, the STRiDE Jamaica team also advocated for anti-dementia medication to be added to the national list of subsidised medications. Continued advocacy is necessary along these lines, especially as therapeutics move from symptomatic to disease-modifying. The research that the STRiDE Jamaica team has completed (publications forthcoming) to illustrate the care pathways and the costs that informal carers bear – financial and otherwise – also point to the importance of government level and private sector level investment in flexible work and/or leave options for carers.

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Building on these efforts, as well, with carers of people living with dementia, and research and private sector colleagues in Jamaica, other Caribbean countries, the US, and Europe, we have also been co-developing feasibility work to assess telemedicine and tele-support models for carer upskilling, taking into consideration restricted internet access and low technological literacy and have been co-designing training for informal carers such as domestic workers. This support must be matched with investment in training and provision of group therapy and group activity and a form of psychoeducation and support for those seeking brain-health support and their carers. We are beginning to work on this with key partners who can ensure that these are built out as low-resource models for quality of care accessible to low-income settings and non-specialist personnel outside of institutional settings.

## Expert essay

# Post-diagnostic dementia support in Kenya

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The healthcare system in Kenya is under-funded (constituting 9.2% of the country's budget compared to Abuja's Declaration of a recommended 15%) and experiences constraints due to inequitable distribution of available health workforce and migration of trained healthcare workers[1]. Similarly, dementia and long-term-care funding is limited and undefined in healthcare settings. The available general services, expected to cover dementia care, are mainly in private facilities and limited to a very small population (20%) with health insurance. The National Health Insurance Fund covers 19% of the population (11% being formal sector employees) while other private insurers cover the remaining 1%[2]. It is therefore highly possible that older people, who are most at risk of dementia, are not covered within these schemes considering that majority have either retired or do not have jobs. As a result, access to care becomes a challenge except in circumstances where family members are financially stable to support the person with dementia.

In addition, receiving timely and accurate dementia diagnosis from symptom onset may take months to years due to lack of awareness, stigma attributed to myths, and misconceptions about people with dementia and their carers resulting in abuse and neglect. Clinical and policy guidelines that provide a basis for best and standard practice in terms of screening, diagnosis, and post-diagnostic support are also lacking. These factors result in misdiagnosis, inappropriate care due to misdirected referral care pathways, and poor-quality care, thus affecting the wellbeing of people with dementia and their carers. To compound the problem, the few individuals who can receive a diagnosis still experience difficulties in accepting and exploring treatment options with healthcare providers. This is due to the poor interaction between clinicians and patients attributed to the limited time available to provide information to people with dementia[3]. A common practice in primary healthcare settings from healthcare providers would be to direct the families to the pharmacy or schedule the next visit without necessarily having a detailed discussion on the condition and future health plans.

## Way forward

**1. Dementia anti-stigma interventions** can help create awareness on dementia and demystify existing misconceptions in order to reduce violation of human rights and encourage individuals to use appropriate dementia care pathways and receive support following diagnosis. Although there are minimal interventions to reduce stigma toward people with dementia, there exist opportunities to develop low-resource models that can improve upskilling of lay providers, for example, community health workers. Within the STRiDE project, the Kenyan team and collaborators developed a dementia anti-stigma intervention for use by lay providers[4] that includes a social contact element to allow people living with dementia to share their recovery journey experiences – see figure 1.

Preliminary findings reveal that carers still face challenges in understanding the needs and preferences of people with dementia. Nevertheless, with psychoeducation, their role became manageable as stated by a carer below. This ultimately improves their wellbeing and is likely to reduce cases of depression among carers.

*“Previously, I had challenges relating with my mother since I was not allowing her to perform any activities. I have recently learned to be patient, responsive to her needs, and allow her to perform any pleasurable activities at home and provide supervision for activities that need my attention, and we are now relating well.”*

*Carer of a person with dementia.*

Although the group sessions were conducted among members of the general public, carers within the group seemed to be active participants with the desire to seek more clarification on dementia detection and care, and how to deal with stigma from the society. Carers also mentioned that the sessions made a huge difference and gave them the motivation to continue with their caregiving role as they were more informed.

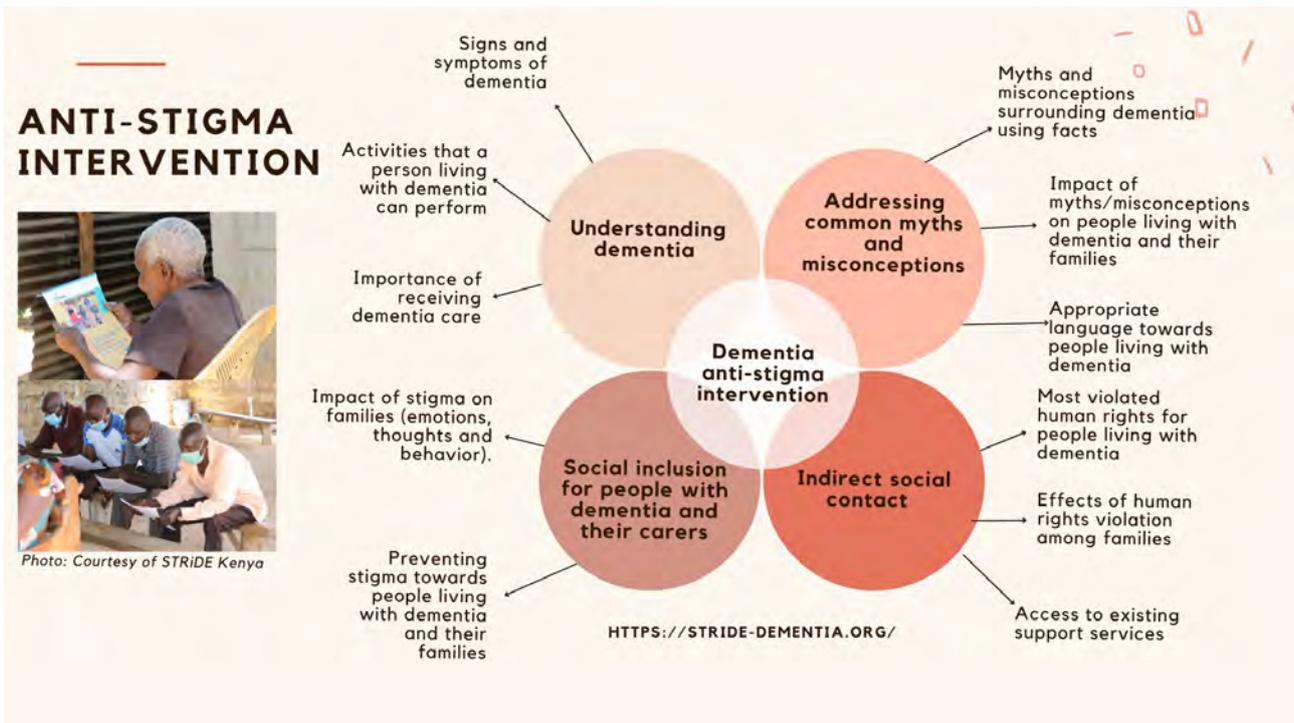


Figure 1: Dementia anti-stigma intervention

Furthermore, Kenya is in the process of developing a national dementia plan that aims at ensuring that people with dementia and their carers receive timely diagnosis, interventions while integrating services in healthcare settings, and employing risk-reduction strategies to reduce the impact of dementia at the individual and family levels. This endeavour is a collaboration between the Ministry of Health and the Kenya STRiDE team, Africa Mental Health Research and Training Foundation (AMHRTF), and Alzheimer's and Dementia Organization, Kenya.

**2. Affordable and quality dementia care:** This includes: 1) psychosocial and pharmacological interventions, 2) treating physical conditions (for example, diabetes, depression, obesity, alcohol abuse, traumatic brain injury) to prevent hospitalizations[5] and reduce cognitive decline, and 3) carer support to improve their quality of life since they are the main providers of dementia care in Kenya. This will build the confidence of carers and enable people with dementia to live their best lives as they contribute to dementia service and policy planning at all levels of care.

**3. Epidemiological studies:** Proper post-diagnostic support is more effective following timely and accurate detection of dementia in order to tailor care to individual

needs. The number of people with dementia is expected to increase by 316% between 2019 to 2050 in Kenya[6]. However, a nationally representative prevalence estimate on dementia is currently lacking[7]. This is in part due to a dearth of standardised tools for routine screening and reporting, including in healthcare settings and residential care homes. In order to improve data collection efforts, it is salient to validate tools and develop dementia registries at primary healthcare levels to document dementia cases. This information could feed into the national data to provide accurate estimates of dementia prevalence that are reflective of diverse regions in Kenya. As a response to this gap, AMHRTF has received funding from Davos Alzheimer's Collaborative (DAC) Healthcare System Preparedness team, to integrate dementia screening for older adults in primary healthcare settings.

Training healthcare workers on detection, systematic disclosure through dialogue following diagnosis, and management of behavioural and psychological symptoms of dementia can also improve recognition of dementia burden in general practice. As such, people with dementia can participate in their healthcare planning and promote person-centred dementia care.

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## Expert essay

# Post-diagnostic support in Madagascar

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**M**adagascar, the fifth largest island in the world, has a population of around 26 million people. Low standard of living and the lack of a healthcare structure, especially in rural areas, lead the majority of the population to treat themselves without the help of healthcare professionals, but with home remedies, self-medication, or traditional methods. In Madagascar, dementia is still “an invisible concept” for a large percentage of the population, and this is a trend that is found within the medical system, due to a lack of information and awareness, about one of the public health priorities in the world.

## Types of support available

When a person living with dementia has had the opportunity to get a diagnosis, even if the type of dementia is not always defined, there are different types of support available, which do not always follow a set path. The choice of the type of support is frequently linked to the feelings of the primary carers and sometimes those of the extended family.

## Spiritual concerns

Many families do not talk about their loved ones' diagnosis and may tend to hide or even lock them away at home. The main reason is the lack of information and awareness about the condition, especially the fear of prejudiced attitudes of society, which does not always know that dementia can be the consequence of a disease, such as Alzheimer's. Members of society sometimes have deeply rooted beliefs and often judge people with dementia as victims of a demonic possession or an act of witchcraft, to the point that they will advise the families to go for spiritual deliverance or even exorcism sessions, which often involve brutal procedures with a very negative impact on the mental health of the individual. This gives a great sense of failure because the person living with dementia has already obtained a medical diagnosis, and sometimes even the carer has already inquired about available support at Madagascar Alzheimer (the Alzheimer association), yet other family members with a very different vision still manage to convince the primary carer of the need to turn definitively to an exorcist or another spirit healer.

## Drug-based therapy

In the capital city, where access to specialized health centres is easier, many people living with dementia are treated with medication, following consultation with specialised doctors such as neurologists, neuropsychiatrists, or psychiatrists, who have been able to establish a diagnosis. Even if the type of dementia cannot always be determined, due to financial issues (for example, the inability to afford medical imaging tests, blood tests,...), a protocol is set up to try to treat the patient as best as possible, even if it is sometimes only a symptomatic treatment, especially when mood and behavioural symptoms affect the quality of life of the patient and their carer. Unfortunately, families' purchasing power for long-term treatment is often limited, as drugs are expensive and sometimes not even available locally (for example, Aricept) and must be purchased externally. In most cases, this can lead to irregularity or even cessation of treatment and does not allow a clear view of the evolution of the patient's condition.

## Non-drug therapy

Non-drug therapies are available, and more and more families seek help at the Madagascar Alzheimer association to find out about the services offered. Our day care centre allows us to work on two levels:

- The improvement of the patient's daily life through our activities given five days a week, with the guiding principle of socialising the patient. Music therapy, art therapy, gardening, story sharing, occupational therapy, physical exercises, brain games, etc. are activities that allow the patient to regain a good level of self-confidence and, above all, to maintain their autonomy. “Humanitude” is the reference method that inspires our centre, and it has always had positive results in slowing down the various loss of abilities due to dementia. Moreover, the values of “Valim-babena” (which refers to the idea of gratefulness and recognition that we owe to the parents who raised us) and “Fihavanana” (In Malagasy culture, “fihavanana” means “mutual help and solidarity” and is a notion of social connection that is the basic principle of collective life in Madagascar – similar to “Ubuntu” in

other regions of Africa) – specific to the Malagasy culture whatever the region or ethnicity – are the foundations of our relational activities with people living with dementia who in majority are elderly people, and very sensitive to these values.



Picture 1: People living with dementia are still very sensitive to the values of "Valim-babena" and "Fihavanana."

- The improvement of the carer's life, who can feel a concrete relief, when the association becomes a safe place where their loved one can spend time one or several days a week. Improving the relationship between the person living with dementia and the carer, by sharing best practices to be used on a daily basis. This breath of fresh air allows for a clear improvement in the mental health of both parties, who can then reconnect with more positive vibes and emotions.

The carer's skills can be improved during three-day training sessions organised by the association, and/or by the monthly support groups giving time for carers to have a break, and to exchange and share new knowledge, solutions, and best practices used on a daily basis with other families.

### What could improve post-diagnostic support in Madagascar?

There are four important steps that could help improve post-diagnostic support in Madagascar:

- Setting up a quality diagnosis protocol that meets the financial realities of the population.
- Giving increased information to general practitioners to raise awareness so they can recognise the symptoms of the onset of dementia and refer the patient to specialised and adapted care if necessary.
- According to the experience of Dr Raharison Andrianaina, neuropsychiatrist/psychotherapist, the observation of the patient in his usual environment can help to better recognise the type of dementia, which will help to give more precise diagnosis and then certainly more effective care in the long term.
- Developing a national dementia plan to apply all the good practices of information, awareness, diagnosis, and post-diagnosis support all over the country.



Picture 2: Awareness is the key to a better quality of life after a diagnosis.

## Expert essay

# Cultural implications for people living with dementia and their families in Mexico

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## Dementia in Mexico

Mexico's population aged 60 years or older represents 12% of total population[1] and it is estimated that by 2050 this proportion will double[2], in parallel with increasing burden of chronic degenerative diseases. People are living longer, but not necessarily free of disability or in good health[3]. In 2014 there were 3.4 million people 60 years or older estimated to have a disability according to the definition of the Washington Group on Disability[4] and who require care assistance. Among these, 9% and 18% were impaired to carry out Activities of Daily Living (ADL) and Instrumental Activities of Daily Living, respectively[5].

The Mexican Health and Aging Study (MHAS) estimated a prevalence of dementia of 5.2% adjusted for age and schooling[6] while results from the 10/66 Dementia Research Group research study show a prevalence of dementia of 8.6% and 7.4% in urban and rural areas, respectively[7]. Acosta-Castillo and colleagues[8] reported an adjusted prevalence (by sex, age, and education) of dementia by state and level of deprivation of 8.0% at national level, ranging from 3.3% in the state of Querétaro to 12.5% in Jalisco, and from 3.9% in people between 60–69 years to 20.6% in the group aged 80 years or older.

## Knowledge of and stigma against dementia

Dementia is widely perceived as part of the normal ageing process; memory loss is almost normalised and, in that sense, little help or formal health care is sought. On most occasions, it is sought in the late stages of the disease. Lack of information and knowledge of dementia, its symptoms, and causes mean that negative perceptions are widely present at the individual, family, community, and society levels. For many, and particularly in individuals with low resources and low educational attainment, Alzheimer's and dementia are

attributed to external factors such as stress, alcohol consumption, sequelae of another illness, of being in hospital, and in some cases, as punishment or someone "wishing you ill."

On the other hand, hiding the illness/symptoms from others outside the household or even the person with dementia in its advance stages is common practice. Reports from the World Alzheimer Report 2019[9] show that among general public respondents to a survey, 41.2% perceive people with dementia as dangerous, and 73% of them said that people living with dementia are impulsive and unpredictable. Moreover, among health professionals non-specialised in brain health (which is most health practitioners), lack of knowledge and training causes dismissal of symptoms, and delayed or absence of referrals and of support strategies for people with dementia or their family carers. While government does not have a negative perception, in general, public employers have negative perceptions that affect their behaviour and services.

On the positive side, Alzheimer's and other dementia associations have increased their participation by providing most of the care and support available for people with dementia and their carers, acting as the main pillar of campaigns to increase knowledge and reduce stigma. For example, the Mexican Alzheimer's Federation, FEDMA, has delivered the Dementia Friends initiative in 17 (out of 32) states and has trained approximately 7,000 dementia friends.

## Dementia care and policy context

While ageing has been increasingly positioned within the public agenda in the past two decades, there are currently no specific dementia policies or programs, nor areas within the Ministry of Health with the mandate to oversee all dementia-related issues. Except for a few publicly funded hospitals nationwide with specialised memory-dementia clinics or services, or highly expensive private services accessible to only a small proportion of the population, no specialised services are available. Therefore, people accessing health

services in any of the health system institutions are subject to the existence/availability of other specialist services to which they could be referred (geriatrics, neurology, psychiatry) and probably receive a diagnosis. However, there are no standardised treatment protocols in place covering all health and social security institutions, nor specific social care programmes for people with dementia or that support their family carers.

Regarding support for unpaid family carers, Mexico does not have a comprehensive national care system that adequately responds to the needs of services and support for this population. In addition, there is no inter-institutional coordination between public and private entities as providers of care services due to the lack of a regulatory body and adequate standards that guarantee the quality of services. There is also an urgent need to professionalise the role of formal carers in care homes for older adults or in-home private services, who currently provide services in a frequently improvised manner, without proper competencies, training, or skills.

To date, families still occupy the fundamental role of caring for their family members with dementia in their homes, with no support from public or government institutions. However, given the demographic change of the population and the structural change of the family unit, it is increasingly difficult to assume that responsibility for care will rest with

family members. As a result, dementia policies and mechanisms to support families through public actions at the community level where the collaboration of the health and social sectors is desirable.

## Prospects for future dementia care policies

In 2014, a national Alzheimer's and other dementias plan was generated as a collaborative effort between the National Institute of Geriatrics, researchers, the National Institutes of Neurology and Psychiatry, Alzheimer's associations, and federal government stakeholders. The main objectives of the National Plan include promoting the wellbeing of people with dementia and their family carers, increasing knowledge and reducing stigma, and generating actions to prevent dementia, when possible, by strengthening the response of the Mexican Health System, in synergy with all responsible institutions[10]. Two initiatives have been recently introduced at the legislative chambers to increase knowledge and awareness, the implementation of dementia diagnosis and management policies, as well as programs for the promotion and prevention of dementia when possible. Hopefully, these first steps will be followed by specific budget allocated so that concrete actions toward achieving sound dementia care policies will be established soon.

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## Expert essay

# Post-diagnostic care for dementia – the Nigerian perspective

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The diagnosis of dementia is often met with deep sadness by family members because it is a serious illness that causes cognitive decline. The diagnosis is often made by either neurologists or mental health physicians. However, in rural communities, alternative care practitioners may be contacted first; these practitioners usually ascribe the illness to visitation by ancestral spirits. In the eastern part of Nigeria, affected individuals are often taken to see two or more service-providers in such places as churches, indigenous healing centres, homeopathic clinics, private hospitals, and patent medicine stores before proper assessment by experts on the disease. They may undergo interventions such as sacrifices and scarification with heavy financial implications, as reported by Uwakwe[1]. By the time the affected person is eventually referred, a lot of money would have been wasted and the illness would have advanced.

Home care is favoured for management, and most families make adjustments to care for the affected person. The spouse and/or the children provide care. However, in some instances, extended family members living in the same abode provide care and they are usually not paid for such services. The carers bear the brunt of the disease and are often stressed. A recent qualitative study revealed that caregivers were overworked (~13 hours daily) and had limited knowledge about dementia[2]. Depression, hypertension, and various other ailments commonly afflict them[3]. However, in recent times, paid domestic workers employed by affluent families end up providing care to people with dementia.

The stigmatisation of people and families with dementia, though universal, is particularly problematic in sub-Saharan Africa. It is due to lack of awareness and poor understanding of the disease. In our experience in a rural community in southwestern Nigeria, dementia was referred to derogatorily as “memory loss disease,” “disease of insanity,” and “dull brain.” Both implied and enacted stigma including shame and the ignoring of people with dementia were evident in a sizable proportion of people in the community[4]. Uwakwe noted that the social stigma of all mental disorders by the public had greatly limited care of people living with dementia[5]. These reasons would explain why home care is favoured, as it saves the family from shame.

Institutional care in the form of seniors' residences is not culturally favoured because of the stigma of destitution associated with placing family members in such facilities[2]. This trend may change as the number of older people is increasing and family sizes are dwindling because of more nuclear family living arrangements. Another reason the trend may change is rural-urban migration for economic pursuits. In the advanced stage of dementia, when constant supervision is required, hospitalisation may be necessary for the management of acute and life-threatening complications. The preference, however, is for the affected person to die at home.

The treatment of someone living with dementia is purely symptomatic and supportive. Medications for memory enhancement and behavioural challenges are prescribed by physicians. The most commonly drug prescribed is Aricept (donepezil). Other anticholinesterase drugs such as galantamine, rivastigmine, and memantine, an anti-glutamate, are not readily available. The cost and availability of the drugs affect adherence to therapy, particularly for families who are poor. The relations are thus forced to seek alternative care. Other memory-enhancing drugs such as ginkgo biloba and vinpocetine (Cognitol) are available and have been tried with minimal or unsustained clinical improvement. Psychotropic drugs are prescribed when behavioural and psychological symptoms predominate with risperidone as the drug of first choice. Co-morbidities such as hypertension, diabetes mellitus, osteoarthritis, and visual and hearing impairment are managed concurrently.

The challenges encountered in post-diagnosis management include inopportune mistakes resulting in home accidents (such as fire outbreaks or the flooding of premises), nocturnal confusion, getting lost, incontinence, physical aggression, suspicion, and financial mismanagement. Family members looking after individuals with dementia often seek the help of psychiatrists in handling such behavioural and psychological symptoms since these can lead to stigmatisation within the community. Education of the public can address family concerns such as prognosis, heritability, avoidance of stigma, and where to seek medical treatment.

## Future care prospects

1. Introduction of “day centres” for older people with dementia to ensure that supervised daytime care is available. This will enable family members to go about their daily duties and at the close of work, pick up their relative with dementia to continue home care. Day centres could be located within existing geriatric centres or be purpose-built.
2. Training on and deployment of cognitive stimulation treatment (CST) for those with mild to moderate dementia. CST is cost effective and was shown to be feasible in low-resource settings by the IDEA study[6]. This group-based, reminiscence therapy brings about modest improvement in cognition, especially language function, and reduces the load borne by carers. It also makes task-shifting in care possible.
3. Use of assistive devices for close monitoring of people living with dementia to increase independence while maintaining safety as well as providing support for the caregivers.
4. Development and implementation of a national care plan for dementia.

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## Expert essay

# Post-diagnostic support in Scotland

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Following many years of campaigning by Alzheimer Scotland, the Scottish Government made a commitment in 2013 that every person diagnosed with dementia in Scotland would receive a minimum of one year of support from a trained and named Link Worker, based on Alzheimer Scotland's "Five Pillar Model of Post-Diagnostic Support."

This guarantee by the Scottish Government is considered world leading, and to date is the only national post-diagnostic guarantee of its kind. Alzheimer Scotland's Five Pillar Model uses person-centred planning to put the person and not the illness at the centre of the support they are offered. Central to this model is the role of Post-Diagnostic Support Link Workers, whose role is to help people to understand their illness, build resilience, and develop their individual abilities and strengths, therefore enabling them to live well with dementia and maintain independence for as long as possible.

High-quality post-diagnostic support can delay admission to residential care, hospital, and other forms of costly health and social care services. There are currently 90,000 people living with dementia in Scotland and around 3,200 of those are under the age of 65. As Scotland's population ages, the number of people with dementia will increase and it is expected that the number of people living with dementia in Scotland will double over the next 25 years.

Receiving a timely diagnosis of dementia is hugely important for people. It provides access to critical help and resources that can enable them and their families to understand and make sense of the changes that are happening, to access peer and community support, and to help plan for the future.

Since 2013 many thousands of people have benefited; however, since this national commitment was introduced, fewer than half of those who are entitled to a minimum year of support have been offered it. Alzheimer Scotland has campaigned continuously for the resources required to ensure that every person diagnosed with dementia is offered this post-diagnostic support.

In partnership with Health Improvement Scotland, Focus on Dementia, and NHS Education for Scotland, Alzheimer Scotland developed tools to evidence the quality of post-diagnostic support delivered. The Quality Improvement Framework comprises four key areas essential for the delivery of high-quality post-diagnostic support: person centred, clear pathways, delivered by well-trained practitioner(s), and ensuring participation of everyone involved. The framework aims to improve the quality of the experience for people with dementia and their families in Scotland, reducing variation in how services are delivered.

A single quality questionnaire was designed to provide important information about how helpful post-diagnostic support has been to people with dementia and carers, and the difference it has made to their lives. The responses from the questionnaire have informed ongoing improvement in post-diagnostic support practice.

Existing gaps in the provision of post-diagnostic support were exposed and widened by the COVID-19 pandemic, which brought disruption to diagnostic and post-diagnostic services. The pandemic and the disruption it caused meant that many people were unable to get a timely diagnosis and the opportunity to access post-diagnostic support. The impact of that disruption is still being felt by many thousands of people who have not been able to get the help they need, and many have experienced a decline in their physical and mental health. Alzheimer Scotland continued to deliver vital help during the pandemic through virtual post-diagnostic support – online or by telephone. While this worked well and will continue to be valuable as part of a blended model, it also means that opportunities for peer support and maintaining community connections have been diminished.

Throughout the pandemic, Alzheimer Scotland has highlighted the growing backlog of people awaiting a diagnosis and post-diagnostic support. We have campaigned to ensure

that sufficient funding is in place to guarantee that post-diagnostic support is offered to every person diagnosed with dementia in Scotland.

That campaign was successful and in November 2021, the Scottish Government announced £3.5 million would be awarded to Scotland's Health and Social Care Partnerships to deliver the post-diagnostic support commitment for every person who had a dementia diagnosis. This has now been

allocated and Health and Social Care Partnerships have been putting their plans in place to use this additional funding to increase their capacity to offer this to everyone who needs it.

This additional funding will expand access to frontline services and strengthen and support wider dementia community projects which benefit people with dementia and their families after a diagnosis.

## Expert essay

# 'Ageing in place' with dignity: post-diagnostic care for dementia in South Africa

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## Background

Dementia is often not recognised as a serious health condition in South Africa and largely understood as a “normal part of ageing” by both communities and the health and social care sectors. Early detection and access to a formal diagnosis, treatment, and support reflect long-standing inequalities in South Africa. Despite active attempts by the State to redress historical inequities in health, adequate responses to dementia (including access to a diagnosis) are largely skewed to the minority who can afford premium health and long-term care. Many older adults living with dementia in South Africa are therefore believed to be either undiagnosed or misdiagnosed and living at home.

## Understanding dementia in South Africa

South Africa is a multi-cultural country with 11 official languages and a myriad of belief systems, customs, and cultural practices. Understanding responses to dementia at a community level is therefore complex, where culture and social beliefs act as both sources of support as well as stigma and discrimination. As with mental health symptoms, the symptoms associated with dementia are often stigmatised and as a result people living with dementia and their families experience social isolation, avoidance, and rejection by communities where dementia is not understood as a medical condition. [1,2,3] In many African countries, the origin of misfortune or illness is often believed to be social in nature [3,4], such as being caused by “social jealousies” or being “cursed” or “punished” for wrongdoing in their past. People living with dementia and their families are often selective about disclosing a diagnosis (if disclosing at all), as awareness and understanding of dementia varies greatly across South Africa.

Spirituality and belief systems also play a critical role in coping with stressors and great personal difficulties. Furthermore, people living with dementia and their families sometimes rely on the social and practical support offered by faith-based organisations, such as lifts to medical appointments, informal respite care, and participation in social

events for older adults and their family carers. Faith-based organisations and spiritual and traditional leaders are often the first port of call for help for many families and play an important role in supporting individual and family resilience. These community systems are therefore an important avenue for increasing awareness and understanding of dementia and could be instrumental in facilitating positive responses that support people living with dementia and their families in culturally acceptable ways.

## The critical role of the family

Despite the heterogeneity of families in South Africa, the immediate family are often the first responders to the needs of people living with dementia. Socio-cultural norms often, but not always, prescribe roles and responsibilities of family members according to age and gender. As a largely patriarchal society, these norms also assign care responsibilities as primarily a female role. Caring for someone living with dementia in the family is therefore often the responsibility of female members [5] and as care needs progress, care provisions become a full-time responsibility that often necessitates these women no longer participating in economic activities. Despite these challenges in a context of widespread poverty, unemployment, and inequality [6], the family largely remains the locus of control for many people with dementia. Responses to health needs and decisions about resources (including finances) are often made *by* families or *within* families. The family therefore plays a critical role in the post-diagnostic support of people living with dementia and approaches that focus on the individual in responding to dementia often fall short of recognising these social structures that inform health outcomes.

## Towards dignified “ageing in place”

South Africa unfortunately does not have a National Dementia Plan (NDP) or strategy, nor does it respond to dementia care in a coordinated way. Building awareness and education about dementia is slow in a country with many competing priorities and there is a great need for formal training on dementia and ageing across sectors.

Commendably, existing policies that guide services for older people are embedded in a philosophy of “ageing in place.” “Ageing in place” promotes the full participation of older people in decision-making, as well as encouraging older adults to remain active within their communities for as long as possible (Jordan 2009)[7]. Government relies heavily on the NGO-sector to provide community-based services to the majority of South Africans, but there remain enormous constraints in funding and support for these structures. In the absence of adequate support for the health and social care needs of older adults at community-level and within their families, “ageing in place” *with dignity* becomes an enormous challenge. Families shoulder the excessive cost of dementia-related tests, prescribed medications, and care support. They also risk impoverishment when care needs demand the full-time commitment of a critical economic resource in a family already living poverty.

Residential care for older adults is, in most cases, not a culturally or financially acceptable response to care needs for many South Africans. Long-term-care facilities are available for those who prefer this option but are usually reserved for the minority who can afford their excessive costs. Therefore, the South African *family* remains a critical de facto support system for people living with dementia from pre-diagnosis to end-of-life. For most South Africans, “ageing in place” cannot be realised without strengthening community-based responses that include dementia care, where services promote early detection, diagnosis, and accessible, culturally acceptable options for care and support. Such a system will retain the family-focused source of care but in a supported manner, rather than the current largely unsupported informal system.

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## Expert essay

# Cultural implications for people living with dementia and their family in the Indian context

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Due to the rise of the elderly population over the last few decades, dementia has moved from a public health issue to a global public health priority based on the sheer number of people affected[1]. While certain aspects of dementia diagnosis and care are universal, reducing the global burden of dementia actually relies on tackling this multifaceted issue through contextualised and localised forms of medical practice and care. Socio-cultural contexts differ across the world, and it is crucial to understand their impact on people living with dementia and their families to ensure that management strategies are effective. India is a multicultural and a multi-ethnic country and this diversity significantly influences dementia awareness and care. With dynamic economic standards and the uneven spread of globalisation, traditional practices of care are constantly evolving to meet current needs, and this combination of conventional and modern practice has a major impact on lives of people living with dementia and their families.

The burden of dementia in India is highly systemic, societal, and projected to rise by 197% by 2050[2]. Currently, the treatment gap for dementia is estimated to be more than 90% due to lack of awareness in societies, low levels of literacy, consideration of dementia as a part of normal ageing, and limited healthcare[3]. The assumption that dementia is a natural progression of age-related frailty leads to delays in obtaining medical care. People's understanding of dementia, the stories told, and the language used to depict symptoms associated with dementia, are determined by socio-cultural contexts. This understanding is also influenced by social assumptions about gender, social class, religion, economic status, and individual biographies within the family context[4]. Thus, stigma remains high and often prevents people from seeking diagnosis or support, leading to social isolation. Even among professionals and healthcare providers,

there is limited dementia awareness. This implies that even after diagnosis, there is a systemic lack of understanding of dementia care leading to limited post-diagnostic support.

Family remains a major social system that plays dual roles in the context of dementia, as a space of care and isolation all at once. A majority of older people in India live in inter-generational families, and dementia diagnosis relies heavily on reports of family caregivers who are less likely to report memory loss and poor cognitive abilities. The responsibility of daily household activities is shouldered by younger family members, and as a consequence, minor cognitive problems go unrecognised. Help-seeking behaviour is also influenced by the reliance on traditional home-remedies, which causes delay in recognising the need for treatment and influences the care of people living with dementia in the Indian context.

Cognitive testing plays a crucial role in assessment and diagnosis of dementia. Many cognitive tools are non-equivalent across cultures and languages. In India, several efforts have been made to incorporate socio-cultural characteristics such as lifestyle, clothing, food, etc., during adaptation of cognitive tools to test semantic knowledge, language, memory, and spatial skills[5,6]. The lack of "formal education" also acts as a barrier within the cognitive testing sphere. Individuals with low levels of literacy are often associated with high levels of occupational complexity (for example, craftsmen with low literacy but high expertise in complex perceptual motor skills). Cognitive tests should be developed to assess cognition in a culture-fair manner across societies.

Management of dementia involves pharmacological and non-pharmacological interventions that reduce symptoms and improve the quality of life. While the majority of drugs used for symptomatic treatment are widely available, they are expensive, with limited accessibility for people from low socioeconomic status[7]. While a few non-pharmacological

treatment options are implemented, socio-cultural and educational diversity makes it challenging to develop a standardised cognitive stimulation therapy (CST) protocol. Playing traditional Indian games, drawing *rangoli* or *kolam* patterns, and singing *bhajans* are culturally relevant activities incorporated into the CST. Ayurveda as a personalised system of holistic medicine has long been accepted in India. With major impetus provided by the Government of India through the AYUSH programme and recently, the Traditional Medicine Program of the World Health Organization, focus is given to develop an evidence base for traditional medicines that bring qualitative change for disorders such as dementia[8].

As a society that relies heavily on established socialisation, families in India are recognised as capable of therapeutic participation. Family members share close kinship links, and this extends to the close engagement with the care process. Social relationships over several members of extended families and social networks that are an outcome of such systems have a largely protective influence in dementia care. However, gender-based disparity in cognitive health is evident. Service utilisation for older women is influenced by inequity in access to education, nutrition, economic independence, and ascribed roles[9]. Formal long-term-care arrangements and social support, especially in advanced stages remain limited. A few low-cost, locally driven carer-based interventions have shown to be beneficial and sustainable. Advance care

directives and end-of-life care plans have to be addressed within the Indian socio-cultural framework. There is a need to develop dementia intervention programmes that are integrated into the collectivistic system that exists in India.

Perceptions regarding the role of life-course factors for maintaining cognitive health vary across different ethno-cultural groups. Risk factors for dementia such as hypertension and diabetes are highly prevalent in India. Early interventions in these lifestyle-factors are being recognised as a public health priority in national programmes that target non-communicable disease management. A few studies from India have found yoga, meditation, and Indo-Mediterranean diet as protection against dementia[10]. It is therefore important to increase awareness and institute preventive public health strategies relevant to the Indian context.

In conclusion, recognising that socio-cultural practices profoundly impact lives of people living with dementia, enhancing efforts to impact public perception, healthcare systems, and policy can contribute to improving their quality of life. Efforts from dementia stakeholders that include healthcare systems, governmental and non-governmental organisations, as well as policy change can contribute toward developing equitable solutions and enhancing the wellbeing of people living with dementia and their families in the Indian context.

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## Conclusion

This chapter explores the impact of post-diagnosis dementia support across several different countries, many located in the Global South. Just as any one individual has a unique experience of dementia, each country's experience is particular to its own socio-economic and political landscape. No two countries are exactly alike, but there are common themes that repeat across borders such as stigma, the emphasis on family carers – particularly women – and the impact of this role on them, the need to consider diverse cultural perspectives, and how technology may bridge the gap and increase access to support and education.

One call to action across all the essays is the need for solid policy change to underpin implementation of best-practice dementia care services. National dementia plans remain the best strategic planning tool to help governments focus on diagnosis, post-diagnostic support, and care pathways for people living with dementia and their carers.

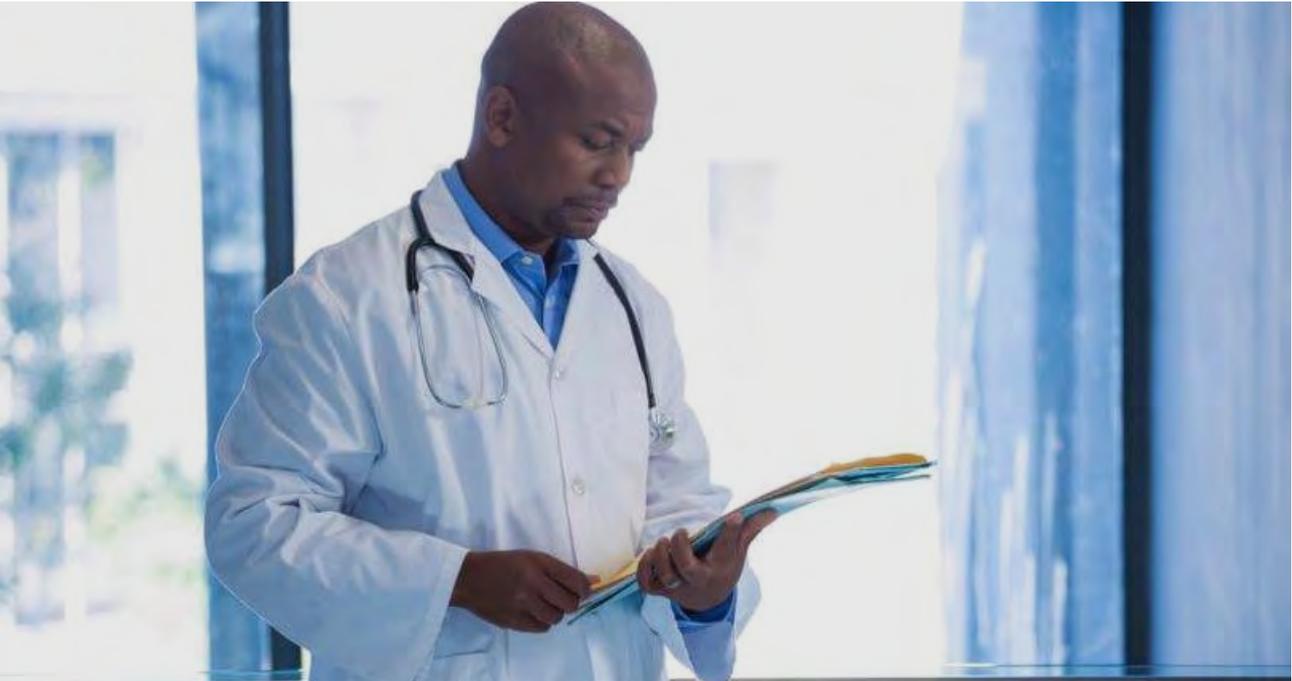
# Chapter 6

## How to achieve comprehensive post-diagnostic support in primary clinician setting

*Serge Gauthier, José A. Morais*

### Key points

- Post-diagnostic support of people living with dementia is defined as "holistic, integrated continuing care in the context of declining function and increasing needs of family."
- This is a process that starts immediately after the dementia diagnosis and concludes at end of life. It is a long-term commitment from clinicians and carers alike.
- The barriers to delivering post-diagnostic support are similar to the barriers that impede the diagnosis of dementia itself, particularly regarding the capacity of primary care sectors and the existing infrastructure.
- A realignment to a task-shifted, task-shared approach with greater primary care involvement is needed.
- Post-diagnostic care for individuals with dementia includes ongoing management of their condition and comorbidities, in addition to support of carers.
- There are innovative capacity-building care models that focus on the delivery of support and services based on the individualised needs of people living with dementia and their carers.
- There is considerable evidence that the carer role is challenging and can have detrimental psychosocial, physical, and financial impacts.
- A multidisciplinary approach that synchronises healthcare professionals within different specialities to communicate and work together is the most effective way to deliver the best post-diagnostic support that people living with dementia and their carers deserve.



## General background

When contemplating the content of this chapter, the intent was initially to focus solely on the impact that a dementia diagnosis had on the day-to-day practice of a family physician. It evolved to encompass so much more – namely, how substantial changes are needed to provide reliable post-diagnostic support to everyone involved, including the individual and their carers. This aspect has long been overlooked. Whether the person with dementia has been in the clinician's care for over 20 years or a new doctor is assigned to their case, disclosing a dementia diagnosis necessarily means embarking on a long journey through the illnesses' different stages.

One option available to clinicians is to refer the person living with dementia to an appropriate specialist. This may be to confirm the initial diagnosis or to make other experts available to help them manage difficult decisions such as when to stop working, driving, and living at home. Unfortunately, this care model that hands over long-term post-diagnostic support (PDS) to other specialists is untenable due largely to the shortage of such specialists and the increasing numbers of people living with dementia. Heightened public awareness surrounding early symptoms has greatly impacted these numbers as the general population now seek out diagnoses earlier. There is no denying that a timely and accurate dementia diagnosis is a powerful tool to help slow cognitive decline. It also allows for pinpointing some reversible causes and allowing family and friends to consider the distribution of care responsibilities and to make medium- and long-term plans. These aspects, including the many obstacles faced by family physicians,

are well explained in the essay by Vladimir Khanassov. In it, he delves into how the existing infrastructure does not lend itself to providing crucial post-diagnostic support.

The prevalence of dementia has prompted many countries to develop national programmes and strategies to address the many issues that surround dementia, while also recognising the various gaps that exist when having to treat comorbidities. Estelle Dubus and Maria Soto Martin have devised a thorough 10-point multidimensional evaluation to draw attention to the complications surrounding dementia, thus helping to prevent and treat them. How can one family practitioner in solo practice handle all this?

Fortunately, there are promising new care models, as detailed by Louise Robinson in the UK and Wales (the PriDem programme) and by Linda Lee and Loretta Hillier in Canada (the MINT Memory Clinic programme). These all share a common foundation, namely that a collaborative approach between primary care, specialist care, community, and national agencies is necessary to promote and implement a person-centred strategy that better serves the needs of people living with dementia and their carers.

A more global approach aimed at reducing the impact of a dementia diagnosis for clinicians is early education about chronic diseases management of conditions such as diabetes, cancer, and dementia starting in medical school, including primary and secondary preventive measures. This will be explored more fully in Chapters 22 and 23.

## Expert essay

# Implications of dementia diagnosis in family practice: reflections on post-diagnostic support of dementia

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Post-diagnostic support (PDS) of people living with dementia (PLWD) is complex and requires the involvement of various services, with the leading role generally ascribed to primary care[1]. A task-shifted/task-shared approach focusing on the development and expansion of primary care in the post-diagnostic support of people living with dementia has indeed been recommended in the 2016 World Alzheimer Report. Post-diagnostic support (or management) of people living with dementia is defined as “holistic, integrated continuing care in the context of declining function and increasing needs of family”[1]. Post-diagnostic support is a process that starts immediately after the dementia diagnosis is rendered and concludes at end of life. From the onset, it encompasses the ongoing management of the individual's dementia as well as any comorbidities, and the assessment and support provided to carers.

While many countries have developed national dementia programmes and strategies, practical guidance of post-diagnostic support content [2,3,4] is sporadic at best. Its delivery varies across countries and depends on multiple factors such as: primary versus specialised-based dementia care, public versus private healthcare system, and solo primary care practice versus multidisciplinary team based including specialist support. A significant number of studies have been published on assorted dementia care-based models,[5,6,7] with the most effective proponent favouring primary care case management that embraces collaborative efforts of family physicians and nurses and focuses on all aspects of dementia care including neuropsychiatric symptoms associated with the disease as well as carer burden and distress[6]. Successful case management models are associated with smaller caseloads, regular appointments with people living with dementia and their carers, and education about the disease as well as proactive and timely follow-ups[6]. Implementation of such initiatives would address the concerns of people living with dementia and their carers regarding the lack of structured post-diagnostic follow-ups[7].

“ **Successful case management models are associated with smaller caseloads, regular appointments with people living with dementia and their carers, and education about the disease as well as proactive and timely follow-ups.** ”

Other models of post-diagnostic management exist, such as memory clinics with specialised care, primary care with specialist consulting support, and integrated primary care memory clinics. However, there is limited evidence supporting their effectiveness[8]. The cost-effectiveness analysis of all these models is either limited or ineffective.

The barriers to delivering post-diagnostic support of dementia to people living with dementia are often similar to the barriers that impede the diagnosis of dementia itself, particularly regarding the capacity of primary care and the existing infrastructure. These include an unwillingness of primary care practitioners to get actively involved in the post-diagnostic management of dementia, the lack of knowledge and skills about post-diagnostic support, minimal or untimely support by specialists, and unsustainable services with inadequate access and a lack of information[5,9].

While many of the barriers are often beyond the control of family physicians (for example, a lack of development and implementation of post-diagnostic support models at the local, provincial, state, or national levels, and access to medical records among the different players within the healthcare system) some challenges can be addressed by the individual primary care practices with appropriate support listed in Table 1.

Table 1

**Actionable items in primary care to deliver best post-diagnosis support**

- Establish improved and ongoing educational and training initiatives at all levels of government, professional boards, and universities.
- Arm family physicians within a practice with additional pre-diagnostic and post-diagnostic dementia expertise. Having a resource clinician on staff will boost confidence and deliver better care.
- Integrate decision-making tests and tools as well as established algorithms available in a person's electronic medical records to provide effective post-diagnostic support.
- Enhance nurses' training and knowledge in dementia care management to facilitate and support family physicians with active follow-ups and liaise with interdisciplinary community services.
- Include pharmacist in the annual medication review of a person living with dementia to avoid polypharmacy (> five classes of medications). This may well be impacted by the presence of comorbidities.
- Perform an evaluation of the carer in an independent appointment.
- Enlist the support of social workers, carer support services such as the local Alzheimer Society chapters, occupational therapists, and more for seamless person-centred care.
- Develop and conduct carer workshops to assist them in understanding dementia, its progression and how to plan for effective care at all stages.
- Integrate virtual appointments within the telemedicine model for follow-ups that can be managed remotely. These include discussion about test results and psychological support for carers. This would cut down on travel times and help with those living in rural or remote areas.

Most people living with dementia are diagnosed and followed in primary care practice. To provide appropriate post-diagnostic support, primary care professionals should be efficiently supported. The multidisciplinary approach

that synchronises all healthcare professionals within different specialities to communicate and work together is the most effective way to deliver the best post-diagnostic support that people living with dementia and their carers deserve.

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## Expert essay

# Managing comorbidities in a person living with dementia

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**T**he medical follow-up of a person living with dementia (PLWD), at all stages of the condition, is part of a global person-centred management approach to prevent and treat complications. Identifying these complications requires a systematic assessment conducted at each follow-up medical visit. We propose a systematic 10-point multidimensional approach covering nutrition, autonomy and physical capacities, gait and balance disorders, neuropsychiatric symptoms (NPS), sensory impairment, iatrogenesis, cardiovascular risk factors, pain, social environment, and cognitive worsening. This assessment must be adapted for the people living with dementia's lifestyle and stage of disease[1].

## Nutrition

Adherence to a Mediterranean-style diet with a higher consumption of mono- and polyunsaturated fatty acids and a lower intake of saturated fatty acids is generally recommended to help reduce the risk of cognitive decline[2]. There is a risk of malnutrition associated with dementia. Regular monitoring of nutritional status involves assessing appetite and food intake, and measuring muscle strength (for instance, using the chair stand test for the lower body) at every follow-up visit[3]. Mini nutritional assessment (MNA) is also recommended to screen a person's nutritional status over time[3,4].

In the case there is a risk of malnutrition, recommendations about dietary consumption should be made. These include: dividing food intake, avoiding night-time fasting, favouring menus tailored to the person's preferences, choosing energy-boosting foods rich in protein, providing personalised assistance to meet the individual's needs, and creating a pleasant environment for mealtime[4]. Food enrichment is also advised. This increases the protein-energy intake without increasing the volume of food consumed. This can be achieved by using butter, oil, cheese, or eggs in meal preparation[4]. In case this management plan fails, or severe malnutrition develops, a nutritional supplement should be prescribed[4].

## Physical function and disability prevention

### Incontinence

Urinary incontinence is an added complication in the evolution of dementia and contributes to a loss of autonomy and social isolation. It must be detected early and managed adequately. The sudden appearance of incontinence should lead to a search for its transient cause (reduced mobility, hospitalisation, infection, faecal impaction, acute retention of urine, etc.)[5]. First-line management should consist of taking a non-pharmacological approach: hygienic and dietetic measures, perineal rehabilitation, and local oestrogen therapy for women. As a second step, a prescription of an alpha-blocker treatment could be considered[6].

### Physical exercise

Daily physical activity helps to maintain mobility, prevent falls, and prolong the independence of a person living with dementia. A daily 30-minute walk could be proposed to achieve better mobility and flexibility with results seen when people aim for 6,000 steps per day[1].

### Physical disability

Early management with rehabilitation intervention should be prescribed, one that incorporates the person living with dementia's preferences and options. In the case of a person who is facing a loss of autonomy, having an at-home occupational therapist evaluate the home environment would be most beneficial[1]. They could make suggestions regarding sustainable changes to the home layout, as well as provide information about personal-use tools that would help the individual in their daily tasks. Another added benefit would be a home that is safer and easier to navigate.

## Gait and balance disorders

Walking facility and the risk of falling should be assessed at each follow-up appointment. The prevention of falls requires an evaluation of the physical hazards that may exist in the

home environment. This can be supplemented by a handy checklist of all potential dangers to be remedied. These include strong lighting, removal of tripping hazards such as carpet edges, and grab bars in the shower and non-slip mats in the bathroom[7]. Regular physical activity is recommended, as are exercises to improve cognitive functions, even at the early stages of the disease[2]. As soon as a carer notices that falls are becoming a potential risk, a programme that reinforces muscle strength, balance, and flexibility should be prescribed and monitored by an appropriately trained professional[8].

For more on this aspect of dementia care, refer to Chapter 9. It will fully explore the issues of mobility and the risks associated with falls. These become even more important when an individual enters the middle and late stages of the disease.

## Neuropsychiatric symptoms

Early detection of mild neuropsychiatric symptoms (NPS) can be a tool that predicts the progression of a person's dementia as well as tracks the emergence and development of increasingly severe behavioural disorders. Carer screening is based on classic NPS scales such as the Neuropsychiatric Inventory Questionnaire[9]. To effectively manage these symptoms, they must be precisely described in order to help pinpoint potential triggers. Triggering factors of neuropsychiatric symptoms may be related to the carer, the person living with dementia, and their environment, and may be modifiable. These symptoms may include agitation, depression, apathy, delusions, hallucinations, impulsive behaviour, modified eating habits, and sleep disturbances. Carers should be regularly questioned during the medical appointment, as their ongoing observations will indicate the prevalence of a person's neuropsychiatric symptoms. Targeting and managing factors associated with NPS could help to prevent their emergence[10]. A non-pharmacological approach should be the first line treatment option. It should include providing education about dementia and its associated neuropsychiatric symptoms to carers. This plays a key role in neuropsychiatric symptoms prevention and management[10]. Psychotropic treatment should be prescribed only if non-pharmacological treatments fail[1].

## Sensory impairment

### Hearing loss

Hearing loss is recognised as a risk factor for cognitive impairment[11]. As such, a person living with dementia should have their hearing tested and be referred to an audiologist if necessary. Going forward, their hearing should be monitored and reassessed frequently[12]. Other impairments to poor hearing levels may be the frequent use of wax earplugs. If they have been pushed back into the ear often, wax build-up may be the result. If this is the case, it can easily be removed by an appropriately trained professional.

## Visual functions

People living with dementia should have an ophthalmologic examination every two years[8]. Evidence of vision impairment associated with dementia risk is not yet widely accepted. However, as vision assessment and correction could improve cognitive functioning[2], we should consider making an eye test a regular part of the dementia screening process.

## Iatrogenesis prevention

Interventions by healthcare professionals, especially physicians, can lead to potential complications, or iatrogenesis. A structured review of all prescription drugs, over-the-counter medication, and supplements prescribed by a physician as well as any treatment a person may decide to take on their own must be systematically conducted. This review should also include treatment indications in accordance with individual national guidelines. Verification must be made to ensure that: treatments are well tolerated with no adverse effects, the risk of drug interaction is minimised, and the duration of the treatment is appropriate[13]. Reviewing prescriptions with a goal toward therapeutic optimisation must be systematic at each follow-up visit. It should be noted that some commonly prescribed medication is associated with increased anticholinergic burden, and therefore may lead to cognitive impairment[8].

Chapter 17 fully addresses the role of acetylcholine and any medication that blocks its intended purpose and invariably leads to anticholinergic burden. These effects may be caused by such commonly used medications such as cough suppressants, tricyclic anti-depressants, and narcotic pain medications, among others.

## Cardiovascular risk factors

These are considered modifiable risk factors for dementia. The management of cardiovascular risk can help delay and prevent the progression of cognitive impairment, although how aggressive these treatments should be remains in the control of the person living with dementia and depends on the stage of their disease and their level of autonomy. In other words, the iatrogenic risk associated with these treatments must be weighted according to the evolution of dementia[11].

## Diabetes

Controlling diabetes through a drug regime is contingent on the person living with dementia's level of autonomy. The target range of glycated haemoglobin may vary from 7% to 9% from the most vigorous individual to the most dependent, respectively[14]. Being vigilant about monitoring their diabetes must be addressed at doctor visits to avoid complications such as hypoglycaemia.

## Hypertension

According to European cardiology recommendations, the ideal target is a systolic blood pressure between 130 and 139 mmHg and a diastolic blood pressure below 80 mmHg. Should antihypertensive therapy be required, regular monitoring and tolerance reassessment must be conducted, as well as safeguarding against developing hypotension (less than 90/60 for adults under 65 years of age, however, most geriatricians concur that for the senior population, this value should be 100/60) which is a risk factor associated with falls[15].

## Obesity

Provide nutritional management counsel in cases of obesity that encourages the adoption of a diet that limits the risk of undernutrition. As well, guidance about the perils of a sedentary lifestyle should also be included in this section. Exercise and nutrition go hand in hand to improve overall health[11].

## Smoking

People living with dementia should receive specific assistance to encourage cessation[11]. There are benefits associated when a person living with dementia stops, even when they are in the late stages of the disease.

## Pain assessment

Pain evaluation is often underestimated or imprecise when examining a person living with dementia. A combination of clinical assessment scales and self-reported pain is required

to obtain a full picture. These measures must be repeated, especially when dementia is in the middle or late stages, as neuropsychiatric symptoms, comorbidities, and difficulty communicating may impede an accurate diagnosis[8,16].

## Social environment and caregiver assessment

Regular assessment of a person living with dementia's living environment as well as that of their formal and informal carers is crucial. Educating carers about the disease will allow them to better understand dementia and help to alleviate some of its associated complications, such as neuropsychiatric symptoms, physical disabilities, or weight fluctuations[8]. In addition, assessments should be mindful of carer burnout manifesting through physical and mental exhaustion, stress, depression, and social isolation. To help prevent this, the creation of a carer self-care plan that includes psychological support or participation in carer support groups should be implemented[1].

## Cognitive assessment

In the effort to promote cognition and wellbeing, propose a range of activities that are tailored to a person living with dementia's preferences. These will help stimulate their interest and engagement. Other options to encourage functional improvement include cognitive stimulation therapy, cognitive rehabilitation, and cognitive training[8,11].

Some of these alternatives are elaborated in greater detail in Chapter 14.

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## Expert essay

# An evidence-informed, primary care-based, task-shared approach to post-diagnostic dementia care: the PriDem programme

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The 2016 World Alzheimer Report urgently recommended research into efficient, integrated, and holistic models of post-diagnostic dementia care and support. It concluded that the current specialist-led, healthcare model of dementia care was unsustainable, in view of our rapidly ageing populations, and urged a task-shifted, task-shared approach, with greater involvement of primary care. Directly addressing this issue, our team in England developed the Primary care-based post-diagnostic Dementia Care (PriDem) programme. The aim of PriDem was to develop, implement, and evaluate evidence-based, person-centred, and sustainable models of post-diagnostic dementia care and support in primary care settings following national research recommendations. Our research would be unique in that it would be co-created with a patient, public, and professional stakeholder group, namely the Dementia Care Community (DCC). It comprised people living with dementia, their family carers, and health and social care providers as well as service commissioners[1].

## Phase 1: Learning lessons from existing international research

We began by synthesising findings from previous research. In terms of effectiveness, a systematic review of research trials and economic evaluations of post-diagnostic dementia care interventions where primary care was substantially involved in care planning and decision-making included 23 papers (10 trials of nine interventions delivered in four countries)[2]. A primary care case management model, usually specialist nurse-led, showed the most promise in terms of patient/carer outcomes and healthcare costs[2].

Next, we sought to identify key factors which facilitated the successful implementation of such primary care approaches. Our mixed methods systematic review included 49 service evaluations of a wide range of primary care models[3]. Key enabling factors included: having clinical dementia expertise within or easily accessible to primary care, primary care leadership, key stakeholder engagement and commitment,

and sufficient funding[3]. Finally, we questioned whether lessons could be learned from the primary care management of other long-term, complex conditions, such as Parkinson's disease, via an analysis of systematic reviews[4]. Having formal collaboration and service integration between key services – for example, a shared care pathway and/or shared review – was one of the important factors[4].

## Phase 2: Learning from national examples of “good practice”

A decade after England's national dementia strategy was introduced, we mapped post diagnostic dementia care and support provision via an e-survey of dementia commissioners[5]. Findings from 82 service commissioners with representation from each region in England revealed: i) considerable geographical inequalities in services, with most focusing on information provision and support within the first two years after diagnosis and ii) fragile and fragmented services due to short-term funding sources. Despite an increasingly diverse population, few areas reported service provision for minority populations[5]. A follow-up interview study one year into the COVID-19 pandemic revealed potential worsening of such inequalities[6].

Building on our survey, we used qualitative approaches to further explore current dementia care provision in England and Wales in more depth[7,8]. Our sample included: 61 commissioners and service managers; 68 service providers (health, social care, and voluntary sector including frontline staff); and 48 service users (17 people living with dementia and 31 carers). Participants had varied views as to whether a primary care approach was appropriate, achievable, and/or desirable. Potential benefits of a task-shifted approach were continuity and familiarity for both people living with dementia and staff and a more holistic approach to dementia care; challenges included the capacity, ability, and inclination of primary care to deliver such services. Conceptual challenges included uncertainties around the nature and length of post-diagnostic support and identification of which tasks

could be shifted to primary care[7]. Barriers to implementation comprised an unsupportive, rigid care infrastructure as well as limited capacity and capability in primary care[8].

Notwithstanding, we identified many examples of post-diagnostic dementia care and support, either led by primary care or where primary care was integrated into a secondary care-led model. With the aim of identifying what a model of good practice comprised, six sites were selected for a case study evaluation. The service models included: a specialist dementia (Admiral) nurse based in primary care, dementia specialist GPs, and secondary care-led memory clinics with formal, integrated shared care support with primary care. There was no one perfect model but all sites delivered good quality care in certain areas. Analysis revealed 20 distinct *core components of post-diagnostic support*, from diagnosis to end-of-life, related to five themes: timely identification and management of needs; understanding and managing dementia; emotional and psychological wellbeing; practical support; and integrating support; the first and last were cross-cutting themes[9].

### Phase 3: Co-development of the PriDem intervention – a task-shared model of post-diagnostic dementia care

Drawing on the key findings from Phases 1 and 2, we used the Theory of Change approach to co-develop our PriDem intervention[10] through an iterative series of workshops,

meetings, and task groups with key stakeholders (n=124), including the research team, people living with dementia, and their families in addition to service managers, providers, and commissioners[1]. We are now in the next phase of the programme, implementing the intervention in primary care and assessing its acceptability and feasibility alongside an economic evaluation. It closely resembles the shared care model adopted in England for the management of other long-term illnesses such as diabetes and cancer, with the placement of clinical expertise in primary care (a dementia specialist nurse) who acts as a liaison between the key service providers [2–4]. The role of the clinical dementia lead is threefold: designing tailored care and support for complex cases; building primary care knowledge and confidence; and developing formal shared care systems[10] to ensure integrated, sustainable services targeted at providing the PriDem core components of care[9]. The PriDem programme has revealed that even in a country with a strong policy commitment to dementia (National Strategy and a Prime Minister's National Dementia Challenge) translation of rhetoric into reality, that is, improved care for families living with dementia, is a major challenge.

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## Expert essay

# Best approaches to supporting the needs of people living with dementia and their carers

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The COVID-19 pandemic has highlighted the urgent need to better support people living with dementia (PLWD) and their carers. The majority of them receive informal care provided by family carers who, in turn, receive minimal support. However, there is considerable evidence that this caregiving role is challenging and can have detrimental psychosocial, physical, and financial impacts. Caring for people living with dementia can result in high levels of stress, family conflict, employment complications, depression, serious health problems, and even greater mortality risk[1]. Numerous studies have identified existing gaps in care for people living with dementia and their carers, highlighting the need for timely diagnosis, knowledgeable healthcare providers, adequate time for primary care visits, greater carer support, better communication with and between care providers, and improved access to services including system navigation support[2]. The prompt and accurate diagnosis of dementia is essential to ensuring early access to interventions that may: help slow cognitive decline, identify reversible causes that can potentially be treated, provide individuals ample time to plan for the future and for people with dementia the opportunity to contribute to care planning decisions. In many countries, dementia assessment, diagnosis, and care are largely provided by specialists,

who in many locations are in limited supply. In countries such as Canada with strong primary care infrastructure and critical shortage of geriatric specialists, national consensus guidelines emphasise that dementia care should be centred in primary care; however, many studies have shown this to be challenging. The estimated rate of undetected dementia is 62% globally, and the many barriers to dementia care in primary care have been well documented[3,4].

Person-centred healthcare is considered the gold standard for older adults[5]. (Table 1) This concept is highly relevant for complex conditions such as dementia as it emphasises timely access to appropriate services and support and meeting individual needs. Care that is person-centred, humanistic, and compassionate is at the heart of the healing tradition in family practice. By focusing assessment and management on the preferences and values of individuals and carers, people can be supported to live well with dementia. Much has been learned about the importance of a multi-disciplinary approach, care navigation, and collaboration across the continuum of healthcare providers and community services to ensure changing care needs are met and enable people living with dementia to stay at home for as long as possible[6]. Ideally, dementia care programmes should meet the

**Table 1. Person-centred care**

- Individualised, goal-oriented care planning based on the person living with dementia's preferences and goals for care
- Ongoing reassessment of care plan and preferences
- Interprofessional team-based care
- One primary point of contact
- Active coordination among all care and service providers
- Continual information sharing
- Integrated communication
- Education and training provided to healthcare providers
- Health education for the person living with dementia and their carers
- Measurable outcomes with feedback from the person living with dementia and their carers

Institute of Healthcare Improvement's Quadruple Aim of better health outcomes, better individual and carer experience, better healthcare provider experience, and lower healthcare costs (Table 2).

**Table 2. Quadruple/Quintuple Aim strategies for improving healthcare**

- Improve health outcomes (measurable improvements in population health)
- Enhance the experience of the person living with dementia (awareness and understanding of their experience to drive quality improvement, and their involvement in decision-making)
- Enhance carer experience (awareness and understanding of their perspective and their well-being to drive improvements in care delivery)
- Reduce healthcare costs (improve system efficiencies)
- Quintuple aim: Enhance health equity (increase access to care for marginalised and vulnerable groups)

Recently there has been movement toward the Quintuple Aim that adds in the importance of health equity for marginalised populations, including older adults[7]. These elements are essential for transforming dementia care and achieving the equitable access that the Quintuple Aim hopes to achieve.

In Canada, innovative new models of dementia care have been developed to better address the needs of people living with dementia and carers. One such initiative that meets the Quintuple Aim stated above is the Multi-specialty INter-professional Team (MINT) Memory Clinic programme[8]. This was developed in Ontario, Canada, and has extended to over 100 primary care sites across the province, including to rural and remote communities and to diverse equity-deserving groups such as the homeless and several Indigenous, francophone, and minority ethnic groups. Most recently,

the MINT Memory Clinic model has rolled out nationally to 10 new sites in three western Canadian provinces. MINT Clinics offer multi-disciplinary dementia care provided by highly skilled primary care teams who have received standardised nationally accredited training. Aligned with the Chronic Care Model, the delivery of support and services is individualised and based on the needs of the person with dementia and carer. Through MINT Clinics and its shared-care approach with the individual's own family practitioner, the model is capacity-building within primary care and reduces the need for direct referrals to specialists by 90% while maintaining high quality care[8,9]. With the MINT Memory Clinic model, most people with dementia and carers can have their needs met within their own family practitioner's office. Core to this model is a collaborative approach between primary care, specialist care, and community agencies including their local Alzheimer Society. For complex cases, digital technologies are used to extend the reach of specialist expertise through MINT Clinics into rural and remote regions that would otherwise not have this access. Various evaluative studies have demonstrated highly satisfied people living with dementia and their carers when presented with quick access to full-service dementia care from one location close to home, within their own communities. Indeed, 95% would recommend the service to others[9]. Healthcare provider satisfaction with the model is high, and cost is reduced by \$51,000 CAD per individual journey as compared to usual care[9,10]. Other Canadian initiatives to improve dementia management in primary care include the Rural Dementia Action Research (RaDAR) programme, which aims to improve care for rural populations in Saskatchewan, and the Quebec Alzheimer Plan, which supports multi-disciplinary Family Medicine Groups to implement a patient-centred approach.

Innovative models in Canada highlight the importance of swift access to skilled multi-disciplinary dementia management within primary care and the need for cross-sectoral collaboration in supporting people with dementia and their carers. Enhanced and more equitable support is critical. To achieve this, dementia care approaches need to espouse all components of person-centred care and the Quadruple, or Quintuple, Aim. Primary care initiatives should be capacity building to meet the needs of the growing numbers of people with dementia and their carers with the goal of helping these individuals to remain living in their own homes and within their own communities with the best quality of life.

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## Conclusion

The impact of a chronic illness diagnosis reverberates around everyone who is involved – the individual with the condition, their carers, and the medical community. When it comes to dementia – a condition with distinct stages, each requiring more attention and effort – the importance of ongoing post-diagnostic support has emerged as a vital component of the treatment process. Evolving the current management of people living with dementia to include carer support, as well as redefining and expanding the role of primary care to a task-shared model, is a direction that must be explored more thoroughly. This can be achieved by providing education, training, resources, and tools at all levels of care management. Making inroads to the adoption of a person-centred approach is a measure that will help a person living with dementia to live more fully with their illness.

The next section of this report will chronicle the progression of dementia through its early, middle, and late stages, then address the management of cognitive and non-cognitive symptoms and conclude with an exploration of care models already begun in this current chapter.

## **Part II**

Progression of dementia and  
general care across stages

# Chapter 7

## Early stage

*Serge Gauthier, Claire Webster*

### Key points

- Important post-diagnosis information should include the impact of cognitive impairment on functional and decision-making autonomy, and education about progression of the illness and how to access support services.
- Diagnosis in early stage is dependent on availability of qualified clinicians, or denial by the person with cognitive decline and/or from family members.
- Reduced awareness of having dementia in the early stages is very common and is associated to psychosocial or neurocognitive factors such as anosognosia.
- Disclosure of diagnosis particularly in early stage should involve the person living with dementia and their carer, allowing enough time to answer the initial questions about what to expect.
- Whereas advance financial planning should be done as early as possible in the course of dementia, advance medical care planning can be a more proactive dialogue, supporting the person living with dementia and their carers to formulate goals of care as they move along the trajectory of the progressive illness.



## General background

The diagnosis of dementia in early stage, whatever its aetiology, offers more opportunities to plan ahead while the person living with dementia is competent enough for making decisions about financial and care planning.

The essay by Marie-Jeanne Kergoat describes the initial steps in the post-diagnosis process that should be taken by dedicated healthcare professionals who are working in the field of dementia upon disclosing the diagnosis to the person living with dementia and their carers, such as: ensuring adequate time to properly inform them of the assessment, the impact of cognitive impairment on functional and decision-making autonomy, providing them with the necessary information about the progression of the illness and how to access support services, as well as the importance of surrounding themselves with a team of multi-disciplinary health professionals who can provide as much assistance as possible throughout the journey.

The essay by Daniel Mograbi and Elodie Bertrand provides a detailed discussion of why so many people living with dementia as well as their carers may be in a state of denial about their diagnosis caused by either psychosocial or neurocognitive factors (such as anosognosia) and offer strategies to understand and manage these realities. As explained within their essay, "Reduced awareness about

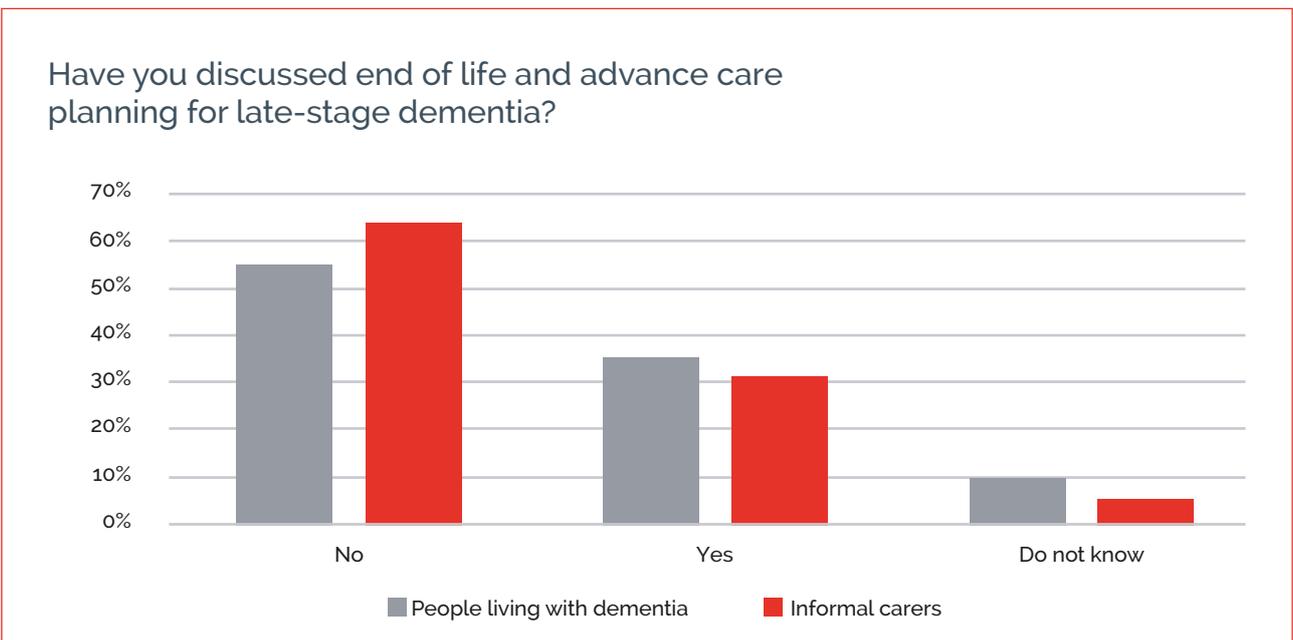
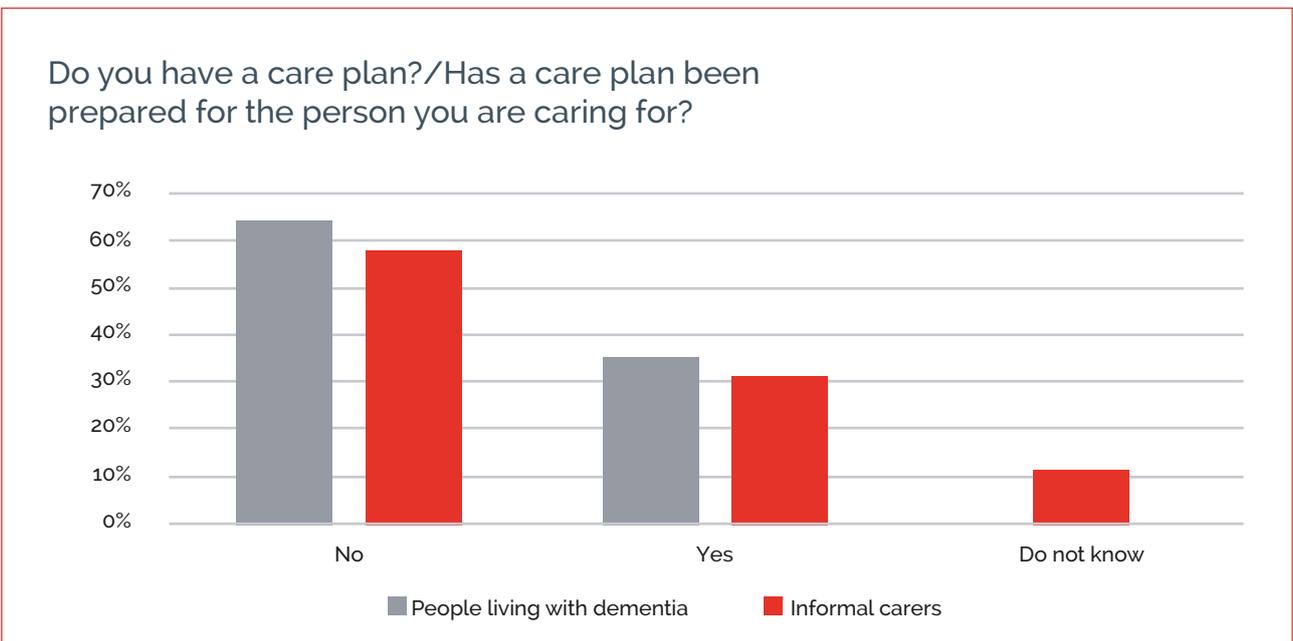
having dementia and its consequences is a common feature of the condition. Impaired self-awareness influences negatively the course of the illness, with unaware people living with dementia being more likely to present a poorer quality of life, to engage in high-risk situations, and to refuse treatment. It also leads to an increased need for family support and has been associated with higher caregiver burden."

The essay by Duke Han and Gali Weissberger describes in great detail the impact that dementia has on financial decision-making and the authors strongly advocate for the importance of financial planning to be done prior to or at the time of diagnosis. They explain how poor financial decision-making may be one of the earliest signs of behavioural changes associated with dementia and provide resources and suggestions to assess a person's capability to manage their finances for as long as possible. "Poor financial decision-making in older age can have a devastating effect not only on the older adult in terms of autonomy and independence, but also on family members, carers, and surrounding communities as the burden of lost funds accumulated over a lifetime can often be broad in reach, and there are fewer opportunities to earn and recoup funds," explain Han and Weissberger.

The essay by Catherine Ferrier provides a thorough background of the history of advance care planning, which was introduced in the 20th century as a result of the evolution of technological medicine which allowed people to live longer and thus required them to make decisions about the type of life interventions that may be needed because of illness and incapacity. With regards to people living with dementia, the author provides a humanistic approach to advance care planning: promoting a more proactive dialogue which supports people living with dementia and their carers to formulate goals of care as they move along the trajectory of a progressive illness, rather than completing a checklist of advanced care decisions while still in early stage of dementia. Most importantly, Ferrier is advocating for better education for healthcare professionals on how to have the "caring conversations" with their patients and family members: "We must teach health professionals

how to discuss serious illness with patients and surrogates: what information to provide and in what way. It is not simple. Like learning a surgical procedure, it requires specialised knowledge and skills, training with feedback from experts, and ongoing practice."

Ferrier's essay takes on all the more importance given the responses to the survey carried out ahead of this World Alzheimer Report. Across the board, a majority of people living with dementia and informal carers indicated that they did not have an ongoing care plan, nor had they discussed advanced care planning. More needs to be done in order for people with dementia and their relatives to be better able to plan for the future, wherever they are in the world, and ease some of the hardships of decision-making as the condition progresses.



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- PART VIII

## Expert essay

# Initial steps by the clinician after diagnosis

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**D**ementia comprises a group of very heterogeneous diseases. The diagnosis should be based on a rigorous approach respecting good clinical practices[1,2]. The high prevalence of these diseases that accompanies an increasingly ageing population makes the general public and clinicians more vigilant to its identification.

Considering the very important impact of this diagnosis on the person living with dementia (PLWD), their life and health trajectory, the clinician should set aside a period of time of at least 30 minutes for the visit during which disclosure of the diagnosis of dementia will take place. With the PLWD's agreement, the presence of a person identified as a family or informal carer is desirable or even necessary. The consultation will focus on the announcement of the diagnosis and the next steps in accompanying the PLWD and their carer, because many of these diseases have a cognitive and physical evolution.

The degree of knowledge about the PLWD on the part of the clinician, his/her expertise in the field of cognitive disorders, his/her role as a treating physician, family doctor, or consulting specialist, or other type of health professional will help find the tone and words to disclose the diagnosis and offer support.

The first step is to name the disease as accurately as possible. The elements of the medical history, physical examination, cognitive tests, biological assessments, and neuroimaging that led to the diagnosis must be summarised in accessible terms, taking into account the PLWD's and carer's level of health literacy.

It is then necessary to take a moment to allow the PLWD and the carer to react. Most often, the reaction may not be surprise or shock, as perhaps they had been feeling and noticing changes for some time already. Rather, it will be a question of professionally and compassionately validating the presumptions experienced by the PLWD[3].

Subsequently, the clinician should then provide comprehensive information on risk factors (including heredity, vascular load, lifestyle) and the expected profile of the disease's evolution in the short and medium term. The clinician should

discuss symptomatic treatment options (for example, acetylcholinesterase inhibitors or memantine), indication and/or contraindication, and their expected benefits. He/she will discuss this with the PLWD and the carer, while specifying potential side effects, and assessing compliance issues. The PLWD's choices are paramount in the decision to use medications and most often there is no urgency to decide immediately. This discussion will be an opportunity to validate the PLWD's desired level of medical intervention.

The next step will be to discuss the impact of cognitive impairment on functional and decision-making autonomy, as well as on psychological and socio-environmental dimensions. This will build on information already collected during the initial clinical assessment: autonomy in activities of daily living, co-morbidities and their treatments, presence of depressive, anxiety, or behavioural symptoms, nature and extent of the aid network, state of legal and financial affairs, environmental security, driving.

Thereafter, the physician, if he/she is a consultant, will have to determine who will provide medical follow-up. A complete consultation report should be sent to the attending physician. Either one should also refer the PLWD and carer to volunteer organisations such as Alzheimer associations, whose mission is to inform, support, and link PLWD and carers to available resources. Also, as is the case in most healthcare systems managing diseases of chronic evolution in general (such as diabetes) and diseases more frequently associated with ageing (such as dementia), front-line professionals such as nurses, occupational therapists, and social workers operating in primary-care clinics in an interdisciplinary mode may be involved. It should be noted that these non-physician health professionals can now be better trained to identify and assess people suspected of having dementia but who have yet to be diagnosed[4]. Post-diagnosis, the team would monitor and meet the needs of the PLWD and carers. One of these professionals becomes a pivotal healthcare person that the PLWD and carer can contact directly if necessary. This type of infrastructure helps to better meet needs without delay. It also helps prevent crisis situations and transfers to hospital emergency rooms and hospitalisation, knowing that in these locations, care is often inadequate for people with major cognitive disorders.

Dementia has a considerable impact in terms of human, social, and economic costs, and this type of outreach coordination is beneficial to ensure the best quality of life for the PLWD and carers. The assistance provided to the carer has a positive influence and delays premature entry into residential and long-term-care facilities[5].

Other aspects of management should be evaluated early and regularly as part of the medical follow-up and/or by the pivotal healthcare person. To name a few:

1) *Drug safety*: monitoring of the adverse effects of drugs prescribed to help cognition, optimisation of drugs in general with rationalisation or elimination of sedative drugs and/or drugs with anticholinergic properties, detection and treatment of depressive symptoms and anxiety, use of cognitive-behavioural interventions rather than drug approaches for the management of psychobehavioural symptoms of dementia;

2) *Weight loss prevention*: ensure good hydration, a variety of foods and nutritional balance, validate that the person can shop, properly store and respect the expiration dates of food, be able to plan and prepare meals, find alternatives in case of disabilities;

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3) *Management of co-morbidities*: conduct periodic physical examinations and revise treatments, maintain mobility, and prevent physical inactivity, apply a multi-domain approach to the prevention of falls (drug management, compensation for vision and hearing disorders, ensure a safe physical environment);

4) *Maintain residual capacities*, preserve communication, and give meaning to life.

Many of these interventions will depend on the physical and psychological state of carers. Great consideration must be given to them about information, support, listening, valorisation, and also to the reduction of tasks and the sharing of responsibilities by offering services such as a day centre, respite care, support groups, and psychological counselling.

All of these initial steps should lead to better outcomes overall, providing shortcuts in post-diagnostic care are avoided[6].

## Expert essay

# Helping people in denial of their diagnosis

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**R**educed awareness about having dementia and its consequences is a common feature of the condition. Previous studies including large samples of people living with dementia (PLWD) report consistently a prevalence of impaired self-awareness above 30%, reaching up to 80%[1]. Impaired self-awareness in dementia has been linked to negative consequences, having major psychosocial implications on three spheres [2]: First, it influences negatively the course of the illness, with unaware PLWD being more likely to present a poorer quality of life, to engage in high-risk situations, and to refuse treatment; second, because impaired self-awareness leads to an increased need for family support, it has been associated with higher carer burden; finally, unawareness of deficits amplifies the cost of dementia for society, through earlier institutionalisation and increased need for care for PLWD and their caregivers.

Lack of awareness is a heterogeneous and multidimensional phenomenon. There is a variability in its severity, which can range from slight minimisation to complete denial of problems. Attribution of difficulties and cognitive impairment to normal ageing is also often seen in PLWD[3]. For some PLWD, exposure to information about their condition can reduce their lack of self-awareness for, at least, a short period of time, while others are less responsive to feedback. Lack of self-awareness also varies in relation to its specificity. The PLWD may not acknowledge some deficits, but present full awareness about other aspects of their disorder. This can be seen in relation to the diagnosis of dementia, with some PLWD acknowledging the existence of specific cognitive problems but denying the diagnostic label[3].

Similar presentations of impaired self-awareness (for example, not acknowledging a memory problem) may have different causes. Traditionally, causes of impaired self-awareness in dementia have been grouped into two main categories: psychosocial and neurocognitive. These two main groups of causes are discussed here separately, but it is important to highlight that in most PLWD, there is a combination of psychosocial and neurocognitive factors leading to the particular expression of awareness of that person.

## Psychosocial factors

When the main causation is understood to be psychosocial, impaired self-awareness has been referred to as “denial of illness.” Denial is considered a psychological defence mechanism, a method of coping with difficult events, for example, the diagnosis of a serious illness. In line with that, it has been suggested that denial and avoidance are common reactions to the disclosure of a diagnosis of dementia[4]. Other important psychosocial factors impacting on the way PLWD perceive and/or report their difficulties include wider social awareness (for example, general knowledge about dementia available to PLWD and carers[1]), cultural values (for example, how ageing is understood in a given society[1]), beliefs (for example, whether illness is seen as a sign of weakness) and illness representations (for example, understanding dementia as a disease or as normal ageing[3]), and personality (for example, negative attitudes towards emotional expression and conscientiousness[5]).

## Neurocognitive factors

Nevertheless, for other PLWD, the main causes of unawareness are neurocognitive in nature, and in these cases, the use of the term “denial” can be misleading. Several studies have indicated specific neuroanatomical and neurocognitive correlates for lack of awareness[6]. When considering this neurobiological basis impaired self-awareness is often termed “anosognosia,” from the Greek: *a*–without, *nosos*–illness, *gnosis*–knowledge. Anosognosia in dementia has been linked to impairment in different cognitive abilities, notably in memory – with the PLWD “forgetting that they forget” – and executive functions – when the main deficit is in self-monitoring[7].

## Management

Denial and psychological factors may play a larger role at the beginning of the condition or in response to diagnosis. In these cases, conveying information of pragmatic value in a non-confrontational manner is essential. Privilege should be given to information on which PLWD and carers may act

(for example, decisions about care and autonomy). Providing a truthful diagnosis is essential for decisions on treatment and advanced care planning[8], and confrontation with a person in denial must be avoided. Nevertheless, communication should consider emotional impact and ideally a diagnosis should be given within a structured care approach, for example, evaluating the need for pre-diagnostic counselling and follow-up appointments to clarifying the diagnosis and prognosis[8].

It is worth noting that some level of unawareness may be protective against depressive symptoms, with high awareness also being linked to reduced perception of living well, self-efficacy, and self-esteem[5]. This needs to be taken into account when prompting the PLWD about their difficulties, for example, avoiding excessive exposure to failure in everyday tasks or neuropsychological assessment, with activities being tailored for the level of performance of the person. Considering the way dementia is represented allows adjusting the language and type of interventions aimed at supporting the PLWD[6], focusing on facilitating support for patients, reducing uncertainty, and managing emotions in relation to the diagnosis[4]. Ultimately, a person-centred approach should be employed in relation to awareness[5].

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## Expert essay

# Financial decision-making in early dementia

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Older age presents with many important financial decisions which have a significant impact upon wellbeing. These include, but are not limited to, how to spend or invest retirement savings or pension funds, how to handle intergenerational transfers of wealth, and how best to avoid scams and fraud situations. Poor financial decision-making in older age can have a devastating effect not only on the older adult in terms of autonomy and independence, but also on family members, carers, and surrounding communities as the burden of lost funds accumulated over a lifetime can often be broad in reach, and there are fewer opportunities to earn and recoup funds.

Evidence is accumulating in support of the notion that financial decision-making may decline in the years prior to and after a dementia diagnosis. A recent study found that Alzheimer's disease and related dementias was associated with missed payments on credit accounts and subprime financial credit scores in the years prior to diagnosis, and these real-world examples of poor financial decisions became more frequent after diagnosis[1]. Another recent study found greater post-mortem Alzheimer's disease neuropathology to be associated with poorer decision-making and scam susceptibility in older adults without a dementia diagnosis[2]. Together, this mounting evidence calls for financial planning to occur at the time of diagnosis, and preferably before diagnosis, when cognitive faculties may be more intact and personal wishes may be easier to communicate. It also suggests that poor financial decision-making may be one of the earliest signs of behavioural changes associated with dementia, though more research is needed in this regard.

It may be reasonable to assume that declining cognitive abilities in the context of early dementia will lead to poorer financial decision-making, and there is evidence to support this[3]. It should be noted, however, that just because someone may have early dementia, that does not automatically mean that the person is unable to make appropriate financial decisions. In a study of over 600 older adults, we observed about a quarter of the sample had a significant discrepancy between their global cognitive abilities and their decision-making abilities[4]. About half of this discrepancy sample showed poorer decision-making abilities

relative to their cognitive abilities as expected, but the other half showed the opposite pattern – better decision-making abilities relative to cognitive abilities. These results suggest financial decision-making may be at least partially dissociable from what is traditionally considered “cognition,” and further suggests that some older adults with poorer cognition due to early dementia may still be able to handle finances independently, at least for a period of time before the dementia becomes more severe.

The results described above highlight the importance of a thorough clinical evaluation that takes into account various aspects of decision-making and does not solely rely on existing cognitive measures when determining the capacity of the older adult to make financial decisions. Some measures have already been developed for this purpose. One example is the Assessment of Capacity for Everyday Decision-making (ACED) developed by Dr Jason Karlawish and colleagues. This measure assesses a person's decision-making according to four primary considerations: (1) understanding, (2) appreciation, (3) reasoning, and (4) choice, and presumes if a person can exhibit appropriate understanding of a problem, appreciate the reasons why it is a problem, reason through ways to address the problem, and then offer a rationale for a choice to address the problem, then the person shows adequate decision-making[5]. Another example is the Lichtenberg Financial Decision-making Rating Scale, developed by Dr Peter Lichtenberg and colleagues, which assesses a person's financial situational awareness, psychological vulnerability, and susceptibility to undue influence[6]. This and other measures developed by his team are freely available at [www.olderadultnestegg.com](http://www.olderadultnestegg.com). Given the importance of assessing financial capacity in older age, multiple other efforts are currently underway to develop tools to better inform upon the financial decisional capacity of older adults with presumed early dementia. Some of these efforts include the development of cognitive, behavioural economic, neuroimaging, and other tools that are more sensitive to brain networks important for financial decision-making but may be missed by current cognitive measures[7]. Importantly, given evidence that financial decision-making may decline years prior to a dementia diagnosis, developing more precise tools may assist in even earlier identification of an underlying

dementing process than that afforded by standard cognitive measures. Such tools may eventually be incorporated into standard cognitive batteries so that repeat evaluations may track declines in decision-making.

In considering a person's financial decision-making ability, it is crucially important to consider contextual factors in the evaluation process. For example, we know that financial and health literacy has a significant impact on decision-making, and this even explains observed racial differences in decision-making in older age [8]. Similarly, early life socioeconomic status also appears to have an impact on decision-making in older age [9]. Not all people will have the same opportunities to develop financial and health literacy due to longstanding, institutionalised systemic structures that propagate race, sex, socioeconomic, and other disparities,

and these historical differences in access and equity should be strongly considered when evaluating a person's financial decision-making.

In summary, financial decision-making abilities may decline in early dementia, and for this reason, we and others strongly advocate for financial planning at the time of, or ideally prior to, diagnosis. Declines in financial decision-making may coincide with declines in cognition; however, rates of decline in the two functions may diverge in certain individuals. For this reason, evaluations of financial decision-making capacity should be comprehensive, include measures specifically designed to evaluate decision-making ability, be regularly considered in repeat cognitive assessments, and in particular, include considerations of contextual and historical factors.

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## Expert essay

# Advance care planning in dementia

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Advance care planning is a reflection and communication process with the goal of ensuring goal-concordant care near the end of life for people who lack decisional capacity[1]. It is grounded in the principle of autonomy, which is prominent in Western societies. The bioethical principles of Beauchamp and Childress[2], which are widely used in clinical settings, also include beneficence, non-maleficence, and justice, but many consider autonomy to have priority over all the others.

In many non-Western cultures, on the other hand, autonomous individual decision-making is a foreign concept. In Asia, for example, there is a convergence towards ethics based on duties and obligations, as opposed to Western rights-based bioethics. Autonomy may belong more to the family than to the individual, and the wellbeing of the whole family be considered when making a medical decision[3].

Advance care planning developed in response to the growth of technological medicine in the 20th century. Despite saving many lives, intensive care and other interventions led to the dilemma of patients being rescued from acute events only to remain gravely ill and comatose, dependent on such care to stay alive but incapable of deciding whether to continue it.

It makes intuitive sense to apply advance care planning also to situations of incipient or possible dementia, as decisions may be needed for several years after decision-making capacity is lost, regarding many aspects of life beyond medical care.

Early attempts to address this need involved creation of the “living will” or “advance directive,” documents in which patients list which medical interventions they would choose or would want to forgo, should they need care and not be able to express their wishes. The limits of this procedure soon became evident[4]. More recent programs, without necessarily rejecting the advance directive, promote a more dynamic process of dialogue, supporting patients and their families to formulate goals of care as they move along the trajectory of a progressive illness. They combine reflection on healthcare goals and choices with naming and communicating with a surrogate decision-maker.

Research is, however, far from proving clear benefit from such programs, despite all the time and resources invested in developing and testing them[5]. A 2020 scoping review of 69 studies could find no effect of advance care planning on goal-concordant care or on patient quality of life, despite success in “process” and “action” outcomes such as increased knowledge and completion of directives[6].

Why such a discrepancy? According to Morrison et al, “Treatment choices near the end of life are not simple, consistent, logical, linear, or predictable but are complex, uncertain, emotionally laden, and fluid. Patients’ preferences are rarely static and are influenced by age, physical and cognitive function, culture, family preferences, clinician advice, financial resources, and perceived caregiver burden [...] Surrogates find it difficult to extrapolate treatment decisions in the present from hypothetical discussions with patients that occurred in the past [...], prior directives are often absent, poorly documented, or either so prescriptive or so vague that they cannot promote informed goal-concordant care.”[1]

Advance care planning relies on “precedent autonomy,” the notion that an autonomous decision in the present is perfectly applicable to an unknown future situation. This contradicts the doctrine of informed consent, which requires the provision of information on the diagnosis, the proposed investigations or treatments, their chances of success and harm in the present situation, and alternatives, before a decision is made.

There is increasing evidence in the field of psychology that individuals predict poorly their quality of life in hypothetical situations[7]. This has been attributed to a number of cognitive biases, including projection bias (projecting current preferences onto future situations), focalism (focusing on what gets worse, not what remains positive) and immune neglect (underestimation of one’s adaptive capacity). For this reason, we often observe a “response shift,” a change in preferences for care that occurs as a person adapts to and accepts advancing illness[8].

What advice should we then offer to people who may develop dementia or are already in the early stages of the disease?

We cannot abandon the notion of planning, a sensible thing to do in any situation of advancing age and progressive disease. Plans must be made for housing, personal care, and financial management. For medical decisions, we can advise patients to choose a surrogate decision-maker, who must know the patient well, their values, hopes, and fears, and what gives them comfort. We can support and educate the surrogate to participate with confidence in medical decision-making, to help identify goals of care in the patient's true present interest, as opposed to some hypothetical past wish, taking into account the person's diagnoses and degree of frailty, which increases as dementia progresses. This approach is more compatible with many non-Western cultures, where family members are naturally involved in decision-making for an incapable parent or other relative.

We must teach health professionals how to discuss serious illness with patients and surrogates: what information to provide and in what way. It is not simple. "Like learning a surgical procedure, it requires specialised knowledge and skills, training with feedback from experts, and ongoing practice." [5] Tools to teach such skills include The Conversation Project [9], Vital Talk [10], and others. Such tools need to be developed and applied further.

We must learn from all the efforts already made, without giving in to the "misleading simplicity of advance directives" [11].

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## Conclusion

This chapter describes the initial steps in the post-diagnostic care of persons in early stage of dementia. This stage can last a few years depending on the general health condition of the person with relatively little cognitive and functional impact. However, it is the most important stage with regards to planning for the future in terms of financial and legal decisions, and medical care, as well as advance directives while cognitive capacity is still intact.

As a result of the wealth of information that is required to be communicated to people living with dementia and their carers, it is important to ensure that clinicians and other healthcare professionals receive adequate training in how to perform assessments, are properly educated in post-diagnostic management and care, and are capable of having compassionate conversations to convey the decision-making process.

# Chapter 8

## Middle stage

*Serge Gauthier, Claire Webster*

### Key points

- In middle stage, functional decline begins to occur in the person living with dementia, requiring more assistance with activities of daily living by the primary carer, who may need additional help and support to ensure quality of care and safety while living at home.
- In addition to assessing the functional abilities of the person living with dementia at home to determine their level of care needs, it should become standard practice for healthcare professionals to also assess the carer's ability and knowledge to provide care in a safe environment.
- Education and training immediately upon post-diagnosis can help carers improve their dementia care skills.
- The need to transition a person living with dementia to a senior living facility frequently results in feelings of guilt; however, there are many warning signs that make it important to consider, especially with regards to safety concerns.
- As dementia progresses, increasing supervision, monitoring, guidance, and hands-on care, particularly around personal care, become relationship-altering factors for spouses and children.
- Neuropsychiatric symptoms are common in middle stage dementia and must be treated using non-pharmacologic, non-confrontational, and pharmacologic therapies.



## General background

The middle stage of dementia represents the transition phase where cognition declines at a much faster rate; functional difficulties now include managing activities of daily living and personal care such as selection of clothes, risk of getting lost in unfamiliar surroundings, and the need for increased supervision. It is also the stage where familial relationships begin to change. Neuropsychiatric symptoms (NPS) such as apathy, anxiety, agitation, aggression, impulsivity, loss of social cognition, and hallucinations and delusions may emerge to the point of interfering with the daily routine and sleep for the person living with dementia and the carer. In this phase, it is important to consult with a clinician and other healthcare professionals to understand how best to manage the symptoms. In his essay "Understanding Behavioural Changes in Moderate Stage Dementia", Zahinoor Ismail explains, "Education is required to inform carers of the nature of NPS, and guidance is required on non-pharmacological, non-confrontational approaches to manage persons with NPS. Further, carer support and respite are also important. Best practices should be followed regarding assessment and management of NPS, with attention to dementia medications, using the best available evidence for antipsychotics and non-antipsychotic medications."

During the middle stage, it is possible for the person living with dementia to remain at home providing there is adequate help by a carer, their surroundings are safe, and care is supplemented by additional home care support and respite for the carer when needed. In his essay, Richard Fortinsky describes the use of functional assessments in understanding the home care needs of the person living with dementia as the disease progresses. A very important point raised by Fortinsky is the current lack of assessing the family carer's ability and or knowledge to be able provide the necessary care in a safe environment. "An area of functional assessment in home care that is not as well developed, even in higher-income countries, is the assessment of the capacities of informal carers. Ideally, carers assessment would be a standard part of home care functional assessment, to determine what needs exhibited by the PLWD can no longer be met by informal carers, whether due to a lack of knowledge about the condition or a physical disability," explains Fortinsky.

There may come a point, however, when a person living with dementia can no longer remain at home due to safety reasons, increasing functional decline, and significant carer stress, as detailed by Matt del Vecchio in "Planning for Transition of Care". His essay outlines the important warning signs that living at home may no longer be possible,

as well as a checklist about what to ask when looking for an ideal senior-living community and coping with "guilt" during the decision-making process. "These decisions are usually filled with emotion, guilt, and anxiety. There is not a 'one-size-fits-all' solution. Caregivers and families typically want to make the decision on their terms. Individual circumstances will normally dictate the outcome," states Del Vecchio.

Informal carers who responded to the World Alzheimer Report survey echoed these complicated feelings about whether to move their loved one to a care home or senior living community:

*"My spouse stated over 30 years ago that she didn't want the nursing home experience at the end of her life. I took a vow to offer her dignity, security, and comfort."*

*"It took me several months of tears and adjusting to him never being able to come home again. Guilt that I was not able to care for him myself anymore. Guilt in having to lie when he asks 'Why won't you take me home?', 'Are we going home today?' [...] For him I am happy as he seems less stressed, for us of course it is hard!"*

*"It was beyond our capacity to meet all of her needs at home. Caring certainly took a toll on me and my physical health. I can rest easy now knowing that she is receiving the best care in the right place and I now get to spend quality time with her when I visit and still get to provide care to her and advocate on her behalf."*

Changing relationships between the person living with dementia and their spouse and children accelerate during the middle stage, interfering with the foundations of communication and interaction which can prove to be extremely challenging for all, including a deep sense of loss and grief. This topic is discussed in detail by Jennifer Graham in "Dementia and Changing Familial Relationships"; she states, "Positive relationships are fostered when the carer can alter expectations to reflect the retained abilities of their family member with dementia. As the disease progresses, as the carers adapt, interpersonal relationships will change. Carers, both spouse and adult children, will find they need to be analytical, flexible, and accepting of each other and of the challenges created in their family member by dementia."

PART I

PART II

PART III

PART IV

PART V

PART VI

PART VII

PART VIII

## Expert essay

# The use of functional assessment in understanding home care needs

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The post-diagnostic dementia journey includes many transitions in care needs and care settings[1]. Among persons who receive a diagnosis of dementia while living at home, some require no care or supervision for quite some time, and others already have begun receiving help. Families and friends most often begin this transition by providing assistance to people living with dementia at home with critically important daily activities such as handling finances, food shopping and preparation, transportation, and medication monitoring and dispensing[2]. As dementia progresses, informal carers often assist with more personal care-related daily activities such as dressing and bathing. Much has been written about the consequences of caring for the health and wellbeing of persons with dementia and their informal carers[3].

## Home care

The need for home care arises when dementia-related care exceeds the capacity of informal carers to help, or when other medical conditions require clinical expertise to be brought into the home. For this essay, home care refers to personal care and more clinically skilled services delivered in the home by individuals who are paid for their services. Home care providers might be self-employed or employed by healthcare organizations in the public or private sector; all are paid for the services they provide in the home.

Availability of home care services for adults living with dementia and possibly other medical conditions varies widely throughout the world. In most higher-income countries, home care is a highly organised sector of the healthcare enterprise, and payment for home care services by individuals or governments can be made through public or private insurance programs. By contrast, in many lower- and middle-income countries, home care is either in the process of emerging as a component of the healthcare system or is virtually non-existent.

## Functional assessment in home care

Functional assessment in home care refers to a systematic approach to determining an individual's health-related needs with the aim of developing a plan for the type(s) of services to deliver in the individual's home. Occupational therapists, social workers, nurses, or other trained professionals administer functional assessments using tools developed by jurisdictions. In the United States, examples of functional assessment tools are the Outcome and Assessment Information Set (OASIS), used nationally for all individuals needing clinically skilled home care paid for by Medicare and Medicaid, including those with dementia[4], and interRAI Home Care, used by several US states and countries for individuals needing home care services[5]. In Canada, each province/territory uses its own functional assessment tool. In England, the National Health Service uses uniform functional assessment tools for home care across the country, and local authorities can conduct assessments if an individual is ineligible for NHS-funded services.

From the perspective of the person living with dementia (PLWD), comprehensive home care functional assessment tools should take into account the degree of cognitive impairment and how cognitive impairment contributes to capacity to conduct daily activities, mood and behavioural changes, and physical limitations hindering capacity to conduct everyday activities of living. The *World Alzheimer Report 2021* contains several excellent essays detailing clinical assessment tools in these health-related domains to help determine needs that are highly relevant to functional assessments for home care services, including assessments that can be conducted remotely.[6–8] Functional assessment tools used in home care in higher-income countries are quite comprehensive in scope and include items that can help determine capacity and changes in these health-related domains.

## Assessment of capacities of informal carers

An area of functional assessment in home care that is not as well developed, even in higher-income countries, is the assessment of the capacities of informal carers. Ideally, carers assessment would be a standard part of home care functional assessment, to determine what needs exhibited by the PLWD can no longer be met by informal carers, whether due to a lack of knowledge about the condition or a physical disability. To date, most functional assessment tools in home care inquire about the availability of informal carers and a few aspects about the amount of care they might provide, but there is little or no uniformity in assessment tools to help determine how home care services could augment informal care or teach informal carers how to improve their dementia care skills in the home. Moreover, there is little focus in most functional assessment tools on the safety of the physical environment in the home for the PLWD. If post-diagnostic care for dementia begins at a point in an individual's dementia journey when cognitive impairment is already a concern, it is especially important that functional assessment tools for home care include both assessment of informal carers and the physical home environment.

In countries where home care is just emerging, the movement appears to be spurred by the nursing and public health professions as an extension of the recognition that ageing populations require healthcare initiatives to promote healthy aging and augment hospital-based care. For example, in Saudi Arabia, home care emerged as a national service in 2008, and there is recognition of the need to improve

assessment procedures to help plan services for growing home care needs[9]. Additionally, a recently published book offers insights to help educate governments, health-care professionals, and non-governmental organizations in sub-Saharan African countries, to understand the concept of home care nursing and its fundamental root in public health services[10]. This book includes a chapter on home care nursing management for dementia.

In the context of post-diagnostic care, clinicians responsible for diagnosing dementia, or for providing primary care after a diagnosis has been made by a specialist physician, should be prepared to discuss possible home care needs during office visits and to refer to appropriate home care services in their geographic area of medical practice. In countries where home care is highly developed, the PLWD and carers should be empowered to inquire about available home care services after a dementia diagnosis is received. Advocacy organizations and volunteer associations working on behalf of the PLWD should regularly engage their local, regional, and national governments to help build links between medical care and home care, and to help develop home care functional assessment tools that assess not only the needs of the PLWD, but also the needs of their carers, and the safety of the home environment. In low- and middle-income countries, prospects for improving assessment of PLWD for home care needs appear to be embedded within governmental, public health, and nursing profession initiatives to develop home care as an extension of hospital care and as a community-based service with increasing attention to the needs of a growing older population with age-associated medical conditions including dementia.

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## Expert essay

# Planning for transition of care

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There will come a point in time when one needs to consider a transition from home into a senior-living community. These decisions are usually filled with emotion, guilt, and anxiety. Some families choose to be proactive and make the move in the early stages of dementia. Others will choose to wait until it is no longer feasible to live at home. There is not a “one-size-fits-all” solution. Caregivers and families typically want to make the decision on their terms. In reality, individual circumstances will normally dictate the outcome.

There are initiatives that can be taken to allow for a smooth and less stressful transition. What can be done to avoid crisis mode?

## Warning signs

Be aware of some of the warning signs that it might be time to transition into a senior living community.

## Safety and security

Many factors contribute to the safety and security in a home environment. Mobility issues can become increasingly challenging. Stairs can be difficult to navigate. Getting in and out of a bathtub becomes a higher risk of slips and falls. Shuffling feet or difficulties using a cane or walker can create instability.

Questionable decision-making due to cognitive decline is another safety and security issue. Wandering is a major concern, particularly for individuals who have unobstructed access to doorways and exits. In fact, six in 10 people living with dementia (PLWD) will wander at least once[1]. Other factors such as the improper use of an oven or appliances can be hazardous particularly if an oven does not get turned off.

## Appropriate care

The carer role is usually thrust upon individuals with very little formal training. Inevitably, care requirements increase over time and the carer role becomes more complex having to deal with both physical and cognitive issues. Physical challenges can include transferring, bathing, lifting, dressing and undressing, toileting, and navigating stairs. Effectively

managing cognitive issues can also be challenging and stressful. Dealing with sundowning (worsening of confusion and agitation in the evening), wandering, physical and verbal aggression, getting up in the middle of the night, confusion, hallucinations, and outbursts can all be extremely challenging. Many carers will manage it the best they can by using their instincts with very little formal training. Ask the question: “Is proper care being provided? Are the support systems in place? Or is my loved one at risk despite my good intentions?”

## Carer stress

The emotional, mental, and physical toll of caregiving can be particularly pronounced for adult children or spouses of those who require care. Carers may experience symptoms such as disabling anxiety, irritability, loss of interest, and withdrawal from friends and family[2]. Marital and family issues such as strained relationships, as well as substance or alcohol abuse can occur. It may be obvious that demands of care have become too great; in other cases, it might not.

## Financial stress

The cost of caregiving may become financially prohibitive, especially if families need to pay for additional support. The personal financial toll of caregiving needs to be considered, as well. Quitting your job or reducing your work hours will result in less income in the short term while sacrificing long-term savings and career growth.

## How to select the ideal senior living community

The process of finding the ideal senior-living community for a PLWD can be overwhelming, time consuming, emotional, and stressful.

When considering options, the priority needs to be the residence's ability to provide proper care. There is a false assumption that all people with dementia-related diseases such as Alzheimer's require long-term care or a nursing home-type residence. This may be true for individuals who require elevated levels of both physical and cognitive care. Examples may include one or two person transfers, assistance

with feeding, full incontinence management, dressing and undressing, high risk of falls, and personal accompaniment to all meals and activities. These are indeed services that are provided in a long-term-care environment.

However, many PLWD require minimal physical support. Their care needs are primarily cognitive in nature. Therefore, it is crucial to find a senior-living community that understands memory care. Do they have the staff that has been properly trained to validate, distract, de-escalate, and redirect? How do they manage resistance to bathing and hygiene? Is the environment and culture one of empathy, patience, and caring? Are there other residents in the senior-living community similar to the one you care for in terms of care requirements, culture, language, religion, and interests? These are important questions to ask when selecting an ideal residence.

Other questions to ask are:

- What is their staff to resident ratios (daytime and overnight)?
- Is there a coded section for individuals that are a flight risk?
- Which activities are provided for physical and cognitive stimulation?
- Is the senior-living community certified?
- What are the visitation rules?
- What is included in the lease and what is considered extra?
- Are there building design elements suitable for memory care?
- How can meals be adapted for dietary preferences or restrictions?

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- What are the lease termination rules?
- What are the evacuation protocols in case of fire?
- What are their infection prevention and control measures?

## Dealing with guilt

The thought of transitioning a family member with dementia to a senior-living community can sometimes produce tremendous guilt and anxiety. Your family may have experienced many changes in the journey together. Accepting the reality of your situation and acknowledging that the progression of the disease is not your fault will help you more effectively deal with the guilt of having to transition someone into a more appropriate care environment.

Remind yourself of the warning signs that it may be time to consider a transition. Is it safe and secure in the existing environment? Is the proper care being provided? Do I have ample support? Am I suffering from carer stress? Is the financial situation secure enough to maintain care at home?

If you cannot honestly answer “yes” to these questions, you will be doing yourself and the person you care for a disservice by trying to keep the status quo. This is also a way to take the emotion out of the decision and make it a rational, sound decision-making process.

And finally, do not be surprised if the PLWD new residence is not as bad as you thought it was going to be. Transitions can be challenging especially in the first few weeks. However, it is common for the PLWD to adapt nicely to the move into their new living environment – sometimes even better than their carers.

## Expert essay

# Dementia and changing familial relationships

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Carers are integral to the care and navigation of the journey through dementia at all stages. This role is most often assumed by a spouse and/or an adult child. Carers need to be aware that change will occur in each person involved in care, personally as well as in their relationships with one another. As the disease progresses, familial roles and relationships inevitably change.

Conditions such as Alzheimer's disease are progressive and ultimately fatal illnesses. They predictably alter an individual's functional abilities. The relationship dynamic between the carer and the person living with dementia (PLWD) mirrors these changes.

In the early stage, forgetfulness and repetitive questions abound creating anxiety about schedules and household tasks. As the disease progresses, increasing supervision, monitoring, guidance, and hands-on care, particularly around personal care, become relationship-altering factors. Relationships require flexibility to ensure comfortable adaptation.

Longstanding roles and individual characteristics of the PLWD and the carer have been studied as predictive of coping with dementia. The relationships between these individuals also change over the course of their disease. While each relationship is unique, there are common observations that are predictive. Research supports that close relationships, prior to the onset of dementia, are often predictive of more positive carer outcomes: lower perceived burden, more satisfaction with the caregiving role, less depression, and lower reactivity to behavioural changes of the person with dementia. Closer prior relationships also seem to indicate a positive impact on the carer's quality of life[1].

The PLWD may express feelings of loss – loss of equality in the family, loss of the role as a parent or spouse, and loss of responsibilities. This is further exacerbated by language, judgment, and emotional changes, all parts of the disease. The PLWD may exhibit anger, despair, anxiety, or irritability as they attempt to maintain their status. As dementia progresses, clinicians note that PLWD lose focus on these deficits. They begin to live more in the present, focusing on their immediate skills and current activities. Carers may also benefit from learning how to live in the present.

Communication and interactions are central to all relationships. Over a lifetime, patterns of communication develop within a family. Carers often assume they can follow established former patterns of interaction, but dementia upends these norms. Children describe this as a reversal of the parent-child relationship. Spouses find the usual banter of married life, reminders, teasing, or reprimands, can result in unfamiliar and unexpected reactions of antagonism or irritability. Discussing the mistakes of the PLWD results in upset. Carers realise that only by altering their own comments and supportive guidance will the interactions improve. Families realise that their “normal” interactions and activities need to change. They describe a new normal, but adapting to every new change is exhausting for carers.

Miller-Otta reports “data from interviews with 12 adult children, .... All reported experiencing shifts in their identity and roles as a child of a parent with the disease, revealed four significant communication changes: communicating with a parent who was the same but different, communicating in multiple roles, correcting or reprimanding the parent, and managing parent's private information.”[2]

Carers report that every new observation of functional decline generates a sense of loss. This creates a recurring cycle of grief, with manifestations in the carer similar to those detailed by Kubler-Ross in the landmark treatise “On Death and Dying”: denial, anger, bargaining, and depression before acceptance of the reality can occur[3]. Initially, carers deny the changes they witness as relevant. They soon find themselves angered by the diagnosis and the changes, bargaining with their loved one or specialist seeking an alternate diagnosis, treatment, or opinion. Sadness and despair are natural reactions. Gradually they begin to realise the inevitability of the disease, and the carer accepts the reality, with each change as their new normal functioning. This cycle repeats with each significant observation of decline. The progression of dementia is frequently described as the Long Goodbye[4].

The fearful prospect of losing one's spouse or parent becomes gradually clearer. Daily and social activities are not shared as before. Carers report a dramatic shift in the reciprocity of their interactions[1]. They often report the PLWD to be apathetic and non-communicative. Positive

relationships are fostered when the carer can alter expectations to reflect the retained abilities of their family member with dementia.

One protective mechanism used by some carers is to isolate and withdraw. Developing emotional distance or detachment can be therapeutic. "It is speculated that withdrawal from the emotional bonds in a relationship may protect the caregiver from declining psychological wellbeing. Caregiving research proposes that there is a loss of intimacy over the course of caregiving where the Care Partners learn to 'become strangers' with the care recipient as an adaptive mechanism." [5]

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Those with close familial relationships pre-dementia are more likely to report guilt in their caregiving role. Carers with a strong sense of obligation or who perceive heightened burden from their role are noted to be prone to mental health difficulties. While adult children may experience resentment due to their multiple demands in addition to this new caregiving relationship, spouses generally do not, accepting increasing responsibilities as part of marital duties.

Relationships within the context of dementia are fluid. As the disease progresses, as the carers adapt, interpersonal relationships will change. Carers, both spouse and adult children, will find they need to be analytical, flexible, and accepting of each other and of the challenges created in their family member by dementia.

## Expert essay

# Understanding behavioural changes in moderate stage dementia

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Although cognitive symptoms (for example, impaired learning, short-term memory, attention, and executive function) are the most common and best-appreciated manifestations of dementia, changes in behaviour (that is, neuropsychiatric symptoms – NPS) are also common. Also known as behavioural and psychological symptoms of dementia (BPSD), these symptoms are almost ubiquitous in Alzheimer's disease (AD) dementia, with a point prevalence of 56% at time of dementia diagnosis, and a period prevalence of 97% over the first five years of illness. NPS include changes in drive and motivation (apathy), affective dysregulation (mood and anxiety symptoms), impulse dyscontrol (agitation, aggression, impulsivity), loss of social cognition, and psychotic symptoms (hallucinations and delusions). When clinically significant, the presence in dementia of NPS is associated with poorer quality of life, greater functional impairment, accelerated progression of dementia, higher rates of institutionalisation, increased risk of death, more neuropathological markers of dementia, as well as greater caregiver stress and burden[1,2].

Indeed, Auguste D., the index patient described by Alois Alzheimer was brought by her husband to the hospital in November 1901 not due to cognitive changes, but due to behavioural changes including affective symptoms, aggression, and suspiciousness; she was thereafter found to have cognitive impairment[3]. Nonetheless, for over 100 years, cognition was the primary focus of dementia care and research. However, in 2011, the US National Institute on Aging-Alzheimer's Association (NIA-AA) consensus recommendations for diagnosis of dementia formally recognised the importance of NPS and included them in core clinical criteria as “changes in personality, behaviour, or comportment – symptoms include: uncharacteristic mood fluctuations such as agitation, impaired motivation, initiative, apathy, loss of drive, social withdrawal, decreased interest in previous activities, loss of empathy, compulsive or obsessive behaviours, socially unacceptable behaviours.”[4] Thus, these symptoms are meaningful and important in dementia.

NPS can result in conflict with family and carers, due to limited understanding and appreciation of the nature of these non-cognitive manifestations of dementia. Many clinicians

and carers believe that BPSD represent a natural response to progressive cognitive impairment, and thus may not formally attend to these symptoms, providing at most supportive measures. Alternatively, diagnoses of psychiatric syndromes can be given, with treatments informed by the management of general psychiatric populations with depression, anxiety, agitation, or psychosis. However, a burgeoning evidence base has established that in the majority of cases, NPS are manifestations of underlying neurodegenerative brain disease[5]. Substantial links have been made with core Alzheimer's disease pathologies such as amyloid- $\beta$  and tau, and neurodegeneration of cortical and subcortical structures, resulting in altered biogenic amine function and network disruption[5]. As this evidence base becomes established, more treatments will be informed by neurodegenerative disease models as opposed to psychiatric ones[6].

Measurement of NPS is essential to the detection of the full spectrum of neuropsychiatric symptoms. Although many instruments are suitable[7], the best known and most established instruments are the Neuropsychiatric Interview (NPI) and its derivatives, which are valid, reliable, and sensitive to change. Based on informant-reported symptoms, the NPI and similar instruments better capture symptoms that may be denied by a person living with dementia (PLWD) due to limited insight or anosognosia, rendering self-reported instruments less accurate[6]. Hence, clinical care guidelines stipulate that reliable informants and carers must be included in dementia assessments[8].

Treatment of NPS follows basic principles of 1) measurement-based care, utilising rating scales to assess symptoms and the response to treatment; 2) ensuring an adequate medical workup is performed to rule out reversible causes; 3) reviewing medications to rule out potential contributors to cognitive and behavioural changes (for example, anticholinergic medications); and 4) implementing non-pharmacologic therapies[6,9]. Traditionally, antipsychotics have been used to manage more severe NPS including agitation and psychosis, again informed by general psychiatric care. Further, calming and sedation are often conflated as treatment targets, whereas the ideal target is to provide calmness without sedation, given the risks associated with sedation.

Additionally, these medications are associated with a greater risk of all-cause mortality and are not indicated for treatment in most jurisdictions (risperidone in some). Appropriate informed consent discussions are required when prescribing antipsychotics, addressing risks, benefits, alternatives, and consequences of not treating NPS. If antipsychotics must be used, treatment should be time-limited with tapering off medications attempted regularly. In reviewing the evidence base thus far, aripiprazole best balances efficacy and safety, with alternatives like the commonly used antipsychotic quetiapine offering little benefit beyond sedation[6,9].

The evidence base supports the utility of other medications, with the best evidence for serotonergic antidepressants. The CitAD study demonstrated the efficacy of citalopram for improving both agitation and psychosis in non-depressed persons with Alzheimer's disease, although this agent was found to be associated with QTc prolongation. The S-CitAD study is currently in progress, which utilises the safer S enantiomer of citalopram, namely escitalopram[2,6]. Many other medications have been studied or are under study, including brexpiprazole, dextromethorphan with quinidine or bupropion, pimavanserin, prazosin, trazodone, and THC- and CBD-based cannabinoids[10]. Clinicians are advised

to monitor this growing evidence base, in order to keep current and safe. Importantly, the utility of dementia medications should not be underappreciated.[6,9,10] A recent study demonstrated that in Alzheimer's disease, patients prescribed cholinesterase inhibitors were less likely to be prescribed antipsychotics. These findings support the notion that neurodegenerative mechanisms are implicated in NPS, which should be explored further[6,9].

In summary, the NPS associated with dementia are core features in the middle stages and warrant clinical attention. Education is required to inform carers of the nature of NPS, and guidance is required on non-pharmacological non-confrontational approaches to manage persons with NPS. Further, carer support and respite are also important. First principles and best practices should be followed regarding assessment and management of NPS, with attention to dementia medications, using the best available evidence for antipsychotics and non-antipsychotic medications. As this evidence base evolves, and new approaches become available, the hope is that NPS can be managed better (that is, by providing calmness without sedation), and more safely (without risks of sedation, falls, fractures, stroke, and all-cause mortality).

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## Conclusion

A general theme emerges from the four essays, the literature overall, and the experience of the editors of this report: *the importance of knowledge*. Knowledge is power: power to the person living with dementia, their carers, and other family members and friends. The more educated you are about the disease, the better you will use all available resources to provide the best quality of care and ensure the safety of and wellbeing of *both* the person living with dementia as well as the carer.

Clinicians need to be vigilant in taking the time to perform the assessments of the evolving symptoms to prescribe the necessary pharmacological or non-pharmacological interventions. It is up to the clinician to assist the carer in determining the level of home care needs and/or recommend a transition to a senior-living facility. This middle stage impacts the health of both the person living with dementia and the carer, who is under increasing stress, particularly if they are not made aware of available resources. Follow-up medical appointments need to be regular and more frequent. A designated health professional should be available on short notice to de-escalate emerging crisis that could lead to hospital emergency room visits and premature institutionalisation.

# Chapter 9

## Late stage

*José A. Morais, Claire Webster*

### Key points

- Late-stage dementia is largely associated with a rapid decline in the person's ability to initiate activities that are meaningful to them, cognitive and linguistic responses, and social interactions. Gait and mobility may be significantly impacted, and the person may also have difficulty eating and swallowing.
- Advance care planning allows people living with dementia to directly participate in the decision-making process for their end-of-life care, while also minimising the need for their carers to make difficult decisions during stressful times.
- Timing of advance care planning is crucial and must be made during the early stage of the condition while the person still has capacity to decide how they would like to receive palliative and end-of-life care. Multiple barriers exist to accessing dementia-specific palliative and end-of-life care services and support, particularly for those living rurally or who are living at home during the final stage of their life.
- The concept of material citizenship incorporates the use of objects to support the continuation of routines and rituals developed over a lifetime, helping a person to feel psychologically safe and to make a new space feel like home.
- Management of late-stage dementia should ensure a person's level of comfort and wellbeing versus aggressive medical interventions causing pain and discomfort.



## General background

The late stage of dementia is associated with a significant decline in a person's ability to function autonomously and will require full-time assistance from a family carer or professional support worker to meet their daily physical needs, including feeding, dressing, bathing, and toileting. In this stage, cognition is considerably impaired and language skills are greatly reduced. Mobility and gait are also impacted, thus increasing the risk of falls, and the decision to transfer a person to a wheelchair may have to be made for their own safety. In addition to the impact on the person living with dementia, the carers often experience a tremendous amount of sadness at this stage as well, as the realisation that end-of-life is approaching and decisions regarding potential placement in institutional or palliative care become imminent.

This chapter focuses on how to ensure the best quality of life and wellbeing for the person living with dementia throughout the late stages as well as the importance of advance care planning. In her essay, Maha El Akoum describes in excellent detail the benefits that advance care planning can have over the course of the person's illness in the decision-making process with regards to preventing unnecessary discomfort as well as reducing stress and conflict among family members. "Advance care planning is a major part of palliative care. Indeed, not only does it

allow people living with dementia to directly participate in the decision-making process for their end-of-life care, but it also limits the need for their carers to make difficult decisions during stressful times," explains Akoum.

Access to palliative care services for people living with dementia at home and in rural areas and the multiple barriers that currently hinder them and their families from accessing these services are discussed in detail in essays by Rose Miranda as well as Elliott et al. Both essays advocate for the necessity of governments to prioritise the need for quality-of-care services for this population during the final stage of their illness.

In this chapter, we are also introduced to the concept of material citizenship, whereby the use of personal objects can assist in the transition process for a person living with dementia from home to a senior-living facility. "The use of objects can also support the continuation of routines and rituals developed over a lifetime, helping a person to feel psychologically safe and to make a new space feel like home," explains the author, Kellyn Lee.

In his essay, Ladislav Volicer recommends the Namaste Care programme as a way for healthcare professionals and family carers to maintain comfort, connection, and quality

of life during the late stage of dementia instead of implementing aggressive medical interventions which may not prolong life. Another issue that characterises this stage of dementia is the intertwined physical and cognitive problem of swallowing foods or drinks, called dysphagia. To learn more about this, you can refer to Chapter 13.

There are many options and decisions to consider relating to end-of-life care and in Felix Pageau's essay, he presents us with the history of how the very complex and controversial topics of MAiD (medical aid in dying), AED (advanced euthanasia directive), ADs (advance directives), and NPS (neurological and psychological symptoms) of dementia are perceived around the world. Pageau highlights that,

while a complex and highly personal decision, medically assisted suicide and euthanasia remain rare across the world when it comes to dementia. His essay is a useful complement to that of Cathy Ferrier in Chapter 7 about advance care planning.

As mentioned in Chapter 7, a majority of people living with dementia (55.07%) and informal carers (63.57%) who responded to our survey indicated that they had not discussed end of life or advance care planning – showing that many families can be ill-prepared for the later stages of dementia. Whether through lack of information or access to resources, this gap must be palliated to ensure a less stressful experience for all during this part of the journey.

PART I

PART II

PART III

PART IV

PART V

PART VI

PART VII

PART VIII

## Expert essay

# Promoting wellbeing and quality of life for persons in late stage through advance care planning

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**T**he concept of wellbeing. Conceptualising and framing wellbeing has been and remains subject to debate and controversy. What is generally agreed upon is that wellbeing encompasses both mental and physical health but is a concept that is outside the medical model, given that its absence or presence is largely subjective and does not constitute a diagnosis. Wellbeing is multidimensional, in that it involves positive functioning across multiple domains including social relationships, health, and material security. For people living with dementia, improving quality of life throughout their entire journey is fundamental for wellbeing, particularly in the late stage. Advance care planning (ACP) for people living with dementia and their carers (although currently extremely underutilised) is of utmost importance and key to improving the quality of care and, as a result, wellbeing through the adoption of a person-centred approach.

*Advance care planning* This is an essential component of palliative care. It is a process that enables individuals with life-limiting illnesses to identify core values, goals, and personal preferences for potential medical treatment and care. The process of advance care planning typically involves four steps: 1) thinking about personal values and preferences when it comes to end-of-life care; 2) communicating these preferences to one's identified spokesperson, a close family member, and one's healthcare providers; 3) recording these preferences by documenting them with an advance directive; 4) reviewing these preferences periodically and updating them if needed. Studies on advance care planning have shown that it can improve concordance between identified preferences for care and delivered care, and can improve healthcare outcomes, even under challenging conditions[1]. Advance care planning has also been shown to enhance families' overall satisfaction with end-of-life care. The goals of advance care planning are centred around 1) minimizing the burden of decision-making on the spokesperson in late stage; 2) reducing the likelihood of conflict between spokesperson, healthcare providers, and family

members; 3) minimising the chances of over-treatment or under-treatment; and 4) maximising the likelihood that the person's goals are met.

*Promoting wellbeing through advance care planning for people living with dementia.* Although the importance of advance care planning for people living with dementia is well recognised, only a minority of these individuals actually get the opportunity to participate in advance care planning[2]. Previous studies have indicated that the reported barriers to completing advance care planning generally include lack of knowledge about the consequences of the disease trajectory, as well as lack of knowledge about the associated benefits and risks of end-of-life treatments, and negative attitudes toward advance care planning[3]. To help encourage its uptake, several guidelines have been developed for it in dementia care. However, their quality has been previously criticised, so there remains an inherent need for improved, evidence-based guidelines to propel advance care planning for people with dementia[2].

Individuals living with advanced stage dementia typically experience neurological issues with gait and mobility, as well as cognitive, linguistic, and functional impairment, whereby up to 90% of them also exhibit significant behavioural changes[4]. They may also have difficulty eating, drinking, and swallowing. The onset of late-stage dementia is largely associated with a rapid decline in a person's ability to initiate meaningful activities, responses, or social interactions. As such, timing of advance care planning is absolutely crucial. People living with dementia, their carers, and healthcare providers must complete advance directives and other important legal documents before the individual reaches the point in their health trajectory where the ability to consider future scenarios and actions becomes completely compromised[5]. Advance care planning is a major part of palliative care. Indeed, not only does it allow people living with dementia to directly participate in the decision-making process for their end-of-life care, but it also limits the need for their carers to make difficult decisions during stressful times.

Advance care planning can promote both physical and psychosocial wellbeing and improve end-of-life outcomes for people living with dementia in several ways[6,7]. Studies have shown that discussions that are initiated relatively early in a life-limiting illness can help manage anxiety about death and can also lead to increased feelings of self-control and autonomy, as well as the individual's satisfaction[8]. Research findings have also indicated that advance care planning also drives a decrease in inappropriate hospital admissions[2]. In the case of physical wellbeing, advance directives can help avoid the unnecessary prolonging of life through inappropriate interventions such as artificial nutrition and hydration (tube feeding) and can address and plan for other fundamentals of care tied to psychosocial wellbeing such as pain management, social support, and ensuring spiritual needs are met[9].

*Family involvement in advance care planning.* While undeniably a difficult and painful process, it is recommended that family members or significant others involve themselves in advance care planning discussions, as they can play an essential role in the process[5]. In addition to providing support to people living with dementia during advance care planning, they also help them clearly indicate and communicate their end-of-life care preferences to their healthcare provider, as well as take on the role of advocate who represents their thoughts and

desires when they can no longer communicate them. Not only has the involvement of family members enhanced the quality of the advance care planning process and invariably improved outcomes for the person living with dementia, but it has also improved the wellbeing outcomes of the carers, namely reduced depression and anxiety, and alleviated feelings of decisional uncertainty and lack of control[5].

## Conclusion

End-of-life care for people living with dementia is often described as poor. Typically, it involves many unnecessary hospital admissions, needless and burdensome treatments, and a tendency to neglect pain management and other symptoms that, unlike other people, individuals living with dementia may not be able to describe or express. Advance care planning has been identified as a means for improving outcomes in end-of-life care for people living with dementia through appropriate pain control and foregoing unnecessary treatments which may do more harm than good. More high-quality research studies are needed, particularly studies that examine outcome measures associated with advance care planning, explore issues with implementation, and provide recommendations for ways to overcome these barriers.

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Table 1. Impact on residents

| Scenario   | Object         | Outcome following Material Citizenship  |
|--|----------------|---|
| A woman living in a care home wanted to deliver newspapers to the other residents. She was prevented from doing so as "it wasn't her job." This was a job for care staff.        | Newspaper      | Care staff now provide her with the morning newspapers, and she delivers them to other residents each morning, stopping and having a chat while doing so. Staff have reported improved levels of wellbeing for her, and the residents enjoy her visits. |
| A woman recently moved into the care home. She was refusing to allow care staff into her room and relationships between her and staff were becoming difficult.                   | The blue chair | A blue chair was brought in from home. She enjoys this chair as it reminds her of her husband. She now allows staff into her room to provide care and relationships are more positive.  |
| A male smoker began pushing people out of the way of a locked door when opened by staff or relatives. He was considered aggressive, and a review of his medication was underway. | Cigarettes     | His cigarettes and lighter were downstairs. These were the items he wanted but this need was overlooked. Once identified, he was allowed to spend his days downstairs. The aggressive behaviour disappeared, and no medical intervention was required.  |
| A woman living in the care home refused to get out of bed. Staff was concerned as she was at risk for developing bed sores and reduced mobility.                                 | Breadmaker     | It turns out she loved to bake bread, so when staff acquired a breadmaker, it gave her reason to get out of bed. She now bakes bread for the other residents.   |

Table 2. Impact on staff

| Prior to Material Citizenship Training  | Following Material Citizenship Training   |
|---|---|
| Staff would often feel uneasy about positive risk-taking.                                     | Management reported staff were now working with a "can-do attitude" in the home.  |
| Staff often worked on the basis of assessing physical harm and overlooked psychological harm. | Material Citizenship provided staff with a safety net enabling them to weigh both physical and psychological risk.  |
| The care home practiced task-oriented routines.   | One manager said: "It has transformed how we work; residents can eat when they choose rather than at routine mealtimes, and are enabled to do more when they want to."                  |
| Staff did not notice some of the great work they already do, commenting "I just do it."       | Staff began to notice the great work they were already doing. They began to record it in care plans and encouraged other staff who hadn't attended the training to adopt this approach. |
| Care home staff lacked confidence.  | Staff are now more confident in the way they work with their colleagues, residents, family members, and external health professionals.  |
| Staff were uninspired and demotivated by mandatory e-learning training.                       | Staff left feeling inspired, valued, and wanted more of this type of training.  |

## Expert essay

# Introducing material citizenship to dementia care

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In Western societies, there is a normative assumption that a person living with dementia will eventually move into a care home. The lack of freedom and respect for autonomy given to people living with dementia in care homes has been investigated and regarded as a threat to human dignity[1]. People living with dementia have the right to choose their place of residence (Article 19 of the Convention of Rights of Persons with a Disability)[2] and have the right to enjoy their property (Protocol 1, Article 1 Equality and Human Rights Commission)[3]. However, many find themselves living in care homes not of their choosing and without their personal possessions[4]. While the dominant person-centred care approach operating in care home settings intends to help minimise the risk of negative, unfair, or harmful treatment and neglect, the experiences of people living with dementia residing in care homes can be far from person-centred[5].

*Object-person relations.* The importance of objects for the enactment of identity and agency is well documented. Everyday objects such as a pair of curling tongs, a set of binoculars, or that certain coffee cup, can be used as a mechanism to support a person living with dementia to demonstrate their identity. The use of objects can also support the continuation of routines and rituals developed over a lifetime, helping a person to feel psychologically safe and to make a new space feel like home. Even in the later stages of dementia, when interactions with everyday objects can become challenging and cumbersome, objects offer insight into relationships and can support choice, control, and agency.[4,6,7] While care home staff believe new residents are encouraged to bring in personal possessions, many view objects as hazardous and dangerous[8]. Physical safety is often explicit and easily understood, whereas psychological harm is often less immediately visible. For example, care home staff may view a resident making a hot drink as a risky proposition and prevent them from doing so, removing their access to such

objects. Physical harm such as being scalded by hot water is more tangible, explicit, and immediate than a decline in self-esteem, self-worth, and psychological wellbeing. The management of care homes is filled with complexity. On the one hand, care homes are driven by regulatory concerns for the safety of residents, while on the other hand, there are demands from advocacy groups and policymakers not to lose sight of the person's agency and free will. Until now, there has been little support for care home staff to balance physical versus psychological wellbeing. This essay will introduce material citizenship[8], a new approach to dementia care and how it can support care staff to enable a persons' right to autonomy and agency.

*Material citizenship.* The concept of material citizenship was developed during the author's doctoral study. It was further developed as a training course through collaboration with care industry partners. Material Citizenship training is an online interactive training programme. It comprises two sessions, both 3.5 hours in duration and delivered four weeks apart. The content of the training is drawn from the doctoral stories and observations of people living with dementia, their relatives, and care home staff.

*Findings.* Drawing on an implementation project carried out between 2019 and 2021, the Tables below show the impact of adopting material citizenship on both residents living with dementia and care home staff.

While dementia care practices have improved over the last two decades, there is still more to do to ensure the rights of people living with dementia are upheld. This essay has focused on the rights of people living with dementia having access to functional objects. It shows that by taking a material citizenship approach, staff can be supported to provide true person-centred care, having positive outcomes for both care home staff and residents.

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## Expert essay

# Palliative home care for people living with dementia

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As dementia is a progressive and incurable condition, people who have it often experience multi-faceted physical, psychosocial, and spiritual care needs that persist for months or years until death[1]. To date, the care needs of people living with dementia (PLWD) often remain unmet. Hence, many of them still live and die with distressing symptoms, problems, and discomfort[2]. In fact, between 2016 and 2060, dementia has been projected as the condition with the highest proportional increase in serious health-related suffering[3].

To address the multi-faceted care needs of people living with dementia residing at home, a palliative care approach has been widely recommended[6]. Palliative care is defined by the World Health Organization as an approach that improves the quality of life of patients and their families who are facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, whether physical, psychosocial, or spiritual[7]. This comprehensive palliative care approach aiming to improve quality of life is crucial, as the care needs of people living with dementia occur frequently, and may be interrelated or expressed differently[6]. Evidence consistently shows that palliative care could improve the symptom burden and quality of life in adults with incurable conditions. While the evidence on palliative care in dementia remains limited, we see a similar trend toward the benefits of this care approach for people living with dementia across several domains, such as symptom management and emergency room visits. For people living with dementia residing at home, the evidence on the effectiveness of palliative care interventions remains limited[6].

In 2019, we aimed to address this research gap and published a systematic review on palliative home care interventions in dementia[8]. This systematic review suggests the potential benefits of palliative care interventions in improving behavioural symptoms, enhancing pain assessment, and reducing resource use for people living with dementia residing at home. These findings are consistent with previous studies and address major issues in dementia care. In particular,

many healthcare professionals are unsure how to support people living with dementia whose behaviours they find challenging. Addressing behavioural symptoms and assessing pain are not only important for people living with dementia but may also contribute to reducing the burden of family carers who are central to enabling them to stay at home for as long as possible[6]. While this systematic review suggests the benefits of palliative care interventions for people living with dementia residing at home, the evidence found is deemed insufficient and generally too weak to robustly assess their effects[8].

This limited evidence may be due to the fact that conducting experimental studies, such as randomised controlled trials (RCTs), in this context is challenging due to ethical, legal, and practical concerns[9]. In response to these research gaps and challenges, we conducted an evaluation study on the effects of existing specialist palliative home care services on the quality and costs of end-of-life care for people living with dementia aged 65 years and older in Belgium[9]. We used linked and routinely collected nationwide administrative databases, also often called “Big Data,” and decedent cohort study design with a high-quality matching on the propensity of receiving an intervention[9], which can be considered the best possible alternative to emulate the aspects of an RCT.

Findings from this evaluation study showed that compared with people who did not receive specialist palliative home care, people living with dementia who did receive it had better quality end-of-life care in the last 14 days of life[9]. More specifically, we found that people living with dementia who used specialist palliative home care were more likely to die at home and have more contact with healthcare professionals in primary care. Further, they had lower risk of receiving inappropriate medications, undergoing surgery, and being hospitalised. These findings concur with an earlier study suggesting similar beneficial effects of specialist palliative home care for a population in need of palliative care and with other intervention studies on palliative home care dementia. Finally, findings from this study showed that specialist palliative home care reduced total direct medical costs of care in the last month of life in older people living

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with dementia, which further confirms earlier studies suggesting that palliative home care can reduce resource use and estimated costs[8]. However, despite these benefits of specialist palliative home care services, three out of the four people living with dementia did not receive specialist palliative home care, and of those who did receive it, about a third received it for the first time only in the last 14 days of life[9]. This finding concurs with widespread reports of poor and late access to palliative care for people living with dementia.

These two studies further highlight that while palliative care has potential benefits for people living with dementia residing at home, the evidence on the effectiveness of palliative care interventions for this population remains limited and their

access to existing specialist palliative care services apparently remains poor and late.[8,9] From the perspective of research and practice, we can address this persistent health problem by making palliative care for people living with dementia a public health priority. This could be achieved by supporting initiatives that aim to improve the quality of life and access to palliative care services of people living with dementia; by allocating research funding to stimulate the development and evaluation of high-quality, cost-effective, and accessible palliative care interventions in dementia; and by boosting national public awareness campaigns regarding the benefits of palliative care for people living with dementia residing at home and the emphasis that palliative care is not only about dying but also about living well until death[10].

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## Expert essay

# An overview of the experiences, needs, and shortfalls of dementia-related palliative and end-of-life care services and supports in rural areas

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As of 2018, the United Nations reported that approximately 45% of the world's population lives rurally[1]. People living in rural or remote areas often experience a lack of health services and support in general[2], and people living with chronic conditions in these locations experience a greater number of barriers to accessing care than do those living in urban areas[3]. The Worldwide Hospice Palliative Care Alliance and World Health Organization acknowledge the benefits of palliative care for people with chronic and life-limiting conditions[4] and state that palliative and end-of-life care are essential in advanced, late-, and end-stage dementia[5]. Yet, multiple barriers exist to accessing available dementia-specific palliative and end-of-life care services and supports, particularly for those living rurally[6,7].

Terms such as “palliative care,” “hospice care,” and “end-of-life care” are at times used somewhat interchangeably to refer to care intended to improve the quality of life and death for people with a life-limiting illness. However, while there are common goals of palliative care and end-of-life care, palliative care can and should begin much earlier than the end-of-life stage. In reality, advance planning for both stages could begin soon after diagnosis[8]. For the purposes of this review, the terms palliative care and end-of-life care were referred to as they were in the cited literature.

To gain a better understanding of palliative and end-of-life care for people living with dementia in rural areas, a recent comprehensive scoping review was conducted by Elliot and colleagues[6] to explore the existing literature on this topic. A summation of the methods and findings of this review are presented here and discussed within the context of other relevant literature. We also provide recommendations for further research.

## Methods

A collaborative research team approach and an iterative process were used across all stages of this review. Systematic, comprehensive searches were conducted across 10 databases and eight targeted websites for relevant peer-reviewed research and other less formal literature, published in English. Of the 4,476 initial records, 24 items were included for synthesis. Both numerical summary data and inductive thematic analysis were incorporated.

## Results

Five main themes emerged: 1) knowledge about dementia; 2) availability, accessibility, and use of services and support; 3) care decision-making, value of a person-centred approach and collaborative care; 4) artificial nutrition, hydration, and comfort care; and 5) quality of life and death.

Among rural-urban comparison studies, the effects of rurality on the findings of this review were mixed, as were the effects of sex and gender. The main gap identified was a lack of rural-specific literature in general, particularly originating from outside the United States.

Three key areas for improvement were identified and discussed in terms of access and use in rural areas, the potential for technological solutions, and nutrition care during end-of-life: 1) increasing knowledge about dementia; 2) having informed, early discussions and decision-making about palliative and end-of-life care; and 3) providing a person-centred approach to care in preferred care settings.

## Access and use of services and supports

Availability and utilization of palliative care and end-of-life services and support were reportedly lower compared to screening, diagnostics, and treatment. Rural hospice care was lacking in general. This review revealed a need for a person-centred approach and for collaborative care so that these services and support could be provided in a preferred care setting (most often in-home). Use of alternative methods of care such as in-home visits, telephone support, and remote technology was viewed as a facilitator for people living with advanced dementia to be able to remain cared for in their own home and/or community.

## Potential for technological solutions

Use of technology to remotely deliver healthcare services and support enhances accessibility and availability for rural dementia care[9], where one key benefit of using technology in these areas was the reduced travel burden for these individuals and their families. However, families in rural settings have less access to technology, which leads to additional psychological barriers when it comes to technology adoption, and this, despite the clear benefits of technology for remote dementia care[9].

## Nutrition care at end-of-life

Providing comfort, and artificial nutrition and hydration during the end-of-life stage for people living with dementia was a noted concern in this review. Often viewed as an

invasive measure increasing discomfort and risk of adverse outcomes, artificial nutrition and hydration are typically not recommended for dementia palliation[10]. In this review, among rural-urban comparative studies, similar findings were reported where rural participants were less likely than urban participants to use or to support the use of life-sustaining measures to delay death (such as feeding tubes). To gain a better understanding of rural-urban differences in attitudes and preferences regarding the use of artificial nutrition and hydration during end-of-life, as well as comfort measures related to nutrition at end-of-life, further research is warranted.

## Conclusion

This review indicates a scarcity of literature in general regarding palliative and end-of-life care for people living with dementia in rural areas. Key points emerged such as the need for increased dementia knowledge (in general and especially for the advanced and end-of-life stages) and having informed, early discussion and decision-making among healthcare providers, people living with dementia, their families, and carers, as well as providing a person-centred approach in preferred care settings. Technological solutions were presented as a means to address issues with access to services and supports, particularly in rural areas. Artificial nutrition, hydration, and comfort care were also discussed. Although further research is recommended, these findings can help inform future research, policy, and the development of services, supports, and intervention strategies.

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## Expert essay

# End-of-life care in institutions

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The most important issue in caring for someone with advanced dementia is the acknowledgement that advanced dementia is a terminal disease[1]. Therefore, the appropriate goal of care may be maintaining comfort and quality of life instead of prolongation on life at all costs[2], with some approaches specifically designed to provide quality of life until the last breath.

Quality of life depends on three factors: medical issues, psychiatric symptoms, and availability of meaningful activities[3]. Aggressive medical interventions decrease comfort and quality of life while they may not prolong life. Table 1 lists the most common conditions for which an aggressive treatment may be provided and palliative care alternatives: infections and nutritional problems.

Infections are quite common as dementia progresses and most people with advanced dementia die from pneumonia. It is not advisable to transfer people living with dementia to a hospital as hospital treatment does not increase survival and causes functional impairment[4]. It also may be unnecessary to treat generalised infections with antibiotics because antibiotics do not increase survival of people with advanced dementia[5]. Tube feeding is associated with increased mortality rate and possible tube-related complications, but not with an increase of survival days and of nutritional status[6].

Assisted feeding can be provided only when it is requested verbally or behaviourally (Requested Assistance with Eating and Drinking – RAED). Dependence on request acknowledges that even people with advanced dementia have some remaining decision-making ability and that some of them prefer dying rather than living in their current conditions[7].

Palliative care may be provided by a hospice organisation when people with dementia live in a care facility and this is considered their home. Inclusion of a person with dementia in a hospice programme is complicated given that, in most places, the requirement is that the person has a survival prognosis of only six months or less. There is no reliable way of making this prognosis and the latest effort using a broad set of criteria is still only correct 67% of the time[8]. Despite this difficulty, in 2019 more people in Medicare hospice care had a principal diagnosis of Alzheimer's disease/dementia/Parkinson's disease than any other disease and people with these diagnoses have the longest duration of stay[9]. In some cases, they provide comfort or satiety, and may in fact cause discomfort with dysphagia/aspiration and the unwanted prolongation of the dying process.

There are two strategies for dealing with people living with dementia who have an advance directive (AD) to stop assisted feeding and drinking. One is “comfort feeding,” a

Table 1. Management of medical conditions

| Condition                    | Aggressive care                              |   | Palliative care   |
|------------------------------|--|---|---|
|                              | Procedures                                   | Burdens   |   |
| Cardiac arrest, heart attack | CPR, ICU hospitalization                     | Broken ribs, discomfort from intubation and ICU environment   | Maintaining comfort, oxygen, morphine   |
| Intercurrent infections      | Hospitalization, IV lines, urinary catheters | Discomfort, loss of function  | Treatment at home or long-term care setting   |
|                              | Possible IV administration of antibiotics    | Restraints, side effects, C. difficile infection  | Maintaining comfort with analgesics (morphine)  |
| Dysphagia or food refusal    | Tube feeding                                 | Discomfort, danger of PEG insertion, loss of food enjoyment and of contact with carers during feeding | Careful hand feeding, comfort feeding or feeding only when requested (RAED), see Text |

term commonly used that is not necessarily accurate since the person may not actually have to be discharged from hospice care because they no longer satisfy hospice prognosis but may be included later again.

Involvement in meaningful activities at most care facilities is inadequate because they are geared toward residents with no or mild cognitive impairment and people with advanced dementia are unable to participate. There are some programmes that were developed specifically for people with advanced dementia; however, most of these programmes involve short infrequent sessions.

In contrast to “comfort feeding,” the other strategy consists in Namaste Care, which is a daily programme of enhanced nursing care that can provide quality of life until the last breath[10]. The Namaste Care programme takes place in a space where there is little distraction and dimmed lights, relaxing music, and the scent of lavender permeates the room. Individuals are placed in reclining chairs, assessed for pain, and tucked in with warm blankets. The loving touch approach by the Namaste carer is accomplished with gentle massages of the persons’ hands, arms, and legs, and hair that is lovingly brushed. The carer does not wear gloves and speaks in a soft tone during these meaningful activities. People with advanced dementia become used to being touched and when they are not in the Namaste Care program, they

rarely reject care. The calm environment and loving touch improve communication and decrease agitation and improve symptoms of depression. Namaste Care allows decrease of psychotropic medications and increases carer job satisfaction. Families are encouraged to participate in Namaste Care. They tend to visit more often and are more satisfied with the care that is provided. Namaste Care helps families, who often feel helpless, to get involved with their relatives. Staff teach them how to offer hand massages, encourage them to play religious music if the person was active in a particular faith, and talk with them when they are in the dying process. Namaste Care was developed for the person who is cared for in a long-term facility, but it can also be taken to the bedside. Many hospices are offering the loving touch approach and creating a calm environment wherever the person is living, be it at home, in a nursing facility, or in an inpatient hospice unit. This programme is ongoing until the person dies. Namaste Care can be implemented without additional staff and with very limited expenses. It is now offered in 11 countries. (Fig. 2).

Behavioural symptoms of dementia usually diminish in advanced dementia, but they can still decrease quality of life if they are not managed appropriately. The management should always try to use non-pharmacological interventions that are listed in Figure 2. It should be acknowledged that the nature of behavioural symptoms depends on

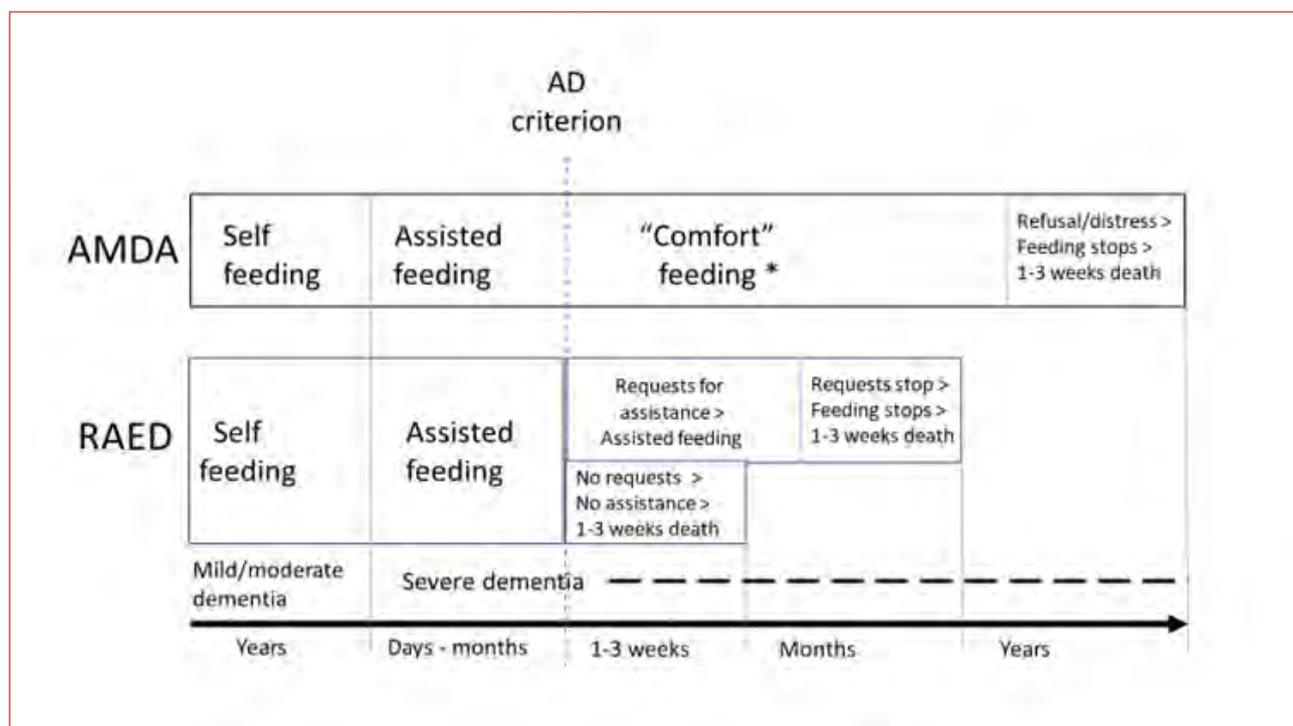


Figure. 1: AD: advance directive, AMDA: American Medical Directors Association - Society for Post-Acute and Long-Term Care Medicine – Ethics Committee recommendation RAED: Request for Assistance with Eating and Drinking

the situation in which the symptoms occurred. For instance, there are two types of aggressive behaviours: reactive and proactive aggression. Reactive aggression is often elicited during carer activities when the person living with dementia does not understand their intention or the need for the

activity. Proactive aggression may occur without a stimulus and is relatively rare. However, sometimes the stimulus is unrecognised. For example, another resident or staff member may have been someone the person disliked before developing dementia and thus elicits the aggression.

Table 2. Types of most common behavioural changes in dementia

|                                      | Occasion: When solitary  | When interacting with others  |
|--------------------------------------|--|---|
| Type of behaviour                    | Agitation (periods of restlessness, repetitive physical movements, wandering, socially inappropriate/disruptive behaviour) | Rejection of care may escalate to combative behaviour                               |
| Factors increasing risk of behaviour | Depression*, boredom, delusions, hallucinations  | Depression*, a lack of understanding of carer intentions, delusions, hallucinations |
| Non-pharmacological interventions    | Provision of meaningful activities   | Improved communication, modification of care procedures                             |

\*Depressive symptoms may include negative comments, anger, unrealistic fears, repetitive health complaints, repetitive anxious complaints or concerns, sadness, and crying.

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## Expert essay

# Dementia and active euthanasia – Should we be ready?

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**I**ncreasingly across the world, governments are creating exemptions to the criminal acts of suicide and culpable homicide to allow for medical assistance in dying. Worldwide, approximately 100 million people now have access to some form of assisted dying legislation. Assisted dying is lawful in nine US states and the District of Columbia, Canada, the Netherlands, Belgium, Luxembourg, Spain, Switzerland, and four Australian states. New Zealand has passed legislation that was approved in a national referendum in 2020. The Constitutional Court of Colombia legalised assisted dying, but the government has not yet legislated. Assisted dying is being debated in many countries and legalization appears likely to spread.[1 p856]

But should medical assistance in dying (MAiD) – an umbrella term comprising assisted suicide and active euthanasia (that is respectively, giving medical means to help someone complete suicide or injecting a lethal dose of medication to an individual) – be considered for persons living with dementia? The Report of the Lancet Commission on the Value of Death[1] seems to believe so. Even though stakeholders around the world are discussing the possibility of extending medical assistance in dying through advance directives, we should first ask the question: “Why is euthanasia available in the Netherlands for persons living with dementia by advance euthanasia directive (AED), but nowhere else yet?”

*Across the globe.* It is a very limited number of countries that allow medical assistance in dying. [1,2] Many nations have not and will not legalise medical assistance in dying in the foreseeable future. Reasons include religious and cultural taboos. As religions are at the foundation of many constitutions[3], major changes would have to occur to allow this legal and medical undertaking in several states. The sanctity of a God-given life is never to be taken lightly in many religions. Even if these religious principles are not written into the constitution of a country, they are ingrained in many cultures worldwide[3]. Moreover, in countries with shorter life expectancy, ageing is a privilege which only a few experience[3,4]. Consequently, medical assistance in dying is not often wished for by older adults in these nations where basic care is not available, and death ensues naturally and

frequently at a young age[4]. As for high-income countries (HICs) around the globe, older adults can be perceived as a burden for whom to care[5]. Western views on ageing and dementia are tainted by the notions of productivity, consumerism, and efficiency. Hence, dementia can be viewed as intolerable, especially when leading to dependency on others[5]. Unquestionably, ageism, ableism, and consumerism influence the discourse on medical assistance in dying, especially for people living with dementia. This is a privileged HIC view on medicine thought to be omnipotent when resources are readily available for most[1].

*Global North.* The simple answer to “Shall we be ready?” is no, and we ought not to be. A perspective of solidarity, community-centred care, and elderly-friendly community should prevail[1,4]. For countries like Canada with an effective division between the State and religions, other arguments must be studied[1]. In the Netherlands, suffering is the pivoting point to proceed with euthanasia[2]. A physician must assess it as the individual is still minimally conscious. As for Belgium and Luxembourg, loss of consciousness is necessary to euthanasia and the disease must be at an irreversible state[2]. In Colombia, the advanced euthanasia directive (AED) guides the person's representative but does legally bind the latter to any decision related to euthanasia[2]. Only the Netherlands permits euthanasia for people living with dementia through AED[2]. Canada is now studying this possibility, as well[1]. However, few people have written out an AED in the Netherlands[6]. Interestingly, studies conducted in the Netherlands showed that most physicians do not abide by advanced euthanasia directives as they are deemed imprecise, inapplicable, irrelevant[2] or simply unreliable[6,7]. Additionally, some nursing homes in the Netherlands have policies stating that advanced euthanasia directive should not be followed in cases of dementia[2].

*Autonomy and medical aid in dying (MAiD).* MAiD promoters nevertheless put forth the argument of autonomy as the main reason for MAiD in advance directives (ADs). This is based on Dworkin's argument of “critical interests”[6]. Specifically, this refers to the core principle that an individual's happiness should supposedly remain stable throughout life[6]. These

critical interests are allegedly continuous and unchanged by life events. Yet, Walsh explains how a cognitive transformative experience modifies an individual's perspective on life so deeply that "[...] preference changes are unpredictable; given the nature of transformative experience itself, they could not be fully considered by someone who is in a process of drawing up an advance directive." [8 p55] Dementia is a transformative experience that ought to be given moral weight in medical decision-making as such [8]. Autonomy is not the guiding principle for decision-making then. To make a choice one, five, or 10 years before a life-changing experience renders the decision ineffective. Indeed, the person has changed, and past autonomy does not reflect the current context in which an advanced euthanasia directive would be activated. The Dutch experience with advanced euthanasia directive being unreliable showed that Walsh is most probably right.

*Suffering and dementia care.* Thus, our last argument pertains to suffering, also often evoked by medical aid in dying defenders. Four potential scenarios can be extrapolated from current knowledge about dementia. These are 1) dementia without concerns, 2) dementia with easily treatable neurological and psychological symptoms (NPS), 3) dementia with difficult to treat NPS or 4) untreatable NPS. For the first category

(1), MAiD is not required as the person has no physical, psychological, or existential suffering. In the two following states (2) or (3), treatment through adequate dementia care is required – for example, a solution to unmet needs such as pain control. Hence, if resources are given to formal and informal carers, they can help reduce NPS and render the person to a state of dementia without concerns. In the situation of advanced dementia with untreatable NPS, palliative sedation can be used. From a clinical perspective, then, in none of the stages or states of dementia is MAiD necessary.

*Conclusion.* Limiting treatments to those that are proportionate and provide best-practice dementia care will alleviate the need for euthanasia. This would also facilitate equity in redistribution of resources between countries. Rich countries should follow the example of lower- and middle-income countries (LMICs) when it comes to caring for senior citizens and accepting natural death without haste or delay [1,4]. The final solution of MAiD for the rise of ageing people worldwide is unethical. Dementia care is to be provided even in HICs where older adults may not be as respected as in LMICs. Thus, the values of LMICs can provide guidance to HICs when providing dementia care for senior citizens – decolonizing geriatrics.

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## Conclusion

As late-stage dementia is a terminal condition, the priorities should focus on providing the person with the greatest level of comfort, connection, and patient-centred care to ensure their wellbeing. This chapter highlights the importance of advance care planning, informed decision-making by both the person living with dementia and their family members, as well as how palliative care at home could provide them with a better quality of life and reduce the stress on family members. However, it remains that insufficient information, education, and access to resources in a post-diagnosis dementia world are a major barrier to resources.

As neurological and psychological symptoms are in full evidence during the late stage of dementia together with the decline of cognitive and physical function, it is imperative that healthcare professionals and carers become better educated in acquiring the tools to recognise, understand, and manage these symptoms in order to provide the greatest level of end-of-life care.

## **Part III**

Care of symptoms commonly  
associated with dementia

# Chapter 10

## Cognitive difficulties

*Pedro Rosa-Neto, Claire Webster, Serge Gauthier*

### Key points

- Cognitive symptoms progress differently depending on the type of dementia and which part of the brain is suspected to be the primary location of the pathological process.
- There are currently no accurate prognostic markers that can clearly anticipate the evolution of cognitive and functional decline, despite being one of the most frequently asked questions by people living with dementia and their carers.
- The support approach for a person living with cognitive decline is quite different for someone who was expecting the diagnosis and is actively seeking all possible resources, compared with someone who was utterly surprised by the diagnosis and is experiencing acute distress.
- A practical and positive way to provide support to a person diagnosed with cognitive decline is to focus on the individual's retained abilities, skills, and interests rather than on what they are losing or are no longer able to accomplish.
- It is important to understand the experiences of those who are diagnosed with cognitive decline while still in employment, so that adequate policies, practices, and support for dementia in the workplace can be developed.
- Maintaining a purposeful lifestyle after paid employment has ended can help maintain a person's sense of self and dignity. Many people continue to work in alternative ways post diagnosis, which might include, but are not limited to, volunteering roles, advocacy or influencing roles with charities, and being involved in research.



## General background

This chapter discusses in great detail the types of cognitive changes associated with different dementias and how cognitive decline can impact the person's ability in the workplace, emphasising the great importance for early intervention and calling for more adequate policies, practices, and support for working individuals. This chapter also highlights how carers can best support a person following a diagnosis of cognitive decline, taking into consideration their current emotions, interests, and abilities, and avoiding focusing on what they are lacking and can no longer do.

Dementia is frequently associated with a progressive difficulty to retain new information.[1,2] However, patients can develop various degrees of mental difficulties alongside or independently from memory problems. For example, dependent on the severity of the condition, people living with dementia might have difficulties in orienting themselves in time and space, problems in communicating (aphasia), or difficulty in carrying out certain movements (apraxia). Indeed, some people living with dementia might show poor judgment, disorganisation, or socially inappropriate behaviour (executive dysfunction)[3,4]. Slow thinking processing, mood oscillation, and motor symptoms such as tremor, gait difficulties, slowness, or lack of spontaneous movements might occur in the so-called subcortical dementias[5].

It is important to clarify that symptoms progress over time, however the rate of progression is variable depending on diagnosis of the underlying cause of dementia, among

other factors.[3,6–9] One might call it rapidly progressing dementia when the people with dementia decline faster than six points per year on the Mini-Mental State Examination (MMSE)[10].

It is important to individualise post-diagnosis plans as the stage of dementia (mild, moderate, advanced), the rate of disease progression, or type of cognitive symptoms affected can dramatically change from person to person. The underlying cause of dementia can dramatically influence post-diagnostic plans. The nature of the professional activities, as well as working environment, plays an important role in these decisions.

The essay by Sarazin et al. describes the various types of cognitive changes associated with different dementias such as Alzheimer's disease, frontotemporal dementia, as well as Parkinson's disease dementia. The second essay by Snow and Logan broadens the discussion on adaptation after a diagnosis of dementia to a "what abilities remain" strategy, one of the pinnacles of positive rehabilitation. Finally, the essay by Ritchie and Lebec discusses how to facilitate the process of positively transitioning from paid to post-retirement options which may include volunteering or advocacy roles, as well as participating in research, which have all been shown to have potential cognitive benefits as well as to strengthen later life resilience by ensuring one has a purpose in life.

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## Expert essay

# How do cognitive symptoms progress over time?

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In neurodegenerative diseases (NDD), cognitive symptoms progress differently depending on the diagnosis. Even if the distinction between cortical and subcortical syndromes of dementia is controversial, it reflects a clinical reality[1]. This classification depends on which part of the brain is suspected as the primary location of the pathological process, as a consequence of which cognitive impairment progresses. In cortical NDD, such as Alzheimer's disease and frontotemporal dementia, cognitive decline follows the progression of brain lesions: typically, the mesial temporal cortex, then the neocortical associative areas in Alzheimer's disease, and the frontal and temporal lobes in frontotemporal dementia. In subcortical NDD, such as Parkinson's disease dementia, mild cognitive impairment progresses to subcortical dementia, which involves less severe memory dysfunction than in cortical dementia and a slowing down of thought processes associated with a dysexecutive syndrome, in the absence of aphasia (looking for words), agnosia (inability to recognise things), and apraxia (difficulty performing voluntary movements).

## Cognitive decline in Alzheimer's disease

In typical Alzheimer's disease, the progression of cognitive deficits is consistent with the extension of tau pathology from the medial temporal regions (entorhinal cortex, parahippocampal gyrus, and hippocampal formation) through the neocortical associative areas, resulting in early progressive impairment of episodic memory followed by aphasia, apraxia, and agnosia[2]. Inaugural cognitive symptoms are characterised by memory impairment for recent events, unusual repeated omissions, and difficulty learning new information. Initially, amnesic symptoms are not associated with a loss of autonomy, and the patient remains independent for common activities of daily living. Temporal-spatial disorientation is also present at the initial stages of Alzheimer's disease. As the disease progresses, patients show difficulty orienting themselves in familiar places during intermediate stages, which then progress to severe disorientation in their personal residence[2]. Patients may develop language disorders, visuospatial and recognition deficits, and difficulties executing the more

complex tasks of daily living, leading to loss of autonomy and dementia. Aphasia may appear as the condition progresses, characterised by decreased verbal comprehension and naming difficulties. As Alzheimer's disease advances, all aspects of language (oral production, comprehension, reading, and writing) can be impaired, resulting in mutism or incomprehensible language in severe cases. Gestural apraxia is mainly observed by asking the patient to perform pantomimes of tool uses or symbolic gestures or to imitate meaningless gestures. Difficulty using objects, as well as dressing apraxia, is observed during moderate to advanced Alzheimer's disease. Patients show visuospatial dysfunction in the moderate stages, first during complex tasks, which require perceptual analysis and spatial planning. Visual agnosia and complex visual processing dysfunction are observed in advanced stages of the disease, with impairment in recognition of objects or faces. Different stages of Alzheimer's disease, from mild to moderate and late (dementia) stages are described according to the progression of cognitive impairment and loss of autonomy. The Mini-Mental State Examination (MMSE) assesses global cognitive efficiency and is generally used to evaluate dementia stage and track the overall progression of cognitive decline. The MMSE is less sensitive to detect cognitive decline in mild than in moderate stages of Alzheimer's disease[2,3].

Importantly, Alzheimer's disease progresses at a variable rate, making it difficult to predict the rapidity of clinical progression[3]. Age of onset influences the rapidity of Alzheimer's disease progression. Longitudinal studies showed a more rapid cognitive and functional decline in early-onset than in late-onset forms of the disease[4].

Atypical forms of Alzheimer's disease, such as logopenic primary progressive aphasia (log-PPA), posterior cortical atrophy (PCA), and frontal variant (fr-AD) are not rare, especially in young patients. In log-PPA, language deficit is the initial symptom, characterised by frequent pauses that disrupt the flow of conversation and the generation of phonologic errors, associated with deficit in sentence repetition[5]. The evolution of the disorder is variable,

PART I

PART II

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PART VIII

but typically can remain isolated for a fairly long time. In PCA, visual and visuospatial deficit are the initial symptoms, then patients develop features of Balint syndrome (ocular apraxia, optic ataxia, and simultanagnosia), Gerstmann syndrome (acalculia, agraphia, finger agnosia, and left-right disorientation), visual agnosia, and transcortical sensory aphasia, whereas episodic memory is preserved or only mildly impaired[6]. Patients come to behave as if they were visually impaired or even blind, due to the increase in neurovisual disorders. The frontal variant is defined by a predominant dysexecutive syndrome associated with frontal behavioural symptoms.

## Cognitive decline in frontotemporal dementia

Frontotemporal dementia syndromes differ from Alzheimer's disease in baseline characteristics and natural history. The behavioural variant of frontotemporal dementia (bvFTD) is defined by an early and prominent behavioural disorder and dysexecutive syndrome with preservation of spatial orientation and praxis[7]. During frontotemporal dementia progression, cognitive decline remains mainly focused on frontal/executive dysfunction[8]. This explains that the use of the Mattis Dementia Rating Scale (DRS) is more relevant than the MMSE to assess global cognitive decline, because the Mattis DRS mainly assesses executive functions, whereas the MMSE investigates mainly the instrumental (retro-rolandic) functions. The difference is particularly pronounced for the conceptualisation subscale of the test, while the decline on the MMSE is less informative[8]. Social cognition, which can be assessed for example by facial emotion recognition, may experience progressive deterioration over time in parallel with behavioural symptoms.

The language variants of frontotemporal dementia include semantic dementia and non-fluent/agrammatic primary progressive aphasia (PPA). Little is known about the natural history of these variants. The progression of cognitive symptoms in semantic PPA is characterised by a loss of verbal and/or visual semantic knowledge (prosopagnosia and associative agnosia) according to the lateralisation of the lesions, often associated with behavioural changes. Agrammatic PPA progression is often associated with difficulty swallowing and sometimes with speech apraxia, which can lead to severe anarthria – the inability to articulate speech.

## Cognitive decline in Parkinson disease dementia (PDD) and in dementia with Lewy bodies (DLB)

Cognitive dysfunction is one of the most prevalent non-motor symptoms in Parkinson's disease. The profile of cognitive dysfunction in Parkinson's disease patients is heterogeneous, but typically is characterized by a subcortical cognitive profile with attention and executive dysfunctions that affect memory as well as visual-spatial abilities[9]. Up to 60%–80% of patients develop PDD within 12 years of disease duration. Worsening of visual-spatial abilities has been reported to predict cognitive impairment and the development of PDD. Language disorders may occur in the transition to dementia in Parkinson's disease[2].

In dementia with Lewy bodies, the rate and nature of the cognitive decline may be distinct from that of Alzheimer's disease or Parkinson's disease dementia. But the differences between these diseases are not fully understood, due, in part, to fluctuations in attentional performance in dementia with Lewy bodies which could explain performance heterogeneity[10]. A more rapid annual decline in MMSE score was described in dementia with Lewy bodies than in Alzheimer's disease or Parkinson's disease dementia, but not in all studies. Verbal fluency deteriorated faster, while memory, recognition, and recall decline more slowly in dementia with Lewy bodies than in Alzheimer's disease. Comorbid Alzheimer's disease pathology is associated with a more rapid deterioration and contributes to the heterogeneity of the cognitive progression[11].

In conclusion, the profile of the cognitive decline varies according to the underlying pathology. Cognitive disorders sometimes extend to other cognitive domains than those initially affected (for example, in typical Alzheimer's disease) or remain more circumscribed for a fairly long time, while increasing in intensity (for example, atypical Alzheimer's disease and frontotemporal dementia). Importantly, the rapidity of clinical progression is not homogeneous, even within a given disease. We currently lack reliable prognostic markers to anticipate cognitive and functional decline and answer the question often asked by patients and their families.

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PART VIII

## Expert essay

# What can care partners do to support a person living with cognitive decline following a diagnosis of dementia?

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After someone receives a diagnosis of dementia from a healthcare provider, what is the best way to offer support? To fully answer this question, one must consider the initial reason that the individual sought the medical care. Perhaps it was for a physical or psychological health concern that was completely unrelated to cognition, such as depression or diabetes. If so, the diagnosis of dementia may have been extremely unexpected. Perhaps the individual went to the appointment because a loved one was concerned and coerced them into the visit, even though they themselves had not noticed any changes. Or perhaps they were aware that something was changing within their own brain and decided that they should investigate further. Even though the outcome of a dementia diagnosis may be the same for each, the mindset of the individual may be incredibly different based on their reason for seeking care.

It is also essential to recognise that the level of knowledge and awareness about the condition of dementia varies drastically among individuals. Many do not realise that there are forms of dementia other than Alzheimer's disease, some do not realise that dementia cannot be cured, and most do not realise that an accurate life expectancy prognosis is extremely challenging for most forms of dementia. Cultural and socioeconomic backgrounds also contribute to variations in knowledge. Additionally, it is important to recognise that, in a prospective study of prodromal symptoms, cognitive decline was detected 12 years before the onset of dementia, using measures of semantic memory and conceptual formation[1]. In other words, people experience functional brain change a decade or more before diagnosis. To provide adequate support, one must consider all of these factors.

It is also critical to consider the abilities and emotions of the person living with dementia. How do they appear to be reacting to the diagnosis? Is the information being retained or lost? What symptoms are they experiencing, and where in progression are they? What abilities remain? Also, are others in their support system knowledgeable about dementia, or rather unaware? The support approach is quite different for someone who was expecting the diagnosis and is actively

seeking all possible resources, compared with someone who was utterly surprised by the diagnosis and is experiencing acute distress.

To support an individual from a medical perspective, encourage a return visit to the healthcare provider approximately one week after the diagnostic appointment. This allows time for the individual to process what was said and heard at the initial evaluation. Also, if the educational information offered by the healthcare provider was not substantial, it may be valuable to offer additional dementia information. The internet provides access to many resources at low or no cost, as do local ageing agencies and other advocacy organisations when available. Seeking education and training for oneself as a care partner is also incredibly essential for being able to provide effective support.

For other healthcare support, a pharmacy consultation to evaluate all the individual's medications can be a useful tool. A screening/assessment of the person's activities of daily living (ADL) and instrumental activities of daily living (IADLs) for current function and challenges is beneficial. Asking a healthcare professional for physical activity recommendations that are well-matched with one's abilities may also be helpful. Encourage the awareness that a combination of a healthy diet[2], physical activity[3,4], meaningful engagement[5,6], social opportunities[7], use of cognitive skills[8], and maintenance of general overall health[8,9] may make it possible for the individual to retain their abilities longer and live well for as long as possible.

Providing emotional support is critical, as well. Offer referrals for opportunities for peer support with others who have a dementia diagnosis, such as support groups. Also, it may be beneficial to offer referrals to other skilled individuals, such as mental health professionals or dementia care specialists. Keep in mind that these are offers that the individual may or may not choose to use, as they may be still processing the diagnosis. If they're not yet ready, try offering these suggestions again at a later date. Again, finding emotional support for oneself as a care partner, such as through a

support group or with a mentor who has experience in the same form(s) of dementia as the individual you support, is equally important.

Other practical ways to provide support include focusing on the individual's retained abilities, rather than on what they are losing. Guiding them to volunteer opportunities and purposeful engagement opportunities is essential. Consider what support systems may be missing, and offer that support, or provide referrals to other skilled individuals who can do so. Options may include assistance with meals, home maintenance, finance, transportation, or living arrangements, depending on the person's current abilities. Also, promote the use of technology as an aid, including alarm reminders, voice-activated commands, maps, etc. If the individual is reluctant to accept support, try selecting two options and asking them to "just try them, for now." Build your interaction and communication skill sets.

What are some offers of support that are typically ineffective? Try to avoid making comments such as "Don't worry, I have a bad memory, too." Trying to minimise the individual's

changes is not productive, but acknowledging the challenges of brain change is. Pushing yourself or the person in new and extreme health promotion programmes in an effort to "fix" things typically results in frustration and emotional distress for both parties. Taking over rather than developing supportive strategies can and does result in premature atrophy in abilities. If the person living with dementia is initially in distress and refuses offers of support, pushing an agenda is not beneficial, but focusing on sustaining a relationship truly is. Also, sharing the diagnosis with others is not a one-size-fits-all solution, but working with consultants who are skilled can help develop an essential team for this new life.

The pinnacle of support may be the acceptance of this paradigm shift: instead of viewing dementia as a death sentence with no effective treatment, choose to consider various dementias as changing disability states. Approaching dementia in this way and encouraging the individual and others in their support circle to do the same can be immensely empowering and enable them to live their lives as fully as possible, with effective support in place for all involved.

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## Expert essay

# Impact of cognitive impairment on employability

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People who are diagnosed with dementia can, and do, continue in employment[1]. While this mainly impacts people who are diagnosed with younger onset dementia (under the age of 65), recent trends to increase retirement age and changes to state pension policies mean that dementia in the workplace will become increasingly common as people routinely work into later life. Despite this, many organisations do not have policies or legislation that protect the rights of people with dementia in employment[2]. It is important that we further understand the experiences of those who are diagnosed while still in employment so that we can develop adequate policies, practices, and support for dementia in the workplace.

Many people who develop dementia while in employment first notice symptoms impacting their work. For some, this may be forgetting a meeting or finding it difficult to learn a new system or process, but for others the impact of symptoms, and their consequences can be more severe[1]. The challenges that employees may experience in the workplace, such as increasing demands to learn new tasks, communicating effectively, or managing risks, can diminish the employee's confidence in themselves to carry out the role[3] and increase the risk of, for instance, making errors in an accounting system or not following health and safety procedures. Dementia is therefore likely to have an impact on occupational competence, as well as compromising the person's sense of identity[3].

Early diagnosis is key to allow the individual, employer, and healthcare practitioner(s) to discuss support and plans around employment. However, for many reasons, diagnosis can be delayed, and can lead to people either leaving employment, being subjected to disciplinary procedures, or experiencing high levels of stress in the workplace which can further exacerbate the impact of symptoms on performance. This leaves people with negative experiences of the workplace, and by the time they have a diagnosis, they have moved on and do not feel like they can return to work[1]. Therefore, the most valuable tool we have in supporting people with dementia in the workplace is early intervention.

Support to maintain employment when an employee has a cognitive impairment can vary depending on the type of work that an individual does. However, it is important that managers, colleagues, and family members all have a shared understanding of the support an individual needs to maintain their employment and that there is an open dialogue between the individual and the employer[1]. Dementia awareness sessions in the workplace can be helpful to ensure understanding within the workforce. Many people with dementia will be able to continue working with supports such as flexible working, creating a quiet environment, and the use of technologies. There is some evidence that designing technologies related to familiar technologies used at home, such as smartphones, could be beneficial for people with dementia in the workplace. Ideally this should be designed in conjunction with the employee, as each person's experience will be specific to their occupation and diagnosis[4].

However, for some people with dementia, continuing in their employment may not be possible, or the individual may decide they no longer want to continue working post-diagnosis. If this is the case, it is important that people are given support to manage the transition and explore the post-retirement options. This will require a multi-disciplinary approach, considering healthcare, employment law, occupational health, and potentially career guidance. Leaving employment following a diagnosis of dementia can lead to a significant financial as well as emotional impact[5]. People living with dementia, however, have a right to be actively involved in decision-making to support their goals, and this includes negotiating a positive transition to retirement, in line with their employee rights. Occupational identity needs redefining in all transitions from employment to retirement, but for people diagnosed with dementia, with possibly less time to plan, this takes on an even greater significance[3]. However, while a person may leave their paid occupation, this does not mean that they cannot continue to make a valuable and meaningful contribution to society. Many people continue to work in alternative ways post diagnosis. This might include, but is not limited to, volunteering roles, advocacy or influencing roles with charities, and being involved in research.

To maintain employability for people living with dementia, attention needs to be paid to the individual's skills, abilities, and interests in the context of the support that is available (through both the physical and social environment) as well as the opportunities available to them[6]. Maintaining a purposeful lifestyle after paid employment has ended can help maintain a person's sense of self and dignity[7]. After leaving work, the transition to a socially active life is likely to require considerable support from support groups, family networks, and job coaches[8]. However, taking up activities, such as volunteering and community engagement, is shown to have significant positive benefits to improve people's health and wellbeing, as well as reducing social exclusion[9] and supporting active ageing. Volunteering has further been shown to benefit cognitive health as well as strengthen later life resilience[10].

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## Conclusion

This chapter is the first in the third section of the report, which focuses on how to address symptoms commonly associated with dementia. Each chapter within this section is meant to be relevant across the stages of the disease and causes of dementia. We hope that the integration of clinical information and management recommendations will prove useful to many readers of this report.

This chapter emphasises how each person's experience of dementia is unique, and that cognitive decline and symptoms will progress differently depending on the type of dementia an individual has, and which part of the brain is suspected of being the primary location of the pathological process. It also highlights important steps a carer can take to support a person who has recently received a diagnosis. Finally, it covers the great importance of encouraging persons living with dementia to participate in meaningful activities and opportunities that correspond and are able to evolve with their changing cognitive, functional, and emotional abilities – as a diagnosis of dementia should not prevent any individual from having a “life's purpose” and being able to engage within society.

# Chapter 11

## Need for assistance in activities of daily living

*Serge Gauthier, Claire Webster*

### Key points

- There are strategies to mitigate the impact of declining autonomy for certain day-to-day activities.
- Familiarity with meaningful places such as a local grocery shop, park, or café can be maintained and even enhanced through community participation.
- The number of people living alone with dementia is increasing around the world, but they are underrepresented in research.
- Cognitive rehabilitation is a goal-oriented personalised behavioural intervention addressing the impact of cognitive impairment on everyday functioning.
- Planning for a transition from driver to passenger is a good example of a structured approach initiated post-diagnosis.



## General background

As discussed by Isabelle Gélinas in her essay "A Functional Perspective on Staging Dementia" in Chapter 1 of this report, there are progressive changes in the person living with dementia's ability to plan and execute activities of daily living, ranging from complex hobbies to the ability to work, take medications safely, select clothes, prepare meals, and manage their self-care (Table 1).

The essays throughout this chapter provide some important strategies for supporting and maintaining the independence of the person living with dementia for as long as possible. Isabel Margot-Cattin and Sophie Nadia Gaber demonstrate that maintaining community participation builds a sense of familiarity and belonging to meaningful places. According to the authors, "community participation has been shown to prevent depression, reduce anxiety, as well as foster one's identity and sense of self, and to offer diverse opportunities for social contact."

Michael Splaine has convincing evidence that the increasing numbers of people living alone with dementia can live well by building a care community, and they should be better represented in large-scale research studies. "Innovations in housing, service delivery, and research protocols are needed to support those living alone with dementia," Splaine states.

In her essay, Linda Clare introduces us to cognitive rehabilitation as a way to build problem-solving skills and strategies for meaningful goals that are realistic and potentially achievable. "Given the right support, people with mild-to-moderate dementia can develop new strategies and learn or re-learn some important information, which helps to maintain practical skills and independence," Clare explains. She recommends that cognitive rehabilitation should be included in the professional curricula of healthcare professionals while in training as well as in practice, a theme extensively covered in Chapter 22 of the report.

One of the most difficult decisions that must be made as dementia progresses is the removal of the person living with dementia's driver's licence, which often represents their ability to remain independent. In her essay, Anne Dickerson describes the categories of driving skills (operational, tactical, and strategic) and how they change with dementia, and argues that best practice is to plan for transition from driver to passenger early in post-diagnosis care. Dickerson explains, "One of the 'red flags' for driving cessation is when the driver gets lost in a familiar area or cannot decide where to go in the middle of an intersection. Since these types of incidents can result in a crash with devastating outcomes, it is important to begin the process of transition prior to non-driving long before this point in the disease process."

Table 1. Functional Changes in the performance of daily activities over the Alzheimer's Disease (AD) Continuum

|                                  |  |
|----------------------------------|--|
| <b>Cognitively Normal Aging</b>  | <ul style="list-style-type: none"> <li>Independent in the performance of daily activities</li> </ul>   |
| <b>Mild Cognitive Impairment</b> | <ul style="list-style-type: none"> <li>Independent in performance of activities of daily living but may experience difficulties (e.g. making errors or decrease efficiency) with more complex activities</li> </ul>              |
| <b>Mild AD</b>                   | <ul style="list-style-type: none"> <li>Sporadic assistance with more complex activities of daily living (e.g. work, demanding hobbies, instrumental activities)</li> <li>Basic self-care activities usually preserved</li> </ul> |
| <b>Moderate AD</b>               | <ul style="list-style-type: none"> <li>Needs assistance and dependent on others for mobility, instrumental, and basic activities of daily living</li> <li>Ability to safely stay home alone is compromised</li> </ul>            |
| <b>Advanced AD</b>               | <ul style="list-style-type: none"> <li>Completely dependent for all activities of daily living</li> </ul>  |

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PART VIII

## Expert essay

# How to maintain community participation while living with dementia?

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Out-of-home participation, or community participation, is an important part of everyday life for many people, including those living with dementia in their community. However, it is also a challenge due to cognitive impairments. People living with dementia and their families report difficulties related to finding one's way, getting lost, being stigmatised and embarrassed, and getting injured. Community participation is understood here as the engagement in meaningful activities performed in places located outside the home; it is contextualised, situated, and embedded in places visited by people[1]. Thus, community participation is experienced as a person-environment relationship while engaging in meaningful activities[1].

Older adults including those living with dementia value community participation for various reasons, such as increased opportunities for autonomy and freedom, physical activity, contact with nature, meaningful relationships, and social interactions[2]. Community participation has been shown to prevent depression, reduce anxiety, as well as foster one's identity and sense of self, and to offer diverse opportunities for social contact. Furthermore, being able to engage in community participation increases connectedness, belonging, and awareness of the environment for people living with dementia[1,2].

Going "out and about" becomes a challenge for many people living with dementia and their families as the disease progresses. Space outside the home is often seen as fraught with risks and considered to be hazardous for people living with dementia, with respect to the complexity of navigating the outside world[3], for instance due to traffic, crowding, noise, and unpredictable road works. People living with dementia and their families report difficulties related to finding one's way and getting lost. Little by little, people living with dementia disengage from social group activities like being a member of associations or clubs and going to social gatherings, exhibitions, or concerts. They also face driving cessation, which increases the feeling of a "shrinking world"[4]. However, results from recent studies conducted in Canada, Sweden, Switzerland, and the United

Kingdom have shown that people living with dementia do not experience a global and linear decrease in their community participation, but rather a shift from visiting social and cultural places to places used for medical and self-care[5,6]. Although the number of places visited while engaging in community participation diminishes, the places that are maintained, such as the neighbourhood, may become particularly meaningful for people living with dementia and their families[1].

Space located outside the home is an unlimited and unspecified environment. For it to become a life-space that people may navigate, people need to perform meaningful activities of their everyday life and experience a relationship with the environment where they situate their life stories[7]. As activities are performed in a specific place, this place becomes a part of the individual's life story and life world, linked to one's identity. The individual is seen as embedded in places, in constant relation with their environment through the performed activity[8], creating an "enacted togetherness" that situates activities into meaningful places. By maintaining and engaging in community participation, people living with dementia build a sense of familiarity and belonging toward their life-space and meaningful places, like the local grocery shop, park, or café.

An "enacted togetherness" supports the experience of familiarity that individuals build over time by repeatedly visiting places and performing activities that feel familiar. Losing this sense of familiarity may lead to insecurities and disorientation, fear of going outside, and disengagement from community participation. Landmarks emerge from the experience of community participation and their saliency may support navigating the life-space[9]. According to a relational and transactional perspective, familiar and lived places support the experience of maintaining one's identity and include an affective (place attachment) and cognitive (identity) link to that place. Familiarity is situated, embedded, and enacted in the experience of embodied places to which people living with dementia travel and visit[10]. People living with dementia maintained a sense of self through the

experience of familiarity in the places they visited. They also shared meaning with significant others that connected them to the places they visited.

By connecting with significant and important places while navigating the life-space, people living with dementia create “territories” in which they feel safe, cannot get lost, and thus may take risks in. These territories are formed from networks of functional, symbolic, relevant, relational, habitual, and familiar places that transcend geography to highlight the interconnectedness of places, activities, and people[10]. These territories are built progressively through repeated occurrences of community participation in meaningful activities and places.

Furthermore, people take objects with them when going “out and about.” These may include, for example, a purse, keys, a cane, a bottle of water, a handbag, or an umbrella. At first glance, taking objects when leaving the house may not seem to be of interest. However, these objects take on

a particular meaning in a relational and transactional perspective on community participation. People living with dementia take these familiar objects to stay connected to their home and to feel safe and secure while participating in their community. The objects embody the idea of home as being secure and familiar. The concept of embodiment shows that objects are also connected to one’s identity and sense of self, thus refuting a mind-body dualism[11], and instead creating an extension of oneself through everyday objects.

Taken together, this recent body of research underscores the importance for health professionals to support and maintain community participation through repeated visits to meaningful places where people living with dementia may succeed in performing activities, to increase familiarity of their maintained territories. Moreover, there is a need for greater awareness of the importance of familiar objects and landmarks to facilitate community participation among people living with dementia.

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## Expert essay

# A demographic and community challenge: people living alone with dementia

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Living with family support is the most common way in which Alzheimer associations worldwide describe the living situation of persons with dementia. And, of course, most do live with family support. The Alzheimer movement was started by family carers of people deeply advanced in the dementia process seeking mutual support. This dyadic paradigm has shaped the development and availability of dementia services worldwide. As a global movement, more diverse voices and experiences of persons living with dementia are beginning to influence programs and services. People living with dementia who live alone are one segment of this growing population.

## Demographics

Living with a child or with extended family members is the most common living arrangement among older persons in Africa, Asia, and Latin America and the Caribbean. However, in Western and wealthy nations, the demographics of dementia are changing. In Europe, Northern America, Australia, and New Zealand, living with only a spouse was the most common arrangement among 65+ aged persons, followed by living alone[1].

In the EU-27, 40% of older women aged 65 years or more lived alone, while the share for older men was 22%[2]. In the United States, single-person households of persons over age 65 are the fastest growing type of household in the country, with 27% of all persons over age 65 living alone[3]. The United States estimates show as many as 26% of persons with Alzheimer's disease live alone[4].

In Europe, the trend has been influenced by lower fertility, divorce, and the dissolution of extended households. In some United States regions, decades-long migration by younger retirees seeking new housing or an "active aging" lifestyle led them to areas like Las Vegas, Nevada. These persons have aged in place and/or lost partners due to divorce or death, and some have aged alone without partners due to societal discrimination – such as that faced by the LGBTQ community. Now these communities' demographics approach 35% of persons over age 70 living alone, the highest risk age group for dementia[5].

## Challenges

Public health authorities have recognized living arrangements as determinants of health and mortality, as well as mental wellness. The psychological impact of living alone as measured by depression and anxiety is also well documented.

Portacolone et al [6] identify the "precarity" of living alone with cognitive impairment, describing distress stemming from the uncertainty of having cognitive impairment that has an unpredictable course, managing their cognitive impairment, and pressures from the lack of appropriate services to support independent living for persons with cognitive impairment.

Some people with dementia who live alone have other complicating situations, such as lifelong mental illness, recent compassionate release from prison or homelessness.

The underlying assumption by aged-care professionals and policymakers is that living alone with dementia must be impossible. They can be biased toward thinking about dementia only in its latter stages, when disability and inability to navigate life take over, an assumption that may lead to premature guardianship and entrance into residential care.

And those who live alone face barriers to participate in the very research that is needed to understand and meet their needs. Research protocols in dementia require a carer to participate, both to increase the reliability of having a presumed to be cognitively intact person reporting on changes in the person with dementia, as well as monitoring safety.

## Emerging work/promising practices

Innovations in housing, service delivery, and research protocols are needed to support those living alone with dementia.

Shared housing in Germany, using long-term-care support funds to provide more choice and flexibility in support, has been an area of innovation since 1995. In one such model a small group of people rent private rooms, sharing common space, domestic support and nursing care, integrating with

post-diagnostic support services for people with dementia. Doetter and Schmid[7] project the feasibility of this model to provide an alternate to more restrictive forms of care.

In the United States, the federal Administration on Aging/ Administration for Community Living has funded more than 70 community-based organisations to deliver services to this unique group, as one of three target special populations. Summaries of many of these programs can be found on the National Alzheimer's and Dementia Resource Center website.

COVID-19 has brought new evidence of the impact of social isolation and loneliness and technological innovations to reduce social isolation, including supporting online learning and interest groups, but these innovations have yet to be studied rigorously.

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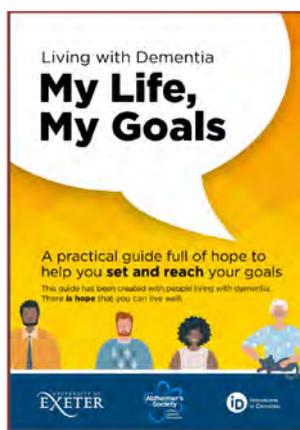
## Expert essay

# Cognitive rehabilitation: a personalised, strengths-based approach to supporting functional ability

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People living with dementia experience difficulties with everyday activities from the early stages of the condition[1]. Changes in the brain affect cognitive abilities and cognitive control of behaviour, leading to functional disability. This in turn can have a negative psychological impact on mood, self-efficacy, and confidence, resulting in additional or “excess” disability. Difficulties increase gradually as the condition progresses. This affects engagement in activities, both those that are essential for daily life and those that provide enjoyment, meaning, and purpose, and makes it harder to participate in family and community life. Declining functional ability is directly associated with reductions in self-reported quality of life and well-being for people living with dementia[2]. With increased dependence comes the need for more support from family members, with implications for their own well-being[3].



Evidence shows, however, that given the right support, people with mild-to-moderate dementia can develop new strategies and learn or re-learn some important information, which helps to maintain practical skills and independence[4,5]. Therefore, while we cannot reverse the underlying impairments that engender decline in cognitive and functional ability, there is potential to tackle both disability and excess disability. This is the aim of cognitive rehabilitation (CR).

## What is cognitive rehabilitation?

CR is a goal-oriented personalised behavioural intervention addressing the impact of cognitive impairment on everyday functioning. The term “cognitive rehabilitation” needs explanation. Rehabilitation, or “re-enablement,” aims to enable people to function at the best possible level given both

their intrinsic capacity, including the nature of their condition and underlying impairments, and their social context and environment. CR is the rehabilitation of people with cognitive, rather than physical, impairments. Originally developed in response to acquired brain injury[6], it has been adapted for people with dementia[7]. CR does not set out to train cognition or improve performance on cognitive tests; rather, it uses a goal-oriented, problem-solving approach to facilitate improved management of functional disability in everyday life. CR is conducted on an individual basis in the setting where the person lives, with carers fully involved and supported wherever possible[8]. CR focuses on what is important to each person and is tailored to the person’s needs.

## What does cognitive rehabilitation involve?

Principles of CR are relevant at any stage of dementia, but the focus here is on supporting people with mild-to-moderate dementia to engage in and manage their everyday activities. CR practitioners work collaboratively with each individual to choose meaningful goals that are realistic and potentially achievable. Goals might relate to everyday functioning, activities of daily living, self-care, communication, social interaction, or personal interests and projects. A structured interview such as the Bangor Goal-Setting Interview[9] or Canadian Occupational Performance Measure[10] can assist in selecting goals and provide a means of assessing progress toward goal attainment. The practitioner evaluates the person’s functional and cognitive abilities and strengths and identifies the reasons why problems are arising with the chosen activity, taking into account any mobility or sensory issues. The practitioner and the person living with dementia then collaboratively develop and implement a plan to facilitate goal attainment, involving a carer where appropriate. This might incorporate the use of compensatory strategies or enhanced learning strategies, the provision of additional resources such as assistive technology, or a combination of these. Through this process of learning and behaviour change, people develop problem-solving skills and

strategies that they can apply to other challenges. Practitioners also provide psychological support as people confront the emotional impact of functional disability.

## How effective is cognitive rehabilitation?

The main research evidence for the benefits of CR for people with Alzheimer's, vascular, mixed, and Parkinsonian dementias comes from single-site and multi-centre randomised controlled trials conducted in the UK and France. CR results in improved ability to undertake activities targeted in the intervention[11–14], and can reduce functional disability and delay the need for institutional care[15]. People living with dementia and carers claim that CR helps them adjust to life with dementia and feel better able to cope, leading to improved wellbeing[12].

## Can cognitive rehabilitation form part of post-diagnostic support?

The benefits of CR when delivered as part of post-diagnostic support in usual community healthcare services are equivalent to the improvements seen in research trials[16]. Typically, practitioners focus on one or two goals over six hour-long sessions. Professionally qualified practitioners can involve support workers in delivering the intervention, so the costs of CR are relatively modest. Care home residents with mild-to-moderate dementia can benefit as well as those living in their own homes[17]. However, healthcare services are often under-resourced and find it difficult to offer this kind of post-diagnostic support.

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One way of making CR more widely available is to ensure that practitioners understand rehabilitation principles and are equipped to apply elements of CR in their work. CR can be included in professional training curricula for occupational therapists, psychologists, mental health nurses, and other practitioners, and short courses and e-learning programmes provided for practitioners and support workers.

## What if professional help is not available?

Building on self-management capability offers another way of making the benefits of CR more accessible. Many people living with dementia and carers, make great efforts to solve the practical problems they face, but could benefit from support with developing effective strategies. Recently, researchers and people living with dementia came together to co-produce *My Life, My Goals*, a self-help resource based on CR principles[18] *My Life, My Goals*, part of the *Living with Dementia Toolkit*[19], offers hope that it is possible to tackle some of the practical challenges dementia brings and “live well” with the condition.

## What does the future hold for CR?

CR is an effective way of tackling functional disability for people living with mild-to-moderate dementia who are interested in managing activities better and maintaining their independence. CR is personalised, flexible, and relatively inexpensive, and can support self-management. Ideally, in the future, CR will form a key element of a comprehensive rehabilitation approach providing strengths-based positive support for people with dementia and their families from the point of diagnosis onwards.

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## Expert essay

# Transportation planning for dementia

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No one has a goal of living in a nursing home. Older adults want to live in their own home and have the freedom to be mobile in their community by driving their personal vehicle. However, for most older adults, the reality is there will be a time when driving retirement is necessary. In fact, research shows that men outlive their driving ability by six years and women by 10 years[1], with driving retirement being accelerated with a diagnosis of dementia. This is often very difficult to accept[2] and many individuals continue to drive regardless of a medical recommendation to stop[3]. It is complicated, as the majority of older adults live in suburban and rural areas with limited public transportation[4]. In addition, if driving is not possible due to medical impairments, public transportation is not an option for the same functional reasons[5]. Since cessation of driving is inevitable with a diagnosis of progressive dementia, there are two important issues: 1) recognizing when the need to stop driving is necessary, and 2) planning a transition process from driver to passenger.

It is difficult for the individual with dementia and/or family members to recognise the need to stop driving, especially early in the process of the disease. As an overlearned, everyday activity, it is a fact the person living with dementia can drive and appears to be “safe.” A reconceptualisation of Michon’s hierarchy of driving behaviours[6] explains this phenomenon[7]. There are three categories of driving skills: operational, tactical, and strategic. The operational abilities are the physical components of driving (for example, steering and braking) which, after decades of driving are automatic. These overlearned skills are retained by persons with even moderate to severe dementia because of motor memory – it is truly “like riding a bike.” It is also why it is impossible to tell someone with moderate to severe dementia that they cannot drive, because in fact, they can. What needs to be said is that they are not *fit to drive* because of the progression of their condition. The tactical level includes behaviours related to *the rules of the road* or immediate decisions during driving manoeuvres (for example, traffic signals, changing lanes, and following lane markings). Tactical decisions are also overlearned, practiced habits with improved roadway designs making it easier for an impaired driver since there are fewer critical decisions necessary with channelled lanes and protected turn traffic lights. The strategic level involves decisions about the mode of transport (for example, vehicle,

walking, biking), the goal of the trip, and how to get to the destination – often manifested during the driving process. For example, when an emergency vehicle blocks the normal route home, the driver must be able to problem solve to negotiate another route. These unexpected route changes are often the cause of older adults with cognitive impairment getting lost in familiar areas. While they are able to physically drive and respond to basic road rules, their capacity to problem solve in reaction to a new dynamic is significantly impaired. Thus, one of the “red flags” for driving cessation is when the driver gets lost in a familiar area or cannot decide where to go in the middle of an intersection. Since these types of incidents can result in a crash with devastating outcomes, it is important to begin the process of transition prior to non-driving long before this point in the progression of their dementia. Moreover, naturalistic driving studies using GPS dataloggers among cognitively normal older drivers are finding decline in daily driving behaviours faster among those with abnormal biomarkers[8,9]. This means changes in driving occur well before an older adult becomes symptomatic with Alzheimer’s[10]. Thus, observation of driving may assist with identification and early intervention of dementia.

In an effort to maintain the individual with dementia’s “independence” as long as possible, the discussion of driving is avoided or put off until it is “necessary.” This, in fact, is a mistake that puts both the individual and potentially the public at risk. Even a minor event with no injuries – hitting a mailbox or getting lost – creates a “crisis.” The immediate “stop to driving” becomes overwhelming to the individual with dementia and the family with no planning in place. Best practice is to plan for the transition from driver to passenger with the initial diagnosis, especially if it is early and the individual with dementia can assist with planning and potentially learning to use alternative services, if available.

Transportation planning is beyond just offering the individual and family information and a list of resources. While there are multiple tools and websites that assist with this process, it needs to be individualised for the individual and family/caregivers within their actual community. Just as one might need a financial planner for retirement planning, specialised services may be needed. Healthcare providers, such as occupational therapists, can address community

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mobility needs through transportation planning, analysing the actual transportation needs of the client – that is, where they need and want to go – with family and friends not only assisting with planning but also helping to address the individual/family's anxiety about not knowing what to do. As part of a funded demonstration project from the National Highway Traffic Safety Administration, a website was developed by an occupational therapist called Plan for the Road Ahead. It is a website dedicated for older adults to plan for their transportation future and is free of advertisements. It includes many interactive tools for practitioners to use with their clients and/or for older adults/families on their own.

### Resources available include:

- The *Checklist of Community Mobility*[11] lists functional abilities (climb stairs, use smartphone) for community mobility. Determining if the client can perform the required tasks independently, with assistance, or with difficulty, guidance statements can assist with determining the appropriate type of transportation need for the client.

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- The *Assessment of Readiness for Mobility Transition*[12,13] is a questionnaire designed to measure the emotional and attitudinal readiness to cope with present and future mobility changes. Feedback offered assists in understanding an individual's attitudes and offers suggestions to assist in transportation planning.
- The *Clinician's Guide to Assessing and Counseling Older Drivers, 4th edition*[14] offers practitioners a comprehensive description of the complexity of addressing driving risk for all older drivers. It offers specific guidance on how to screen for driving risk, how to best approach driving evaluation, as well as starting the transportation process.
- *At the Crossroads: Family Conversations about Alzheimer's Disease, Dementia, and Driving* is a downloaded guidebook developed by the Hartford Center for Mature Market Excellence® and the MIT AgeLab to help people with dementia and their families prolong independence while encouraging safe driving. It provides suggestions for monitoring, limiting, and stopping driving.

## Conclusion

This chapter provided some very enriching recommendations on how family carers and healthcare professionals can assist the person living with dementia with their functional needs throughout the course of the illness to maintain their autonomy for as long as possible, whether they are being cared for by someone or living alone. The principles of community participation and cognitive rehabilitation have been explained with emphasis on meaningful goals that are realistic and potentially achievable, as well as the transition from driver to passenger in maintaining autonomy in transportation.

The key, however, in being able to fulfil all of these recommendations, is the importance of ensuring that family carers and healthcare professionals are provided with the necessary education and skills training to ensure quality of care and safety of the person living with dementia.

There are additional multiple day-to-day issues arising in the care of a person living with dementia which are discussed in detail throughout this report, such as managing finances in Chapter 7, employability in Chapter 10, and physical safety in Chapter 13.

# Chapter 12

## Emergence of mood and behavioural symptoms

*Serge Gauthier, Claire Webster*

### Key points

- Nine out of 10 people experience mood symptoms such as depression, anxiety, apathy, agitation, and irritability throughout the course of their dementia.
- Some neuropsychiatric symptoms (NPS) such as delusions, hallucinations, and sleep behaviours or disturbances may be more prevalent in specific types of dementia such as dementia with Lewy bodies.
- The Neuropsychiatric Inventory Questionnaire (NPI-Q) is an important tool that assists clinicians in understanding the behavioural and psychological changes experienced by people living with dementia who have trouble in providing a reliable description of their symptoms and provides insight into the level of distress experienced by the carers.
- Failure to manage significant mood and behaviour disorders can lead to severe stress and burden for family carers as well as for formal healthcare providers in long-term-care settings.
- Dementia education, combined with support and skills training in using non-pharmacological strategies to manage NPS, needs to become a global health priority for family carers and formal healthcare providers.



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## General background

Although dementia is better known by the public at large as memory decline and trouble with word-finding, changes in mood and personality as well as the emergence of behaviours such as agitation and aggression are often some of the worst symptoms people living with dementia and their carers may have to face. For the purpose of this report, behavioural and psychological symptoms of dementia are identified as a group of neuropsychiatric symptoms (NPS). They are discussed throughout this report in terms of management (Chapters 8, 17, 19).

The purpose of this chapter is to clarify the fact that NPS emerge over time throughout the course of conditions associated with dementia. Some NPS can precede the diagnosis of dementias, a topic discussed in Chapter 5 of the World Alzheimer Report 2021 under the term Mild Behavioural Impairment (MBI), for which the MBI check list was provided.

In this chapter, Lee et al present the Neuropsychiatric Inventory Questionnaire (NPI-Q), an important tool that is useful in assisting clinicians in understanding the behavioural and psychological changes experienced by people living with dementia.

A discussion on the importance of education of carers about NPS has been written by Laura Gitlin, who outlines how the failure to manage NPS can lead to severe distress and burden for family carers as well as for formal healthcare providers in long-term-care settings. She offers guidance on how to combine education on dementia with support and skills training and proposes the DICE approach (describe, investigate, create, evaluate), with the caveat that this non-pharmacological strategy needs to be adapted and validated for implementation around the world for family and informal care providers.

## Expert essay

# How do we measure mood and behavioural symptoms across the stages of dementia?

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Mood and behavioural symptoms are common in dementia. Nine out of 10 people with dementia experience mood and behaviour changes (also known as neuropsychiatric symptoms; NPS), with presentations varied over the course of illness:[1,2] mood syndromes such as depression, anxiety, apathy, agitation, and irritability appear in the early stage of dementia; psychosis syndromes such as delusions and hallucinations emerge in mild and peak in moderate dementia; and behavioural disturbances are more frequent and often distressing in the later stage. While some NPS are more prevalent in a specific type of dementia – for example, sleep disturbances such as parasomnia and specifically rapid eye movement (REM) sleep behaviour disorder (RBD) are typically present and can be an early manifestation of dementia with Lewy bodies – both the number and severity of NPS tend to worsen over time[1,2]. Importantly, they lead to higher risks of morbidities and mortality, regardless of the clinical manifestation and the underlying type of dementia: NPS are associated with poorer clinical outcomes, greater cognitive decline, more carer stress, earlier institutionalisation, and risks of self-neglect, violence, and suicide[3–5]. Although we are now gaining a better understanding of the underlying causes of different NPS, their clinical manifestation is often the result of a complex interaction between the pathological underpinning of the specific cause of dementia, the individual's own personality and prior experience, and the present environment.

A collaborative multi-disciplinary personalised care plan that is sensitive to the background, culture, and values of the people living with dementia and takes into account the circumstances, availability of resources, and carers' own needs is therefore crucial in managing the heterogeneous and varying presentations of NPS in an appropriate, evidence-based, and person-centred manner[6]. As early detection facilitates timely management, which optimises the physical and

mental health, functioning, and quality of life of both people living with dementia and their carers, healthcare professionals need to be mindful of the presence of NPS, and screening for these symptoms should be integrated as part of the initial and follow-up assessments.

An ideal clinical screening tool needs to be sensitive and specific enough to identify the common NPS in various stages of dementia, yet broad enough to capture the wide range of symptoms. It also needs to be simple and quick enough to administer, yet sensitive enough to detect changes over time or improvement following interventions, with good validity across different types of dementia. As some people living with dementia might have anosognosia, apathy, impaired judgment, or language deficits and thereby experience difficulty in giving an accurate account of their mood and behavioural changes, the information provided by carers is invaluable to clinicians in assessing the severity and extent of NPS.

The Neuropsychiatric Inventory Questionnaire (NPI-Q) is an informant-rated questionnaire that is particularly useful in assisting clinicians in understanding the behavioural and psychological changes experienced by people living with dementia who have trouble in providing a reliable description of their symptoms. Not only does the NPI-Q allow carers to report the frequency and severity of NPS of the person living with dementia, but it also evaluates and provides clinicians with insight into the level of distress experienced by the carers[7]. The NPI-Q assesses 12 symptoms, namely: delusions, hallucinations, agitation/aggression, depression/dysphoria, anxiety, elation/euphoria, apathy/indifference, disinhibition, irritability/lability, aberrant motor behaviour, sleep, and appetite/eating disorders, that are present over the previous month[7]. It has been translated into various languages, demonstrated to be valid and reliable across different cultures, and often used in clinical trials[8].

While the NPI-Q is helpful in screening a broad range of NPS associated with dementia, clinicians may also want to consider administering rating scales that focus on a specific domain, especially in situations in which the main purpose is to identify treatment outcomes of a particular syndrome. For instance, the Cornell Scale for Depression in Dementia (CSDD) can be used for monitoring the treatment response in depression among older adults with dementia. The CSDD is a semi-structured clinician-rated interview of both the person with dementia and the informant (carer)[9]. Hence, similar to the NPI-Q, the CSDD allows clinicians to better understand the depression syndrome in people who have moderate to severe impairment in cognitive function or those who might not be able to describe their depression.

NPS contribute around 30% of the cost of dementia care[10]. As cost-effective interventions are available to mitigate the severity and impact of NPS to the persons living

with dementia and carers, failure to recognise these symptoms could result in significant negative consequences for the individuals, families, and societies. Accumulating literature suggests that NPS associated with dementia became even more prevalent during the COVID-19 pandemic, possibly due to either a direct effect of COVID-19 infection on the brain and cognition among the survivors or the indirect adverse impact of the pandemic on people with dementia and informal carers[11]. In addition to enhancing the awareness of older adults and carers on NPS through health education at the community level, promoting the importance of screening in clinical setting and offering training to healthcare professionals on the administration and interpretation of the results of these tools are essential in enabling early detection of these debilitating symptoms among people living with dementia.

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## Expert essay

# Does education of formal and informal care help in managing mood and behavioural symptoms of dementia?

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**D**ementia-related neuropsychiatric symptoms (NPS) are almost universal, occur across all disease aetiologies and stages, and have significant negative sequelae for people living with dementia, their family members, and formal providers. If untreated, dementia-related NPS are associated with more rapid cognitive decline, mood disturbances, increased risk for hospitalisation, and poor quality of life for people living with dementia. For family carers (for example, relatives, neighbours, friends, fictive kin), behavioural symptoms are associated with more time spent caregiving, increased risk for nursing home placement, distress, and burden[1]. Managing more than four behavioural symptoms concurrently is a tipping point such that families experience even greater distress and depressive symptoms compared to those managing fewer symptoms simultaneously[2]. When behavioural symptoms are present in care settings (hospital, assisted living, adult day, nursing home, home care), formal providers (for example, personal care aides, home health aides, nursing assistants, nurses, health and human service professionals) similarly experience heightened distress, and typically spend more time in direct care with agencies experiencing staff attrition[3].

As behavioural symptoms are a central clinical feature of the dementia process, identifying and then attending to their prevention and management in any care context is an imperative worldwide health priority. Nevertheless, family carers and formal providers typically do not have access to dementia education, nor the knowledge and skills necessary for the effective prevention and management of dementia-related NPS. Moreover, carers (family and formal providers) do not always understand that behavioural symptoms are part of the dementia process, can be a form of communication and/or an expression of need, and are not “intentional,” and that there are evidence-based non-drug approaches to systematically identify behavioural symptoms and deploy strategies for their prevention and/or mitigation[4]. Preparing a workforce including family carers to prevent and manage behavioural symptoms needs to be based on the best evidence as to how to effectively impart dementia education and behavioural management strategies.

Over the past 30 years, there has been an explosion of research evaluating different approaches for supporting carers overall and in managing behavioural symptoms. A wide range of interventions (>200 for family carers alone) designed to provide dementia education and skills have been developed and tested using randomised trial methodology and have been found to effectively reduce depressive symptoms and distress in carers and behavioural symptoms in people living with dementia[5]. Common elements of effective interventions include dementia education, instruction in problem-solving, and strategies tailored to the care context. Education is important but, alone, is insufficient. To improve family mood and wellbeing, dementia education needs to be combined with support and skills training in using nonpharmacological strategies (for example, simplifying communications, cueing techniques, environmental modifications, pleasant events, exercise, discretionary activities tailored to interests and abilities). Unfortunately, these proven interventions for families remain in the realm of research with few implemented and fully integrated in care settings. The few studies embedding proven education and skills training interventions in health and community-based care settings report positive outcomes. However, the reach of these approaches is geographically limited, involve only a fraction of families in need, and are not typically sustained following grant funding[6].

As for formal providers, there is a small but growing corpus of research evaluating education-type interventions that are designed to enhance dementia knowledge and behavioural management. A recent review of six systematic reviews of 40 studies involving formal providers in nursing home facilities in the United States concluded that there was insufficient evidence of tested education interventions to recommend any one approach for widespread adoption and scaling[7]. In a scoping review of reviews (n=6) and evaluation of an additional 29 individual trials of interventions for formal providers, a similar conclusion was drawn of insufficient evidence and methodological challenges precluding the recommendation of any one approach[3]. However, promising approaches appear to be training in effective communication

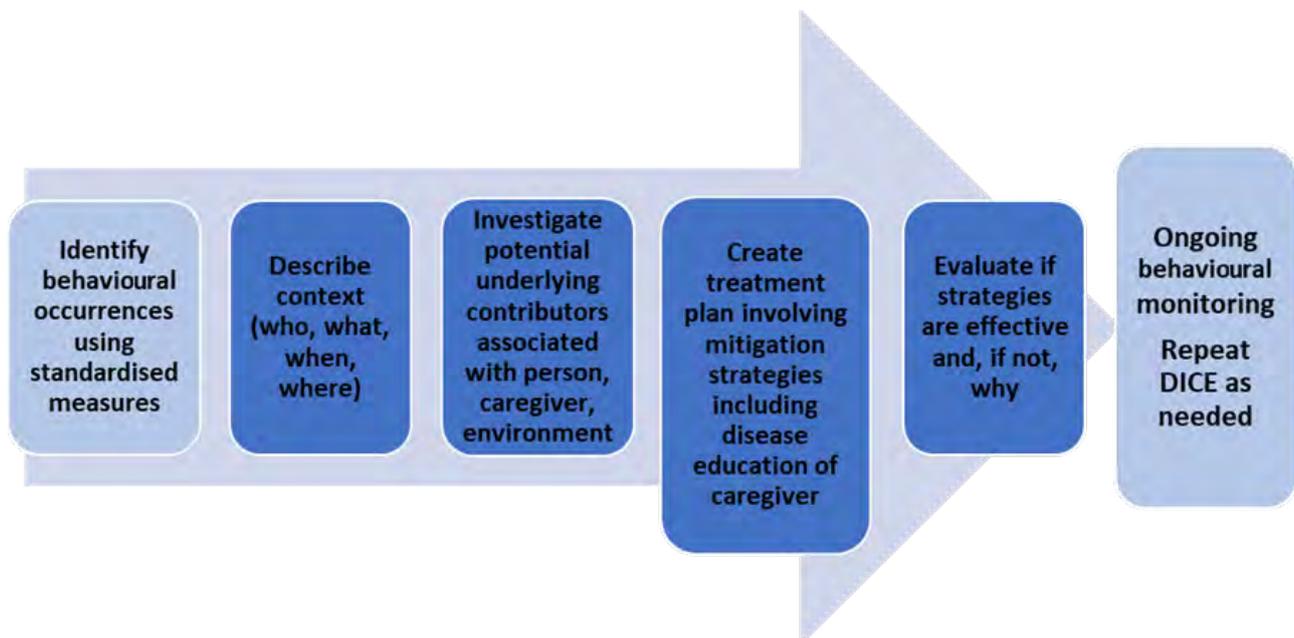
techniques, person-centred approaches, and use of dementia care mapping. Unknown is if interventions developed and tested in the United States can be adapted for delivery in other countries or are as effective in different cultural contexts[8].

Despite the need for more methodologically robust research in this area, there is a systematic problem-solving technique that can be used now to address behavioural symptoms with utility in different care settings and with positive outcomes for both family and formal carers. As shown in Figure 1, this involves first identifying a behavioural symptom of most distress or a safety risk to the person or carer using standard measurement and then applying the DICE approach[9]. DICE entails first, **d**escribing the behavioural occurrence; secondly, **i**nvestigating underlying contributing factors to that behaviour which are related to the person (for example, fatigue, hunger, pain, underlying infection), carer (for example, stress level, complex communications, lack of daily routines), and physical environment (for example, clutter,

unclear wayfinding, too cold or hot); third, based on the investigative stage, **c**reating a treatment plan that provides mitigating strategies along with dementia education and support; and fourth, once strategies are implemented, **e**valuating their effectiveness, and if they are not effective, determining why. The DICE approach is followed by ongoing assessment and continuous monitoring of behavioural symptoms and deploying the approach as needed. Variations of DICE have been evaluated in randomised trials including an online platform (WeCareAdvisor) and shown to reduce or eliminate presenting behavioural symptoms in people living with dementia and improve overall wellbeing in carers[10].

The lack of dementia awareness among formal providers and carers, limited payment mechanisms for behavioural assessment and then deployment of dementia education, support, and other therapies, and limited expertise of formal providers in the use of nonpharmacological strategies make attending to behavioural symptoms and fully supporting families an unfulfilled yet pressing dementia care need.

Figure 1. Six steps in behavioural symptom management involving DICE approach



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## Conclusion

Without a doubt, managing mood and behavioural disorders in dementia, identified as "NPS" throughout this chapter, places a tremendous burden not only on the person living with dementia, but on both informal and/or formal care providers. Understanding the causes of NPS is crucial to handling their appearance and finding solutions that can mitigate their impact on the person living with dementia and their carers, as exemplified by the DICE approach. Oftentimes, behaviours that are attributed to people with dementia being "difficult" in fact stem from environmental factors or physical pain, which they may struggle to verbalise.

Most importantly, the majority of carers in both the family and healthcare settings have not been provided with the necessary dementia care education or skills training required to manage these symptoms from a non-pharmacological approach. More research is needed to explore the causes of NPSs and evaluate evidenced-based non-pharmacologic and pharmacologic treatment strategies adaptable to homes and care facilities around the world.

PART I

PART II

PART III

PART IV

PART V

PART VI

PART VII

PART VIII

# Chapter 13

## Changes in motor function and senses

*José A. Morais, Pedro Rosa-Neto*

### Key points

- Although the main clinical hallmark of dementia is cognitive impairment and decline, motor impairments, such as bradykinesia, extrapyramidal rigidity, and gait disorders have been commonly described, mostly in the late stages of dementia.
- It has been shown that motor impairments can precede cognitive impairment. Therefore, motor changes have been proposed as potential clinical biomarkers to help predict dementia syndromes.
- Sensory health is crucial when living with dementia, and physical, cognitive, and social activity are beneficial for maintaining functioning.
- The long-term goal of addressing sensory health in dementia is to create environments and opportunities that enable people to be and do what they value throughout their lives.
- To ensure sensory accessibility for people living with dementia, we need to detect sensory difficulties, assess needs, decide on goals, intervene, and support the individual and those around them in maintaining functioning.
- Adopting sensory-inclusive care is foundational to improving function and quality of life for people living with dementia. It can also reduce carer burden by facilitating efficient, effective, and meaningful communication between older adults living with dementia and the people who care for them.
- Often underreported and overlooked, falls are among the most prevalent geriatric syndromes. Falls are one of the leading causes of disability and morbimortality amongst older adults, especially those living with dementia.



## General background

There is no denying the impact cognitive impairment has on a person's life and activities, especially when considering how our mental and physical resources are required to make the most of daily function. A person-centred multi-disciplinary approach to managing dementia symptoms necessarily mandates an overview of the changes one can expect to encounter throughout the course of the condition. With the aim of propelling comprehensive dementia care forward, this chapter focuses on the importance of assessing and managing sensory, mobility and swallowing impairments associated to dementia in order to boost independence and improve quality of life.

As precisely noted in the first essay by Walter Wittich et al, sensory screening should be an imperative component of the dementia care plan. An accurate evaluation of hearing and vision functions as potentially treatable ensures that communication is maximized for physical, cognitive, and social pursuits and interactions after the dementia diagnosis. The plan should also determine the risk factors as well as advance feasible coping strategies for both the physical and cognitive deterioration associated with these impairments.

Manuel Mantero-Odasso posits that motor changes such as mobility and gait impairments may be early biomarkers predicting the onset of cognitive decline. It has long been

suspected that changes in gait share common neurological pathways with cognition. That is why ongoing mobility and gait testing in clinical settings should be conducted concomitantly with cognition assessments.

Unfortunately, the problem of gait impairment coupled with dementia is more than theoretical, as it has devastating effects on a person's functioning and greatly contributes to the risk of falls, as described by Borda and Duque in their essay. Contributing factors include age, frailty, loss of muscle mass, comorbidities, and environmental considerations.

As the disruption of the normal neurological pathways continues to progress, coordination of movement becomes more erratic, causing apraxia or difficulty in performing tasks such as swallowing food or drink. This serious health condition is called dysphagia and is skillfully addressed by Dharinee Hansjee. The act of swallowing requires cognitive awareness and visual recognition among other things and as a person enters the latter stages of dementia, it becomes increasingly difficult. Adopting an early person-centred approach that takes into consideration advance care directives helps empower the person living with dementia and their carers by valuing their preferences.

## Expert essay

# Sensory health to support function and wellbeing in people living with dementia

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## Introduction

Physical, cognitive, and social activity are beneficial for maintaining functioning when living with dementia, and sensory health is crucial. The prevalence of hearing and/or vision loss is high among older adults across lower-, middle- and higher-income countries, but it is often unacknowledged or unaddressed [1][2]. For those people living with dementia, sensory and motor changes may precede cognitive symptoms by several years [3]. Hearing impairment has been identified as the largest potentially modifiable risk factor in mid-life for the development of dementia in late life [4]. Similarly, vision impairment is associated with an increased dementia risk [5], and the combination of vision and hearing impairment increases this risk further [6].

Here we provide an overview of the importance of sensory aspects for communication functioning in people living with dementia when they interact with carers, family and friends, and their larger community. The long-term goal of addressing sensory health in dementia is to create environments and opportunities that enable people to be and do what they value throughout their lives. A prerequisite for this person-centred approach is to understand the sensory abilities and needs of the person in their context [7]. However, individuals may be unaware of their sensory impairment(s) because the onset and progression can be insidious and functional consequences misattributed to other causes. Alternatively, they and their significant others may be aware of a sensory impairment but feel that addressing it is not a priority because of more acute concerns, misconceptions about treatments, or its acceptance as a normal progression of ageing. Stigma, costs, or negative attitudes from self or others (including healthcare providers) about sensory loss, dementia and/or ageing may deter help-seeking behaviours and uptake of interventions. Notably, for people living with dementia and sensory loss, it is especially important to plan care that is individualised and optimises the person-environment fit. Such plans should be implemented as soon as possible and updated as needed, as it is never too late.

If the person with dementia already has a history of sensory impairment and rehabilitation, this information must be considered in care planning so that functioning can be maintained. For those without a prior history of sensory care, the detection and assessment of sensory abilities and needs should become a key part of integrated care planning. Around the world, many Alzheimer associations have co-created innovative programmes to engage people living with dementia and their families by providing dementia- and age-friendly opportunities for participation. Such programmes are key to maintaining quality of life after diagnosis. To take full advantage of such programmes, they need to be sensory-accessible. To ensure sensory accessibility for people living with dementia, we need to detect sensory difficulties, assess needs, decide on goals, intervene, and support the individual and those around them in maintaining functioning.

## Detect

Sensory and cognitive impairments can have similar functional consequences. Importantly, sensory loss may exacerbate cognitive difficulties such as understanding, recognizing, or remembering information. Sensory screening provides useful insights into underlying reasons for functional difficulties that may otherwise be misattributed to cognitive impairment. Screening starts the moment a healthcare provider communicates with an individual, where difficulties may be readily observed. A recommended approach is to ask about function in terms of experiences communicating in daily life [1][8]. Whereas people will often deny having a sensory loss, they are more likely to report having difficulties conversing in groups or in noisy environments or recognising facial emotions at a distance or in low light. An alternative is to use standardised screening questionnaires that rely on self- or other-report [1][2]. For individuals who do not self-report problems, sensory testing should be used to screen for unacknowledged impairments [1][8]. When sensory impairment is detected, referral for more extensive assessment is indicated. The World Health Organization

(WHO) recommends regular screening for adults that is context-appropriate and provides guidance on vision and hearing screening and referral [1][2].

## Assess and decide

Individuals with suspected hearing and/or vision loss should be referred to the next available level of specialist care, such as audiology/otolaryngology or optometry/ophthalmology [8]. Assessment is essential to determine the degree and type of sensory loss. More importantly, the assessment should include an evaluation of functional needs to inform care planning. The 2019 WHO guidelines for Integrated Care of Older People (ICOPE) have identified hearing and vision as key capacity domains for functioning [9]. Therefore, managing sensory loss is a crucial component of care for older adults, especially those living with dementia [10] where sensory impairment can exacerbate cognitive difficulties. Furthermore, decisions about how to optimise the individual's participation and functioning will depend on

their social and physical environment, including consideration of available support by health allies, such as family, friends, and the cultural and community context of the person living with dementia (Figure 1).

## Intervene and support

Sensory interventions should include considerations across three domains: changes in behaviours and attitudes, use of technologies, and environmental modifications [1][2]. **Changes in behaviours and attitudes** may include perceptual training (e.g., auditory, visual and/or tactile), communication strategies, self-advocacy, and counselling. The **use of technologies** includes recommendations for, and training in the use of, devices (for example, hearing aids, visual magnifiers, adapted warning signals, interfaces with televisions and telephones), medical interventions (such as cochlear implants, cataract surgery), or assistive technology systems for listening and viewing during group activities. **Environmental modifications** include changes to the

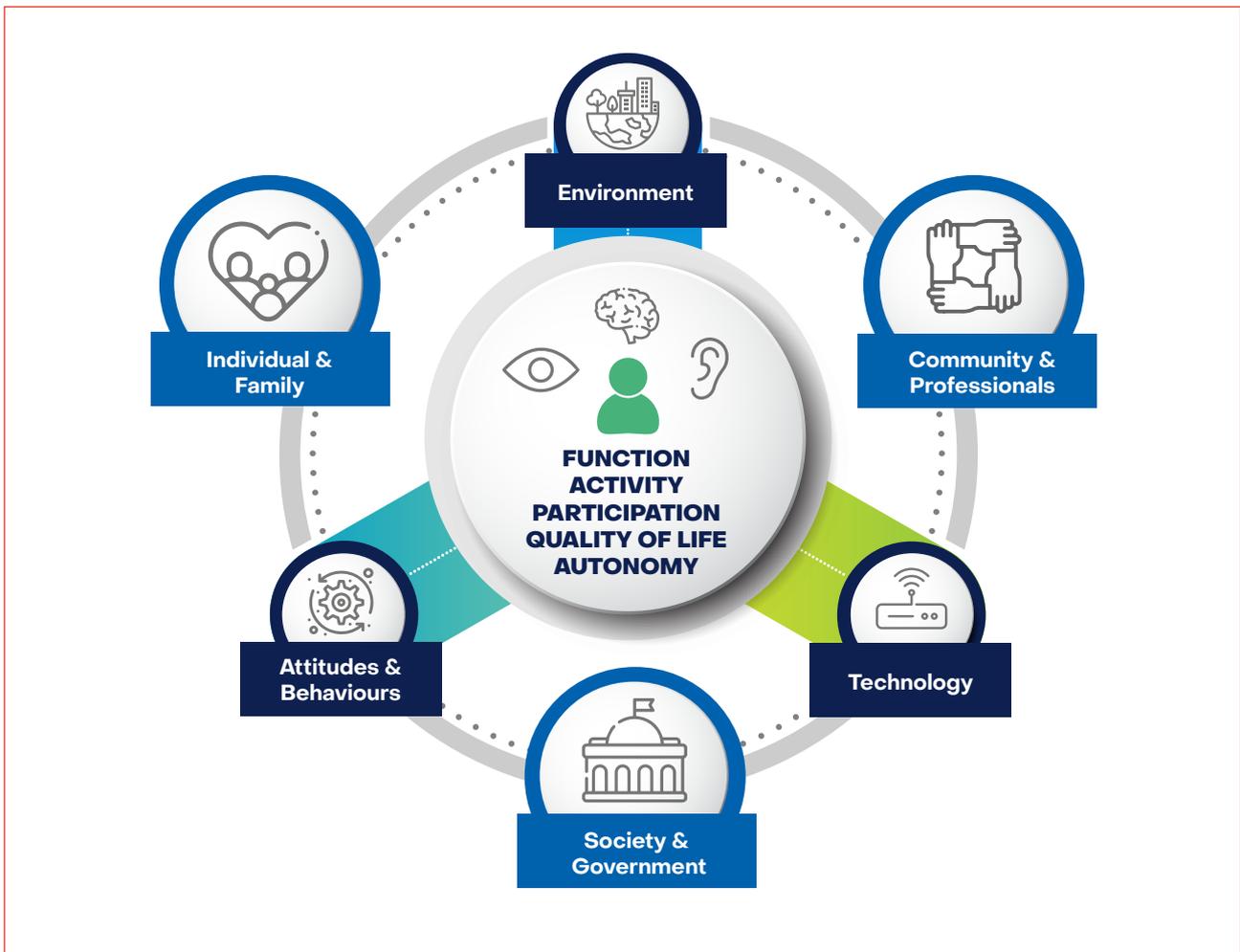


Figure 1. The central goal of addressing sensory health is to improve optimal functioning, activity, participation, quality of life and autonomy of people living with dementia. These goals can be achieved through adaptations of the environment, the provision of assistive technologies, and changes in attitudes and behaviours. Such changes can be applied at the individual and family level in their immediate environments, in the broader community and team of healthcare professionals, as well as in social and government policies.

physical environment (for example, noise reduction, contrast enhancement, lighting) or the social environment (such as skill training for communication partners to accommodate sensory needs). Support to maintain functioning over time depends on regular follow-up as well as re-evaluation of changing needs.

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## Conclusion

A 2021 international consensus document took a first step towards the systematic integration of sensory and dementia care [10]. Adopting sensory-inclusive care is foundational to improving function and quality of life for people living with dementia. It can also reduce carer burden by facilitating efficient, effective, and meaningful communication between older adults living with dementia and the people who care for them.

## Expert essay

# Should changes in mobility and gait be assessed regularly across the stages of dementia?

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**G**ait impairments are ubiquitous in Alzheimer's disease (AD) and other dementias [1]. Although the main clinical hallmark of dementia is cognitive impairment and decline [2], motor impairments, such as bradykinesia, extrapyramidal rigidity, and gait disorders have been commonly described, mostly in late stages [2]. Large epidemiological studies have also shown that gait disorders, particularly slowing gait, may be present at early stages of dementia or even predict who will be at risk of progressing to dementia [3].

Specifically, in older adults with mild cognitive impairment (MCI), a condition that can progress to dementia, there can be a coexistence of specific cognitive deficiencies and gait abnormalities which provides support to the theory that there is a transition period whereby cognitive loss occurs concurrently with gait slowing [4]. These motor impairments are not benign, as older adults with MCI are at higher risk of falling, with double the incidence of their cognitively healthy counterparts. This higher risk of falls has been related to poor attention and executive dysfunction affecting the brain's gait control.

Cognition and motor function decline with ageing, and it has been shown that motor impairments can precede cognitive impairment. Therefore, motor changes have been proposed as potential clinical biomarkers to help predict dementia syndromes [5]. Several motor domains have been associated with cognition, with lower limb motor skills, mainly gait performance, being more commonly tested and studied. For instance, changes in gait speed have been found up to 12 years before clinical diagnosis of mild cognitive impairment [6]. Previous systematic reviews of potential dementia motor markers have shown that gait speed is associated with future dementia in general. From an epidemiological perspective, studies have shown that gait speed is associated with further cognitive decline [7]. Interestingly, a mobility test such as "Timed Up and Go (TUG)", that involves getting up from a chair, walking three metres, turning, and then sitting back down, has associated cognitive decline when dual-task abilities were assessed in this cognitive switching test.

There is a continuum from cognitive ageing to dementia, and gait impairment has often been described in people living with dementia, especially at the onset of symptoms. However, it may also be detectable at different times of the natural history of the disease, namely in the early asymptomatic stage. Physical activity and mobility are generally reduced in older adults with cognitive impairment, as can be seen in older adults with dementia who have reduced daily life activity and impaired daily life gait when compared to age-sex matched controls [8]. Three important signs of progression, characterised as "early", "dual", and "longitudinal" can be described. Previous research has focused on older adults without overt neurological symptoms during the "early" cognitively normal ageing stage. Studies looked at age-related gait impairment as a risk factor for cognitive and brain structural changes as well as dementia risk [6]. Research showed that mild gait impairment was evidenced when the "dual" incidence of gait and cognitive impairment was demonstrated [9]. The operational concept of motoric cognitive risk (MCR) syndrome focusing on dual gait and subjective cognitive impairment, has been shown in these targeted population studies, posing a higher risk of dementia when associated with both rather than the risk associated with gait abnormalities only [9]. Older adults with gait abnormalities were twice as likely to develop dementia, while older adults with motoric cognitive risk were more than three times more likely to develop dementia. However, motoric cognitive risk is defined by a one-time diagnosis, and the "longitudinal" phase encompasses recent work that has focused on longitudinal changes over time, rather than one-time assessment, such as motor and cognitive trajectories before dementia and dual decline in memory and gait [10]. In line with previous findings on motoric cognitive risk and dementia risk, those with dual decline in gait and cognitive function had higher dementia risk than those with mobility impairment only, evident in various older populations. Initial evidence also suggested that tracking trajectories over time may provide an additional predictive value of future dementia risk than a one-time assessment.

Another importance of examining trajectories over time is the possibility of investigating underlying mechanisms by tracking concurrent pathophysiological changes. Potential mechanisms underlying gait-cognitive interactions in ageing and dementia syndromes includes atrophy of selected cortical and subcortical areas [11], white matter disease and amyloid-β deposition burden, and accentuated depletion of neurotransmitters. These common mechanisms at the brain level are associated with concurring cognitive and gait impairments because control of gait and cognitive performance rely on shared brain networks and regions [11].

An emerging approach to assess these interactions is using the dual-task gait paradigm of walking while performing a concurrent cognitively demanding task as a “brain stress test” on individuals at risk of cognitive decline or progression to dementia. Recently, the dual-task gait test has been shown to predict dementia in mild cognitive impairment, and in cognitive healthy populations [12]. Evidence also shows the feasibility to perform the dual-task gait test in clinical settings and have the capability to differentiate cognitive subtyping [13]. These studies support a recent consensus recommendation of using this gait speed and dual-task gait tests in memory clinics.

In addition, tools are urgently needed to address the unmet needs in neurological and geriatrics practices to make timely and accurate cognitive diagnosis; categorize the stratification of the condition; estimate risk prediction; track the progression of the condition; and make decisions regarding intervention optimisation and maximising therapeutic response (such as medication selection, dementia staging, and targeted support).

There has been recent research conducted with body-worn sensors to monitor gait in older people living with dementia. Case in point, one such study showed that clinic as well as home-based monitoring was feasible and accepted by people living with dementia. Results from free-living environment suggest that people living with dementia had higher variability, more walking asymmetry, and a slower pace when compared with controls [14]. This shows great promise for the use of body-worn sensors to monitor gait prior to dementia progression, and throughout the course of the condition, which would provide valuable insight into the utility of gait as a clinical tool for the diagnosis and monitoring of dementia. What’s more, we just have shown that high gait variability is associated with Alzheimer’s disease when compared with other dementia subtypes.

An additional valuable use of using motor or gait testing at different stages of cognitive decline is assessing the appropriate use and prescription of assistive devices in older adults who are cognitively impaired. Assistive devices, such as canes and walkers, are important strategies to improving mobility and reduce the risk of falls in older adults, but also can pose a cognitive challenge. It has been shown that learning to use a mobility aid poses a high gait and cognitive demand on older adults with Alzheimer’s disease [15].

In conclusion, current knowledge supports the role of gait disturbances and quantitative gait analyses be used as a motor biomarker to predict cognitive decline and the various types of dementias; define subtypes of cognitive profiles, and as a complementary methodology to assess progression from mild to moderate dementia. Recent consensus provided resources on how to operationalise gait testing in specialised clinics [16].

Figure 1. Motor tests to assess gait in at risk older adults or with cognitive impairment in different settings

| Level | Motor Test  | Characteristics and Requirements  | Time to Conduct  | Application   |
|-------|---|---|------------------|---|
| 1     | <ul style="list-style-type: none"> <li>Slow gait</li> </ul>   | <ul style="list-style-type: none"> <li>Time to walk a known distance</li> <li>Chronometer required</li> </ul>                                     | 1 min            | <ul style="list-style-type: none"> <li>Community screening</li> <li>Population research</li> <li>Resource in low tech settings</li> </ul> |
| 2     | <ul style="list-style-type: none"> <li>Slow gait</li> <li>Dual-task gait</li> <li>Gait variability</li> <li>Spatial navigation</li> </ul> | <ul style="list-style-type: none"> <li>Known distance</li> <li>Assessor training</li> <li>Wearable accelerometer or gait mats required</li> </ul> | 10–20 min        | <ul style="list-style-type: none"> <li>Memory clinics</li> <li>Research</li> </ul>  |
| 3     | <ul style="list-style-type: none"> <li>Video Gait and Biomechanics</li> </ul>   | <ul style="list-style-type: none"> <li>Gait lab</li> <li>Provided also measures of posture and balance</li> </ul>                                 | 20 to 40 minutes | <ul style="list-style-type: none"> <li>Research</li> </ul>  |

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PART I

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PART VIII

## Expert essay

# Why and how to prevent falls

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Often underreported and overlooked, falls are among the most prevalent geriatric syndromes. Indeed, falls are one of the leading causes of disability and morbimortality amongst older adults, especially those living with dementia. Falls have an annual incidence of 30–40% in the population aged 65 years and older. In addition, falls lead to 87% of all fractures. Further, fractures associated with falls account for approximately 10% of all causes leading to long-term care needs in older adults. In addition, falls are the second leading cause of unintentional injury deaths worldwide, with people over 60 years being the age group that suffer the greatest number of fatal falls [1]. Approximately 30–50% of people living in long-term care institutions fall each year, and 40% of them experience recurrent falls [1]. Every year, in the United States, about \$50 billion are spent on medical costs related to non-fatal fall injuries and \$754 million are spent on expenses related to fatal falls [2].

Falls are especially consequential in people with neurodegenerative diseases. Established conditions in people living with dementia such as frailty, polypharmacy, gait disturbances, extrapyramidal motor impairment, postural instability, rigidity, loss of balance, poor visuospatial abilities, and neuropsychiatric symptoms are common risk factors associated with falls events [3]. A recent study of people living with dementia reported that over a 2.5-year follow-up, 31.1% of older adults living with dementia had a fall, and 17.7% suffered a fracture [4]. Additionally, an incidence of 56% of at least one fall over 12 months in people living with mild Alzheimer's disease (AD) and 55% of people with moderate Alzheimer's disease has been reported [5]. Compared with older adults without dementia, people with Alzheimer's disease doubled their risk of falling (22.8% vs. 10.9%; RR: 2.08) and more than doubled their risk of a fracture (12.8% vs. 5.1%; RR: 2.51) [3]. The incidence of falls in this population increases with age, especially when conditions such as frailty and sarcopenia (loss of muscle mass, strength, and function) become more frequent. At diagnosis, the prevalence of frailty in people living with dementia is up to 40%. In fact, frailty has been demonstrated to be a strong predictor of future falls [6]. Furthermore, sarcopenia is common in dementia and a risk factor for adverse outcomes. In institutionalised

older people living with dementia, 68.78% fulfil the diagnostic criteria for sarcopenia, and in those older adults with sarcopenia, there is a significantly higher risk of falls than non-sarcopenic individuals [7].

Falls occur because of a complex interaction of risk factors. Therefore, as part of a comprehensive clinical assessment of people living with dementia, it is imperative to evaluate their fall risk. There are several fall assessment tools available and these provide a good estimation with adequate validation of a person's likelihood of falling. Doing these assessments is a prerequisite to timely and adequate care to reduce this risk. The earlier a high risk is identified, the more the negative consequences can be prevented. In addition, evaluating a person's functional capacity is a crucial part of the assessment process as loss of function and mobility limitations are among the main risk factors for falling, particularly in older people living with dementia [5].

The first step to preventing falls is to know what conditions, diseases and medications can cause those events. Several factors increase the odds of falling. Comorbidity is very frequent in dementia; therefore, conditions such as cardiovascular and cerebrovascular diseases, anemia, or hypoglycemia are common triggers of falling events. Dehydration and electrolyte imbalance are also recurrent as a person living with dementia may become unable to communicate or recognise that they are thirsty or forget to drink. In addition, osteoarthritis makes joints sore and stiff and can interfere with balance and mobility. People with pain in one joint like the knee or hip are 53% more likely to fall. This number increases to 74% in those with two affected joints [8].

In consort with the high comorbidity burden experienced by older people living with dementia, polypharmacy is a common condition at diagnosis for this population. Indeed, the proportion of people with polypharmacy and the number of medications keep increasing as the condition progresses and starts to include other medications such as neuroleptics and benzodiazepines that are markedly associated with high fall risks. Furthermore, polypharmacy and/or inappropriate medication can cause falls due to side effects and drug interactions, poor compliance with dosing, confusion about

the different drugs and self-medication that can cause drowsiness, loss of reflexes, agitation, and visual disturbances, among others [5].

In addition, the groups with significantly higher fall risk include older adults who are single or widowed, have less education, are unemployed, and have lower relationship satisfaction. It is reported that perceived poor social support and loneliness are associated with a combined 37% increase in fall risk while depression is associated with a 47% increase in falls [9]; all these conditions had a higher prevalence in older people living with dementia.

Conversely, a person's environment could represent a risk factor for a fall, particularly in older people living with dementia who have major challenges adapting to environmental changes or even minor hazards. Those common environmental factors include inadequate and brittle furniture, slippery floors and stairs, looser rugs, insufficient lighting, cracked or uneven sidewalks, slippery shower or bathtub with no rails, stairs without railings, or steps that are too large or worn through.

Regarding the approach to fall prevention in this population, it is imperative to identify and manage ongoing causes of falls. Overall, identifying orthostatic hypotension, autonomic symptoms, and depression, and encouraging physical activity may provide several core elements for the most fruitful strategy to reduce falls in people living with dementia. A comprehensive medication review is recommended, and active deprescribing should be performed when appropriate. In addition, screenings for vision and hearing health should

be conducted while attention should be paid to foot care, including looking for corns, calluses, and ingrown toenails, which are frequent sources of gait impairment. A thorough overview of the individual's environment (in some cases requiring a home visit) should include checking an individual's footwear and clothing.

As mentioned above, fractures are one of the main consequences of falls; therefore, preventing, identifying, and treating osteoporosis is a fundamental part of the comprehensive management of a person living with dementia. Indeed, an odds ratio of 6:9 for fracture prevalence between people with and without Alzheimer's disease has been reported. At the same time, research indicates that undertreatment of osteoporosis in people living with dementia is common, even though osteoporotic fractures are common among these individuals [1]. In addition, sarcopenia and frailty are preventable and reversible conditions where interventions such as exercise, nutrition and deprescription have shown to be effective. Specifically, balanced nutrition with appropriate protein intake and multicomponent exercise have shown benefits in reducing falls [10].

In conclusion, highlighting the need for more effective and individualised fall prevention is critical in managing older people living with dementia. Fall efficacy enhancing programmes for these individuals should take a multidisciplinary and multidimensional approach that include self-care, frailty, chronic diseases, osteoporosis, sensory loss, foot injuries, cognitive impairment, living environment, socioeconomic status, social interaction, and gender into account. See Figure 1.

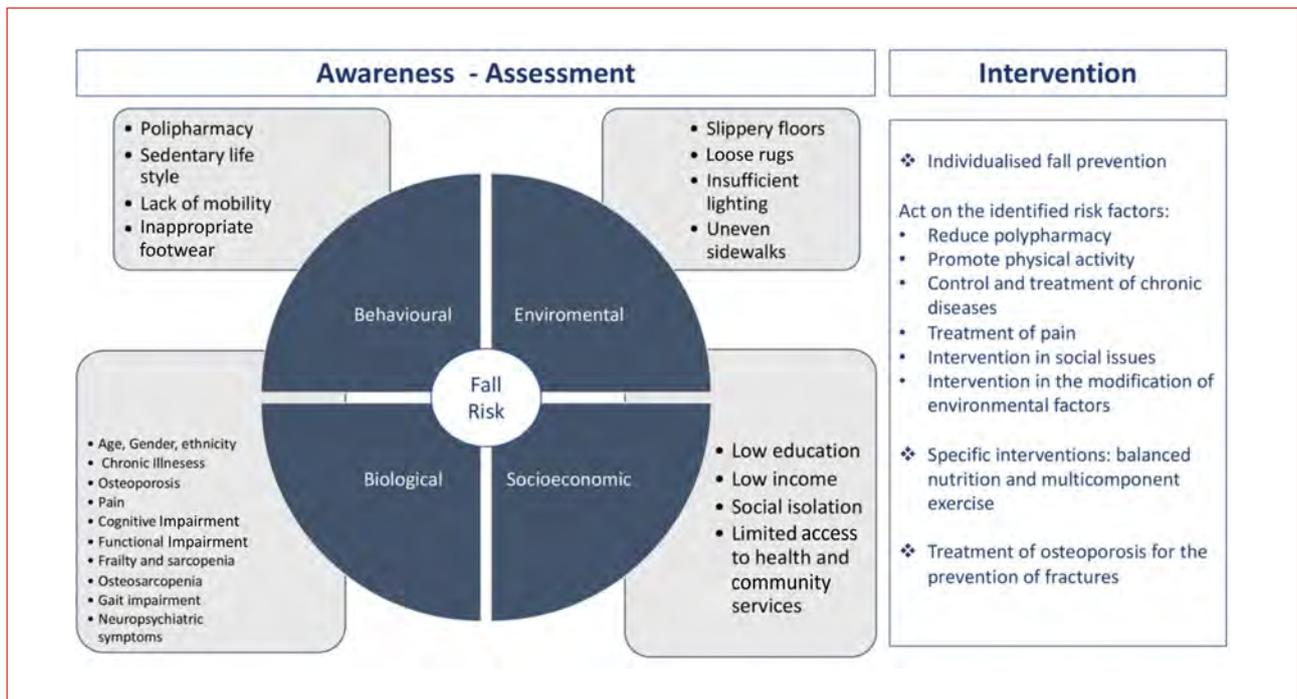


Figure 1. How to prevent falls: Awareness, assessment, and intervention (Modified from WHO 2008).

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## Expert essay

# Addressing choices and preferences of individuals with dementia and swallowing difficulties

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Swallowing difficulties or dysphagia, become more prevalent with increased age [1], ranging from 7% to 22% in the general population and dramatically rising to nearly 60% in adults who reside in long-term care facilities. All types of dementia may be associated with dysphagia, which is a growing concern due to the associated health risks of malnutrition, dehydration, weight loss, functional decline, and a general decrease in quality of life [2].

Eating, drinking, and swallowing (EDS) requires cognitive awareness, visual recognition of food/drink, physiologic response, motor planning and execution of patterned sensorimotor responses [3]. With all the related behaviours that go with eating and drinking, there is much more involved than just the act of swallowing. People living with dementia, who experience deficits in attention, initiation, orientation, recognition, executive function, decision-making and apraxia will subsequently experience difficulties with eating and drinking.

The physiological role of the swallow is to prepare the food in the mouth (the bolus) and ensure its passage from the mouth to the stomach, without compromising the airway. However, swallow physiology alters with advancing age and health. The reductions in muscle mass and connective tissue elasticity result in loss of strength [4] and range of motion [5] affecting oral and pharyngeal structures involved in the process of swallowing.

In the early stages of dementia, individuals may not have the focus, attention, and sensory awareness to chew down and propel the food bolus [1]. The entire process of eating, drinking, and swallowing is slower with an increased number of swallows, leading to a delay in oral preparation of the food bolus. Over time, these subtle but additive changes can contribute to increased frequency of residue penetrating into the upper airway, in addition to post-swallow residue in the pharynx [5].

The cumulative cognitive and physiological changes in older adults living with dementia and eating, drinking, and swallowing difficulties, can impact the development of aspiration

pneumonia, which has been extrapolated from the literature as the most common cause of death amongst this population group [6]. The development of aspiration pneumonia may occur due to a combination of dysphagia and contributory factors such as poor oral hygiene, being dependent on others for assistance when eating and drinking, and high support needs for positioning during mealtimes [7, 8]. There is, however, no direct relationship between dysphagia and aspiration but rather several factors that can contribute to several risks. Dysphagia is one of the contributing factors with aspiration being one of the risks. Other risks can include choking, malnutrition, dehydration, distress, and social isolation.

The decision-making around eating and drinking, taking cognisance of the resultant risks, is therefore complex, involving the assessment of nutritional options and recommendations, weighing up benefits and risks, prognosis, and capacity to consent. The individual living with dementia is central to the shared decision-making process.

As ethical dilemmas cloud decision-making, it is about how the process around choices and nutritional planning can be structured to be explicit versus the grey area of ethical uncertainties. For people living with advanced dementia, the focus is on their quality of life. This warrants allotting the needed time and dignity to establish the individual's wishes, recognise the risks and problem-solve how best to address these risks. The 'how' is the catalyst to galvanising the decision-making process from grey to black and white, which can only be achieved through collaboration with the multidisciplinary team.

A referral to a speech and language therapist will facilitate an individualised assessment with possible food/fluid modification and recommendations on what appears most palatable and comfortable. Discussions with the individual and those closest to them should take place about what is important in relation to eating and drinking for the individual themselves. Food preferences, mealtime routines, cultural, religious, and spiritual beliefs associated with food

are essential to the assessment but also to understanding the psychosocial impact of dysphagia and its associated interventions on a person's wellbeing.

A person's cultural knowledge and values create unique beliefs and perceptions that shape their understanding of health and illness, the ways that they access healthcare services, the actions they take to seek support, their expectations of care, and response to recommendations [9]. These are intrinsic components clinicians should be aware of to help facilitate accessibility and responsiveness to culturally diverse communities living with dementia.

Liaison with the dietitian is pertinent to optimising nutritional intake while involvement of the physiotherapist is necessary for not only maximising the individual's position and posture but also when planning respiratory care jointly with the medical teams. Consultation with the nursing staff is paramount in acknowledging and minimising risks with scrupulous mouth care while supporting the individual to follow eating and drinking recommendations as much as is possible. Integral to safe medicine administration is engaging the pharmacist or a medical team member to review medication, which is frequently overlooked in practice. Medical teams might undertake an assessment to establish the individual's decision-making capacity or liaise with the speech and language therapist to carry this out, should

be meticulously documenting the discussions including the completion of anticipatory care plans, and advance directives, when required.

Taking this approach means the risks of aspiration, dehydration and malnutrition in people living with dementia and eating, drinking, and swallowing difficulties will be reduced by adhering to the five fundamental "Ms": **multi-disciplinary** care, **mealtime** preparation, **maximising** positioning, **mouth care** and **medication** review [10].

Ultimately, health and care systems globally should be harnessing a person-centred approach by empowering individuals to make decisions about their care in anticipation of a deterioration of swallowing, at the time of a diagnosis of dementia. At whatever stage decisions are made, it is fundamental that these decisions are captured within anticipatory care plans, advance care directives and communicated across primary and secondary healthcare services. Suggestions on a multidisciplinary framework for shared decision-making can be found within the Royal College of Speech and Language Therapists multi-professional guidance on eating and drinking with acknowledged risks [11]. The guidance aims to clarify the assessment, decision-making and documentation processes required to achieve person-centred, multidisciplinary, and multiagency care planning with clear methods of review for individuals.

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## Conclusion

Dementia is a complex syndrome that affects the body in a multitude of ways and this chapter has laid out how this cognitive condition can affect how you hear, see, walk, and eat – aspects of daily life that we largely take for granted until a dementia diagnosis is rendered and makes them challenging. These issues may start before the appearance of more expected dementia symptoms – thus, addressing and trying to correct them early on is beneficial to the overall treatment plan of dementia. The progression of dementia and its consequences vary for each person, making a multidisciplinary approach to care management all the more relevant.

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PART VIII

# **Part IV**

Current and future  
non-pharmacological  
interventions in dementia

# Chapter 14

## Cognitive interventions

*José A. Morais, Claire Webster*

### Key points

- Arts programmes in dementia care, like music therapy, are low-cost alternatives to pharmacological treatments for a variety of outcomes such as reducing neuropsychiatric symptoms (NPS) and providing opportunities for social interaction and engagement.
- As the arts involve expressions of human feeling, they may play a unique role in helping people living with dementia to connect inwardly and with others in deeply meaningful ways.
- Cognitive Stimulation Therapy (CST) is a manualised group intervention for people living with mild-to-moderate dementia aimed at improving cognitive function through themed group activities that implicitly stimulate skills. No specialist equipment or medical knowledge is required, it is culturally adaptable, and low cost.
- Cognitive training (CT) involves the formal training of abilities and processes such as memory, information processing, attention, and executive functions, through practice of structured tasks of increasing difficulty designed to challenge such abilities.



## General background

The definition of "intervention" in medical settings can vary quite a bit depending on the source, but overall, most people have come to understand it as a plan that may encompass diagnosis, direction, prevention, control, and therapeutic treatment options to help cure, treat or improve a specific condition or disease.

When it comes to dementia, a chronic and incurable condition, prescribed medications aim to slow its progression and ease its myriad of symptoms. That said, other innovative non-drug interventions intended to slow the decline of cognitive function and curb its adverse impact on personality, behaviour, loss of interest, and mood among others, have come to the forefront in the dementia discourse. This chapter features four compelling essays that present key concepts in these companion therapies.

The disciplines of music and arts therapy have been recorded since the prehistoric era, but the 1940s saw a real emergence of modern-day programmes in the medical field. In her essay, Kate de Medeiros highlights the unconventional duality of combining arts programmes to reduce neuropsychiatric symptoms and provide an outlet

for heightened expression, connection, and meaning for people living with dementia. Meanwhile, Hervé Platel and Mathilde Groussard ably detail how advances in neuro-cognitive research are now the backbone in determining the many benefits of music therapy on communication, emotional, psychological, and social building pillars.

Turning to Cognitive Stimulation Therapy (CST), Aimee Spector and Emily Fisher skilfully shine the spotlight on this approach, which promotes group activities to stimulate cognitive function as well as creates a sense of wellbeing and belonging. Another major advantage of these types of interventions are its low cost, which makes it ideal for implementation in rural areas and/or lower- and middle-income countries.

Finally, Alex Bahar-Fuchs et al. provide a detailed account of the structured task-oriented approach of cognitive training. They contend that this evolving model merits further study and standardisation in the post-diagnostic domain to evaluate whether people living with dementia can transfer this training into applicable skills of everyday life.

## Expert essay

## Arts in dementia care

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Arts programmes in dementia care have gained attention as potentially low-cost alternatives to pharmacologic treatments for a variety of outcome areas, such as reducing neuropsychiatric symptoms (NPS) and providing opportunities for social interaction, engagement and connectivity that are typically not possible in many care settings. Yet, the effectiveness of arts programmes has been decidedly difficult to evaluate using conventional research designs. This is, in great part, due to differences in the goals of the arts, aimed at creating transformative and meaningful moments, compared to other types of interventions designed for targeted, longer lasting, and more easily measured results. To further consider the role of the arts in dementia care, this essay provides an overview of definitions of and differences among various arts approaches, a summary of key findings, and future considerations.

## An overview of definitions

“The arts” is a broad term describing many different types of creative expression such as visual arts, dancing, poetry, music, and others. “Cultural arts” refers to “the practice of creating perceptible forms expressive of human feeling” [1] by individuals or groups. In addition to active participation through creative expression (singing for example), the cultural arts can be passively experienced (such as listening to another person sing). The participatory arts, a subset of the cultural arts, describes a collaboration between artists or artist-trained facilitators and participants aimed at creating original self-expressive works [2][3][4]. Key features of participatory arts include active and voluntary participation, interaction with others, and a focus on valuing all contributions, regardless of how small. Both the cultural and participatory arts are concerned with creativity, imagination, engagement, and expression of feelings which lead to transformational moments [2][3][4]. In contrast, “art therapy,” a form of psychotherapy delivered by a licensed artist, differs in purpose from the cultural arts in that it uses an art medium to achieve a specific outcome (for example, reducing anxiety) [2][5]. Finally, “arts interventions” refers to any type of intervention in which some form of art is used (such as music) but not necessarily under the direction of an artist (this could be an activities coordinator who leads

a sing-along session) [6]. These distinctions underscore the importance of considering the “who” and “why” of an arts-based intervention in addition to its outcome.

## Challenges in arts interventions research

The focus of this essay is on the participatory arts for which there are four basic categories: language-based arts to include poetry, storytelling, and theatre; dance; visual arts such as drawing, painting, and museum-curated experiential programmes; and music [2][5], which will not be discussed since it is the focus of a separate essay. As previously mentioned, several challenges have been noted regarding evidence for the effectiveness of participatory arts in dementia care. First, study designs and instruments used for pharmacological and non-pharmacological therapy-based interventions are poorly suited for participatory arts interventions [2][3] given that the focus of the arts is on expression, connection, and meaning making rather on a particular mechanism of action. In addition, although quality of life instruments is commonly used in arts-based intervention research, many are vague, poorly administered, and are cross-sectional without adequate follow-up [2]. Arts-based studies tend to use qualitative, observational designs with small, highly selective samples [3] [5] [7], making them difficult to generalise to other populations. There is also a lack of consensus on what comprises “success”. For example, should the effects of an arts intervention last minutes, hours, or weeks? [2] Finally, there is little agreement on what the “it” is in a given intervention [4][8] that contributes to its success. For instance, is it the tactile process of drawing, the cognitive act of transferring a mental image onto paper, both, or something else altogether?

## Findings for three participatory arts categories

**Language-based arts.** Language-based programmes have been linked to improved quality of life for people living with dementia in the community and for long-term care residents and staff. Programmes such as TimeSlips [9], a facilitator-trained improvisational storytelling activity; the Alzheimer’s Poetry Project, which uses a call-and-response

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technique for reciting familiar poems [6]; and embedded theatre projects such as the “Penelope Project” [3] and “I Won't Group Up,” based on the *Odyssey* and *Peter Pan*, respectively, feature opportunities for novel social language use and self-expression typically not found in care settings. Many studies using language-based interventions report increased social interactions among residents, increased conversational abilities, and a stronger sense of community [3][6], although these findings are primarily observational.

**Dance.** Dance programmes are often delivered in residential care or hospital settings and consequently involve people with more advanced stages of dementia [3]. Although some studies report small changes in neuropsychiatric symptoms and increased mobility for people living with dementia [3], most report positive outcomes related to a sense of meaning, expression, and increased sense of community [5].

**Visual arts.** Outcomes associated with artist-led drawing or painting interventions include increased social and psychological wellbeing [3]. Curated, art-encounter museum visit programmes include “Meet Me at MoMA” and ARTEMIS (ART Encounters: Museum Intervention Studies). These programmes typically involve people with early to moderate stages of dementia [4]. Some studies report new learning and increased aesthetic perception for museum-based engagement programmes. A recent randomised control design involving people living with dementia and their carers found that people who attended a series of museum intervention and art-making sessions over six weeks showed significant improvement in apathy, depressed mood, and anxiety, as assessed by carers, compared to the control group [10]. Studies also report positive impact on socialization opportunities by people living with dementia and their carers.

## Future considerations

While it is worth noting the existing research limitations on participatory arts-based interventions on the one hand, it is also important to consider what such interventions do

bring to the lives of people living with dementia. Since the arts involve expression of human feeling, they may play a unique role in helping the person living with dementia connect with themselves and others in deeply meaningful ways. It is therefore important to consider the arts as a key component of care rather than as a treatment.

It is also worthwhile to think beyond individual change and instead to consider the role that the participatory arts can play in shaping a sense of community, especially within long-term care settings. Community extends beyond people living with dementia and involves all levels of care staff as well as friends and families. Infusing an arts-based intervention within a care community can potentially have a positive effect on the overall environment.



**It is also worthwhile to think beyond individual change and instead to consider the role that the participatory arts can play in shaping a sense of community, especially within long-term care settings.**

Finally, any arts intervention should be grounded in personal preferences of the participants. “Prescribed” art or forced participation is counter to the improvisational qualities inherent in an effective arts programme. Not everyone enjoys poetry, dance, or other forms of artistic expression. These preferences must be respected or else the arts become nothing more than another activity. Overall, participatory arts may offer opportunities for communication and self-expression that are well aligned with the emotional and social capabilities of people with living with dementia.

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## Expert essay

# Music therapy

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## Definition and fundamentals

**M**usic therapy historically appears in the field of art therapy, initially using a psychoanalytic approach. It is crucial to specify the different kinds of musical interventions proposed to people with neurodegenerative pathology. The word “therapy” already elicits confusion and raises various questions for family carers who may believe that musical interventions can heal. In the context of neurodegenerative conditions, this word clearly connotes to “manage”, “support” or “take care”, rather than to “treat” or “cure”. These ambiguities prompt some professionals to avoid using the term “music therapy” but rather to speak of “musical interventions”, “music medicine” or even “neurologic music therapy” to account for certain types of music-based practices.

There is a traditional differentiation between two main techniques: active music therapy, which consists of using sound-producing objects, musical instruments, or the voice, and receptive (or passive) music therapy, based on listening to music. In practice, it has been found that music therapists tend to combine both techniques.

## Scientific background

Biological and neurological processes have long been absent from music therapists' fields of interest, even though the musical experience largely indicates sensory, physiological, and neurological mechanisms. Consequently, most of the studies published in scientific journals mainly address social, psychological, and behavioural disorders, essentially using wellbeing scales and questionnaires. In contrast, very few studies address cognitive assessment, comprising among others, motor and emotional responses, language skills, attention, memory.

Thanks to the progress in neurocognitive research in the field of music cognition, notably using brain-imaging techniques, a better understanding of the neuropsychological mechanisms at work while listening to or practicing music has brought on a renewal of music therapy practices. This scientific work has shed light on the active ingredient underlying the benefits of musical interventions. Music interventions for people with dementia, notably Alzheimer's disease, are now driven by this scientific literature [1].



## Main processes involved

In order to improve the specificity of approaches, it is crucial to have a better understanding of the underlying mechanisms that lead to the positive effects of music interventions. Three main mechanisms help researchers and clinicians to optimally design music interventions according to their therapeutic targets.

- **Sensory and emotional appreciation:** People living with dementia can perceive and understand the emotional connotations of musical material and react when listening. They usually maintain their sensory and emotional appreciation for music when other cognitive (especially verbal) abilities are completely impaired, and this, even in the late stages of the condition. Although there is a debate about the alteration of the perception of emotions in neurodegenerative diseases, aesthetic judgment and emotional appreciation seem largely preserved in dementia, especially in Alzheimer's disease [2]. This preserved responsiveness to music allows for the use of recognised emotional and neurophysiological effects of music on mood and behaviour.
- **Mnesic processes:** Memories of old songs and melodies from people's youth have proven to be very resistant to the amnesia characteristic of dementia, with semantic memory remaining relatively well-preserved, even at the late stages of the condition [3] [4]. This fact could point to why music is a favoured

medium to use during reminiscence therapy as it triggers autobiographical memories and engages people living with dementia to reconnect with their past and identity. This, in turn, could contribute to diminishing anxiety or depression. Moreover, music could be used as a mnemonic proxy to decrease the difficulties of verbal learning, particularly at the beginning of the condition.

- **Social cognition:** For most people, music is a very social activity. Even when listening to music alone, it often triggers our sense of belonging to a social group or reminds us of our relationships. This social aspect of music may be a fundamental aspect in supporting the communication and connection between people living with dementia, their family carers or care staff [5].

### Neurophysiological correlates

It has been well established that listening to music can have an arousing effect, associated with dopamine release [6–7], which stimulates people and makes them temporarily more efficient when performing different types of tasks. This may

also explain why music can sometimes help alleviate apathy in people living with dementia. Calming music has been shown to reduce feelings of stress, as well as the body's physiological response to stress (that is, a decrease of cortisol levels [8]). Similarly, this may be why music's soothing effect may decrease anxiety and aggressive behaviours in people living with dementia. Thus, the emotions elicited by music could shed light on how music could facilitate the encoding of new information [4, 9].

Although not all types of music interventions have been subject to measures of effectiveness, standard interventions (receptive or active) show a validated impact for the reduction of behavioural disorders as well as cognitive and social stimulation in people living with dementia. By default, musical interventions have an excellent cost-effectiveness ratio, as they are inexpensive, especially for passive listening or singing activities, and do not require people to have any special skills. The considered costs relate to the staff time required to lead these activities (which is the most economical solution), and possibly to the setting up a room dedicated to musical activities. Of course, it is recommended that the

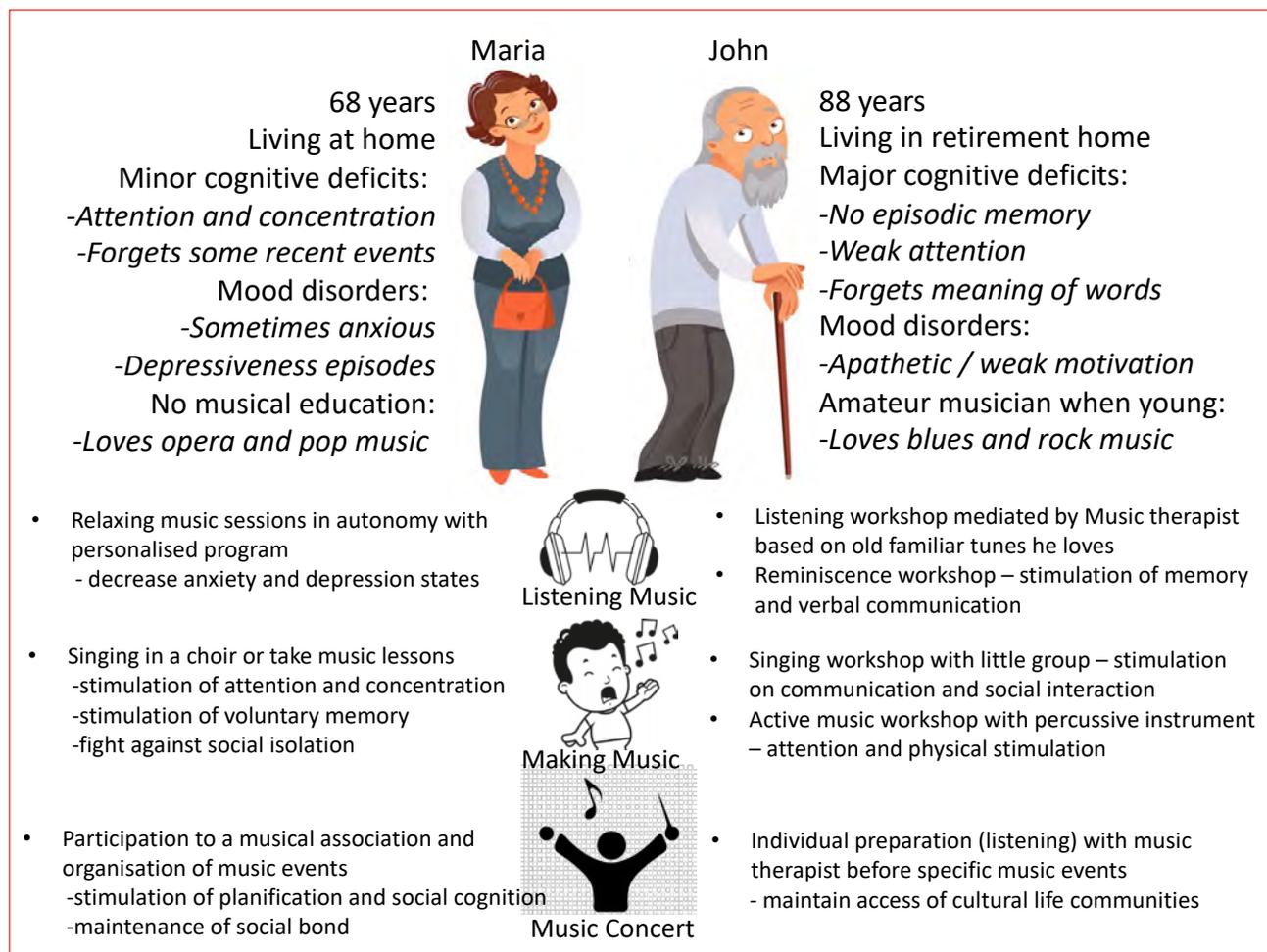


Figure 1. Profiles of two people living with dementia and of feasible musical interventions and primary expected goals

intervention (even when it is simply a matter of listening to music) be mediated by a professional recruited specifically for this purpose, which will increase its scope and effectiveness.

## Indication and clinical advice

During the mild stage of dementia, when distress, depression and anxiety are associated with the decrease of cognitive performances, receptive musical therapy as a psycho-musical relaxation technique is very useful to reduce these disorders [10]. During the advanced stage, when verbal communication declines and apathy becomes one of the biggest behavioural symptoms to contend with, music interventions such as singing workshops are very pertinent to fight against apathy and to stimulate verbal communication. Thus, at all stages of the condition, receptive or active musical interventions have complementary impacts (see Figure 1). Music can be relaxing or stimulating, and this dual quality brings to music intervention an undeniable interest in neurodegenerative diseases.

All people living with dementia, regardless of the stage, can benefit from this type of intervention if singing in a group setting is an activity that brings them a measure of satisfaction.

- Behavioural disorders: mainly anxiety and depression at the beginning of pathology; apathy and language disorders for people living with dementia in the moderate to advanced stages.
- Cognitive stimulation: reminiscence therapy, semantic and autobiographic memory stimulation, language fluency, motor coordination.
- Social cognition: social exchanges, cognitive and affective empathy.

Some people may not be receptive to certain types of musical intervention. Further to an assessment of the auditory perception, it is important to ascertain if music stimulation elicits positive emotions, and thus potentially represents a “reward”, for the person. Before recommending such an intervention for an individual, using a scale such as the Barcelona Music Reward Questionnaire (BMRQ) could be very useful to measure whether music is an area of interest and pleasure.

## Session parameters

Preferably, the practitioners should be dedicated professionals with academic training in music therapy for people with dementia.

Use a dedicated space (music room), or by default ensure that the activity is ritualised in the same institutional context or at home.

Individual or group sessions of 4 to 8 participants.

- Period: Cycles of six to eight sessions.
- Frequency: At least once a week.
- Duration: 60-to-90-minute sessions.

Ensure that participants with hearing impairments are properly fitted with hearing aids.

1. Remind everyone of the context and introduce everyone;
2. Warm up (in case of active interventions and singing workshops);
3. Content/specific goal of the workshop;
4. Playful conclusion.

It is important to discern whether that people participating are becoming increasingly comfortable during the sessions and enjoying the workshop's content

- In terms of psychosocial benefits, there are many geriatric scales to measure wellbeing or self-esteem, as well as mood scales [Behavioural Pathology in Alzheimer's Disease Rating Scale (BEHAVE-AD), Neuropsychiatric Inventory (NPI), Cohen-Mansfield Agitation Inventory (CMAI), etc.].
- At the cognitive level, it is possible, for example, to measure the increase a feeling of familiarity for the music heard in workshops, as well as the quality of personal memories recall in reminiscence workshops. Other cognitive measures are possible [1].

## Training and/or knowledge required to provide the intervention

Numerous master's degrees in music therapy are offered today, even if the professional recognition of these courses is quite heterogeneous between countries. These courses increasingly include content concerning cognitive neuroscience studies and offer practical training courses that allow future graduates to become familiar with a specific pathological population. In the context of the management of neurodegenerative diseases, it is essential that practitioners understand the neurocognitive disorders and the consequences of their behaviour. Methodological training is also recommended so that practitioners know how to assess the impact of their interventions.

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## Expert essay

# Cognitive stimulation

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Cognitive Stimulation Therapy (CST) typically describes a manualised group intervention for people living with mild-to-moderate dementia. It aims to improve cognitive function through themed group activities, which implicitly stimulate skills (including memory, executive function, and language) through tasks including categorisation, word association and current affairs. Learning theory and brain plasticity suggest that targeted mental stimulation, for example through building new semantic connections, can lead to the development of new neuronal pathways. Social theories suggest that creating an optimal and supportive group environment can enhance skills and increase wellbeing. The most robust evidence-base stems from a 14-session group CST programme developed by a team in the UK [1], which has now been translated and culturally adapted into over 10 languages and is in use in over 35 countries. This specific programme will be the focus of this essay.

The programme typically runs twice a week over seven weeks, with sessions lasting 45–60 minutes. While it is a manualised intervention, sessions should be flexibly tailored to the groups' interests, needs, cultural backgrounds and cognitive/sensory abilities. Sessions typically begin with music and warm up activities, orientation (using a board to prompt), a brief discussion of current affairs followed by the main, themed activity (Table 1). The 'Key Principles of CST' (Table 2) are integral, particularly those relating to 'mental stimulation', the focus on 'opinions rather than facts' and developing 'new ideas, thoughts and associations'. Groups typically include five to eight participants and one or two facilitators. Cognitive stimulation therapy is suitable for most people living with mild-to-moderate dementia, but those with severe auditory or visual impairment, or with behavioural symptoms that make it difficult to participate in a group programme, may not be suited.

Table 1

## Cognitive Stimulation Therapy Session Themes

|                      |
|----------------------|
| Physical games       |
| Sound                |
| Childhood            |
| Food                 |
| Current affairs      |
| Faces / scenes       |
| Word association     |
| Being creative       |
| Categorising objects |
| Orientation          |
| Using money          |
| Number games         |
| Word games           |
| Team quiz            |

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Table 2

| Key Principles of Cognitive Stimulation Therapy                |
|--|
| Mental stimulation   |
| New ideas, thought and associations                            |
| Using orientation, sensitively and implicitly                  |
| Opinions rather than facts                                     |
| Using reminiscence as an aid to the here-and-now               |
| Physical movement  |
| Providing triggers and prompts to aid recall and concentration |
| Continuity and consistency between sessions                    |
| Implicit (rather than explicit) learning                       |
| Stimulating language   |
| Stimulating executive function                                 |
| Person-centred   |
| Respect  |
| Involvement and inclusion                                      |
| Choice   |
| Fun  |
| Maximising potential   |
| Building / strengthening relationships                         |



Cognitive stimulation therapy in rural Tanzania (Aimee Spector)

## The research evidence

A review amalgamating 22 systematic reviews and incorporating 197 unique studies [2] found that Cognitive Stimulation demonstrated the best evidence for increasing cognition amongst all psychosocial interventions. The CST programme was initially evaluated (n=201) as a randomised-controlled trial [1], with significant improvements in cognition and quality of life following seven weeks of CST. Over the past 20 years, benefits of this specific programme have been demonstrated from studies in multiple languages and contexts. A systematic review [3] included twelve studies from Hong Kong, Japan, Portugal, Tanzania, the UK, and USA. All twelve examined impact on cognition, with nine demonstrating statistically significant improvements. Several studies also demonstrated benefits to quality of life and depression. A more recent meta-analysis [4] included 44 global randomised-controlled-trials, all evaluating interventions more broadly described as 'cognitive stimulation', with programmes varying in content, dose, and duration. They found improvements in global cognition, memory, quality of life, activities of daily living and depression.

A follow-on trial of 'maintenance CST' [5] evaluated the effects of a further 26, weekly sessions following the initial 14 session programme. This trial showed that quality of life continued to improve significantly for those receiving cognitive stimulation therapy sessions at six months; and with greater

benefits to cognition for those on cholinesterase inhibitor medication, suggesting a synergistic effect. A trial of 'individual CST' delivered by family carers [6] found benefits to the dyadic relationship and carer quality of life, but no significant changes in cognition or quality of life in the person living with dementia. This indicates that the group format confers particular benefits, a theory supported by a growing body of qualitative research on this CST protocol [7]. The literature points to a sense of group learning, cohesion, and normalisation, especially when working together on cognitively challenging tasks; with quotes such as "It helped us know that we were in the same boat" often reported. The evidence also suggests that facilitation by a non-family member and ideally a healthcare professional is advantageous. Finally, it has been found that cognitive stimulation therapy is more cost-effective than usual care, with a recent economic analysis finding that offering CST to every new case of dementia in England would still be cost-effective [8].

## CST in practice

Cognitive stimulation therapy is the only non-pharmacological intervention specifically recommended to improve cognition, independence and wellbeing by the UK National Institute for Health and Care Excellence guidance. Consequently, routinely offering CST as a post-diagnostic



*Cognitive stimulation therapy in the UK (Aimee Spector)*

intervention is a mandatory requirement for accredited memory clinics in the UK. The World Alzheimer's Report in 2011, which focused on early intervention, recommended that CST should be routinely given to people with early-stage dementia. This was followed by published guidelines on how to culturally adapt CST [9], both likely to have contributed to its global development. Cognitive stimulation therapy is now part of routine dementia care in many countries including Brazil, Denmark, Hong Kong, India, Norway, and the USA.

In principle, cognitive stimulation therapy can be delivered by anyone who works with people living with dementia, including care staff, nurses, occupational therapists and psychologists. This reflects the wide range of settings in which CST is delivered, including hospitals, care homes, memory

clinics, and third sector groups. Facilitators require skills including an ability to be person-centred and flexible, adapting the content of the sessions and their style of interaction to the needs of the group; and an ability to manage individual and group dynamics. Facilitators should follow the CST manual, now available in multiple languages; and ideally attend a one-day cognitive stimulation therapy training course which is offered globally [10].

## Future directions

During the COVID-19 pandemic, many services rapidly shifted to virtual delivery of cognitive stimulation therapy. An international team co-developed and successfully tested a framework for delivering CST through Zoom [11]. The work indicated that virtual delivery was feasible for many, but that further research is required to establish whether benefits can be mirrored through online groups. The work has created opportunities for people previously unable to access groups, such as those infirm or without access to transport, but also highlighted inequality in access to digital technology.

Three key ingredients lend itself to the successful implementation of cognitive stimulation therapy: it does not require specialist equipment or medical knowledge, training, or skills; it is culturally adaptable; and is low cost. This points to the pressing need for ongoing and sustainable cognitive stimulation therapy programmes in diverse parts of the world, with particular scope within lower-and-middle income countries where medical treatment is often limited or unavailable.

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## Expert essay

# Cognitive training for people with mild to moderate dementia

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## What is cognitive training?

Cognitive training (CT) involves the formal training of abilities and processes such as memory, information processing, attention, and executive functions, usually through practice on a range of structured tasks of increasing difficulty designed to challenge such abilities [1]. Despite some overlapping features, cognitive training is distinct from both cognitive stimulation therapy (CST) and functionally oriented cognitive rehabilitation (CR), which are covered in other sections of this report. Reducing the confusion and inconsistent use of these terms [2] is key to improving our understanding of their potential and appropriate application in various populations and settings and advance clinical practice in the field of nonpharmacological treatments for people with or at risk of dementia.

## What are the different types of cognitive training?

Multiple techniques are included under the general umbrella of cognitive training, all of which focus on improving or maintaining abilities using structured tasks [3]. Cognitive training can target one (single domain) or several (multi-domain) abilities and may rely primarily on rehearsal or incorporate the use of internal (such as mnemonics) or external (for example, smart phone use) cognitive strategies. Tasks may be delivered in laboratory-style fashion (for example N-Back), be gamified to improve engagement, or be designed to be analogous to everyday activities (such as memorizing names, navigating an environment, or setting a table). Cognitive training may be delivered one-on-one or in small groups and may be supervised (in person or remotely) or unsupervised. Traditionally relying on pen-and-paper tasks, CT has been delivered through computerized platforms in recent years, including increasing use of virtual and augmented reality technologies. Finally, cognitive training may be delivered as a standalone intervention, or packaged as one of several interventions in multi-modal/

multi-component interventions (for example, physical activity, neuromodulation, etc.). Emerging evidence suggests that the simultaneous/concurrent delivery of cognitive training and physical activity may be advantageous relative to their sequential delivery [4].

## How does cognitive training work? What are the mechanisms?

A key assumption underlying cognitive training is that cognitive processes and abilities that underpin everyday functions can be trained, owing to principles of neuroplasticity. Thus, the premise is that training on tasks that engage distinct (or interactive) cognitive processes will facilitate restoration and/or compensation, such that performance will improve when the individual is faced with similar but novel tasks as well [3][5]. Evidence from animal and human studies has shown that cognitively enriched environments and CT more specifically are associated with structural and functional neuroanatomical changes. Evidence from a recent meta-analysis of 19 studies has shown that following cognitive training, increases in task-related activation was found in a wide-range of regions depending on specific nature of the training used including in the dorsolateral prefrontal cortex bilaterally as well as in medial temporal and parietal structures, while functional connectivity patterns at rest both increased and decreased [6]. While the majority of studies included in this review focused on people with mild cognitive impairment (MCI), and therefore the findings need to be treated with some caution in relation to dementia, they nonetheless offer some explanation regarding neuroanatomical mechanisms of CT. Additional work in this area will help care providers select techniques that are most appropriate within the context of the underlying aetiology and current clinical stage [3].

## Does cognitive training improve cognition in people living with dementia?

Earlier synthesis efforts were based on a small number of primary trials, often of low quality, and found no evidence that cognitive training is associated with any benefits for cognition or any other clinically meaningful outcome in people with mild to moderate dementia [1,5]. In some cases, this led to the premature conclusion that cognitive training is unlikely to be of benefit to people living with dementia. Unfortunately, this inaccurate interpretation led to recommendations against cognitive training in some practice guidelines [7]. However, a recent, rigorous update of the evidence found that CT is associated with moderate gains for cognition in the short and medium term in those with mild-moderate dementia, and the confidence in this finding has also increased [8]. As is the case in the field of cognitive training more broadly, efforts are now directed to improve our understanding of the optimal intervention parameters and individual factors that increase the likelihood of cognitive gains and their transfer into meaningful everyday activities [9].

## Does cognitive training improve other meaningful outcomes in people with dementia?

To date, there is relatively little evidence that cognitive training is associated with gains beyond cognitive performance in people living with dementia, although a recent systematic review found that it may alleviate symptoms of depression in people with dementia [10]. Importantly, most primary trials of cognitive training have not been designed in such a way that would provide sufficient power to detect effects on secondary, non-cognitive outcomes. In addition, evidence suggests that cognitive training is not associated with any harm [8].

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## Translation of cognitive training into clinical practice

Barriers to the uptake of cognitive training in clinical practice can be classified of as those related to the treatment/intervention, those related to the person living with dementia, and those related to clinicians and to healthcare systems more broadly. Treatment factors include the general paucity of cognitive training treatment parameters. Likewise, the inadequate design of some commercially available CT programmes for people with dementia and unresolved issues related to dosing parameters and unsupervised practice between treatment sessions. Factors related to the person living with dementia include a range of behavioural determinants related to motivation, capability and opportunity, computer literacy, pre-existing and co-morbid psychological factors such as depression or anxiety, and social/environmental supports. Careful assessment of the person with dementia and the implementation of adequate behaviour-change techniques that take such factors into account are required to optimise treatment outcomes [11]. Finally, enhancing education and training related to the delivery and empirical support for cognitive training will enable primary care clinicians and suitably trained relevant allied health clinicians (for example, neuropsychologists and occupational therapists) to advocate for or even offer treatment. In several countries, there is a push to increase the amount and range of post-diagnostic services and treatments for people with dementia within their public healthcare systems [12]. Cognitive training, delivered by a suitable healthcare professional, is an evidence-based approach that can be paired with both existing and pending pharmacologic agents to provide comprehensive care for those living with dementia. Such synergistic approaches may be especially impactful in light of the current or next-generation disease-modifying or arresting medications.

## Conclusion

As the worldwide population continues to age and life expectancy increases, so do the cases of dementia. As a result, new therapeutic avenues in dementia care have emerged in recent years. These strategies to enhance one's quality of life – either by tapping into and rejuvenating interest in specific leisure activities such as music and arts, or alternatively, by challenging decline with stimulation therapy and cognitive training – have firmly made their way into the dementia framework. Thus, the traditional definitions of dementia management, support and treatment have necessarily been expanded.

An optimised care programme can now include these personalised, non-pharmacological cost-effective strategies that can take place in individual and group settings. These interventions have been shown to help improve verbal skills, alleviate depression and anxiety, as well as preserve functional abilities in people living with dementia.

# Chapter 15

## Multidomain interventions for the person living with dementia

*Claire Webster, Pedro Rosa-Neto*

### Key points

- The ability to maintain functional independence when faced with physical, cognitive, social, and emotional challenges is an important indicator of wellbeing.
- Cognitive interventions should be tailored to individual needs and circumstances considering cultural, ethnic, racial and health factors, previous life interests and the wishes of care partners.
- There remains a knowledge gap in terms of best practices regarding multidomain interventions for people living with dementia.
- Effective programs address deficits, build on assets, and consider the person's social and physical environment. Home-based programmes may better serve people with mild to moderate dementia; programmes based in hospitals or long-term care facilities may involve people with more advanced dementia.
- Exercise of at least moderate intensity should be part of a regular routine, as both aerobic (walking) and resistance exercise (Tai Chi, yoga, dance and Pilates) have the potential to improve cognitive outcomes and have psychological benefits.
- Maintaining and improving nutritional status is an integral part of the healthcare of a person living with dementia, as weight loss and malnutrition have been associated with the progression of dementia and cognitive decline.



## General background

In this chapter, we are introduced to a variety of non-pharmacological interventions that are intended to support the person living with dementia. The appropriate use of these interventions constitutes an important part of treatment and management of dementia symptoms. Integration of exercises, nutrition, and cognitive and social interventions may have a significant impact on mitigating cognitive decline in people with dementia. In fact, the benefits of non-pharmacological interventions demonstrated in laboratory provides the base for future pharmacological interventions [1–3]. Although it seems reasonable to stimulate dementia patients from various perspectives, little is known about what type of intervention to prescribe and in which phases of dementia these interventions are more beneficial. Meta-analyses conducted in dementia and mild cognitive impairment (MCI) associate exercise or cognitive training with small to moderate positive effects on global cognition. Thus, multidomain interventions for the person living with dementia constitute an important knowledge gap to be addressed, with significant therapeutic personal and societal impact [4–8].

When considering the various options, an assessment should be made considering the person's needs and life interests, cultural, ethnic, racial and health factors, skills, and abilities, as well as the person's social and physical

environment, especially if they are still living at home. For example, the presence of severe cognitive impairment (e.g., apraxia, visual impairment), behavioural issues (e.g., agitation) or concomitant diseases (e.g., osteo arthritis, heart problems) might limit exercise programs.

It is also very important to take into consideration the carers' ability to implement the intervention safely and ensure that they have access to the necessary resources and support services.

The first essay by Brodaty et al, titled "Non-pharmacological interventions for people living with dementia as part of post-diagnostic care", presents us with an in-depth summary of the many different types of interventions designed to stimulate cognitive function such as cognitive stimulation therapy, cognitive training, cognitive rehabilitation, communication skills training, psychological therapies, occupational therapy, as well as leisure and pleasurable activities that can be implemented at home or at long-term care residences.

The essay by Louis Bherer makes a great case for the important impact that exercise – combining both aerobic and mind-body exercises, performed at a moderate

level at least three times a week – can have on cognitive function as well as on a person's sense of psychological well-being.

In her essay, Guylaine Ferland provides an overview of how nutrition is an essential component of the healthcare and wellbeing of the person living with dementia and how a

person's ability to eat changes as the condition progresses over time. She provides some very practical strategies to manage and understand the changes in eating habits of the person living with dementia as well as how carers can adapt to these changes and learn to limit distractions.

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## Expert essay

# Non-pharmacological interventions for people living with dementia as part of post-diagnostic care

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There is increasing evidence that many different interventions can improve the quality of life, function and goal attainment in people living with dementia and care partners [1]. The ability to maintain functional independence when faced with physical, cognitive, social, and emotional challenges is an important indicator of wellbeing. More traditional techniques – music, reminiscence and art therapies are covered in Chapter 14 and exercise and physical interventions in this chapter.

**Cognitive-oriented therapies** such as group **cognitive stimulation therapy** and **cognitive training** including computerised cognitive training are associated with modest benefits for cognition in people with mild to moderate dementia and these benefits often extend to mood, quality of life, goal satisfaction and overall wellbeing [2]. There may be added benefits from combining cognitive exercises with physical exercise. As with other non-pharmacological interventions, cognitive interventions should be tailored to individual needs and circumstances considering cultural, ethnic, racial, and medical factors, previous life interests and the wishes of care partners. It is likely that emerging technologies such as mobile health applications, augmented reality and assistive technology may enhance the delivery of cognitive-training [2].

**Communication skills training** with a speech pathologist or clinical neuropsychologist can be particularly helpful for people living with dementia who have communication or speech difficulties. While high quality evidence of efficacy is limited by the difficulty of conducting randomised controlled trials, there are excellent qualitative and case series reports [3]. There are specific techniques for semantic dementia or non-fluent progressive aphasia, logopenic dementia and dementias following strokes. Beyond better communication and speech, additional benefits have been reported in mood in people living with dementia and stress levels in care partners.

**Psychological therapies** may be used to treat depressive symptoms and anxiety that commonly occur in people living with dementia. Psychological therapies include **cognitive behaviour therapy (CBT)**, **interpersonal therapy** and **validation therapy** as well as group psychotherapy and non-manualised individual counselling techniques [4] [5]. Other strategies include provision of peer support and activity-based therapies. Evidence for some efficacy is available for CBT for depressive symptoms and for quality of life but not for anxiety with little support or evidence for other therapies listed [5]. Generally, psychological therapies are indicated for people with mild to moderate dementia and aim to improve their depressive or anxiety symptoms and not necessarily cognition or function.

**Occupational therapy** programs aim to assist people living with dementia to perform activities of everyday living. This was achieved by assisting the person and often the person's care partner, modifying the task or modifying the environment. Some programs focused on behavioural outcomes. Sessions, typically of 90 minutes or longer duration, are delivered at frequencies varying from twice weekly to monthly.

**Leisure and pleasurable activities** are desired by all people. An occupational therapy approach involves active listening to people living with dementia and care partners and co-designing a pleasurable event schedule, and providing appropriate modifications, such as simplifying activities or reducing the number of steps involved, introducing equipment or assistive technologies and educating the care partners and family to enable people living with dementia and care partners to participate in enjoyable and fulfilling activities [6].

**Cognitive rehabilitation** focuses on improving daily function and is personalised to meet each person's individual goals. Compensatory strategies are employed such as

external aids, environmental adaptations, and procedural learning [7]. Cognitive rehabilitation includes memory strategies, providing practice sessions, directing to relevant services, and offering support for study partners [7]. Home-based cognitive rehabilitation demonstrated improvement in functional independence based on ADL measures or global performance measures. Outcomes were less positive in clinic or centre-based programs [8].

**Dementia rehabilitation programs** are well summarised in a comprehensive review [8] of 28 rehabilitation programs, mostly in community dwelling participants with mild to moderate dementia (n=21). Interventions were usually conducted in conjunction with care partner input and in their own homes, and often led by an occupational therapist or a multidisciplinary team. Some included environmental assessment and modifications.

**Multidisciplinary home-based rehabilitation** considers dementia, comorbid medical conditions, and the physical and social environment. Programs are individually tailored addressing the concerns expressed and the goals nominated by the people living with dementia and care partners [8]. In the USA, the COPE program [9] demonstrated less functional dependence for people living with dementia over four months but not at nine months; care partners achieved greater benefits in wellbeing knowledge and skills. In Australia, the Interdisciplinary Home-Based Reablement Program included a stronger emphasis on interdisciplinary teamwork with greater nursing and allied health involvement as well as minor home modification, assistive devices (8). At four months, the program demonstrated positive outcomes in goal attainment, mobility and independence and function as well as wellbeing and confidence of the person living with dementia. After 12 months, there was less decline in functional independence compared to a control group. A similar, but more intensive multi modal intervention in Italy found a significant improvement in function in some functional measures, but this was not maintained at three months' follow-up [10].

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## Elements of success with interventions

Successful programs are more likely when preceded by a comprehensive assessment with the person living with dementia and the care partner, tailored to meet their needs and wishes (i.e., person-centred) and are home-based, allowing the therapist to assess the person's ability in their everyday physical and psychosocial environments. Effective programs address deficits, build on assets, and consider the person's social and physical environment. Home-based programs may better serve people with mild to moderate dementia; programs based in hospitals or long-term care facilities may involve people with more advanced dementia. Physical comorbidities are known to be common in dementia and should be addressed [11].

The most common successful outcomes were function and goal attainment; others were wellbeing, confidence, and improved care partner outcomes. Positive outcomes were often, but not always, associated with more intensive interventions, with greater training for the health professionals and individual goal setting in conjunction with the person living with dementia and the care partner. Sessions were typically for 90 minutes with interventions over 5–12 weeks with most studies conducting follow-up assessments over 3–12 months.

## Conclusions

Nihilism, despair, and inactivity have no place after a diagnosis of dementia. In the same way that people who have had a stroke or heart surgery are offered rehabilitation and continued support, those diagnosed with dementia deserve the opportunity to live positively, build on their assets and compensate for their disabilities using a rehabilitation framework. This requires planning in partnership with the person living with dementia and their care partners, access to multidisciplinary support, information, and positive attitudes from health professionals. Where multidisciplinary services are not available people living with dementia and families should be directed to information and online supports, such as local Alzheimer associations.

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## Expert essay

# Effects of exercise and multidomain intervention on cognition in mild cognitive impairment and people living with dementia

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There is a global agreement in the medical and scientific community that a large proportion of dementia cases could be prevented or postponed. This new trend comes from scientific evidence showing that adults reporting higher engagement in an active lifestyle, with physical activity and exercise at the forefront, had a lower risk of developing dementia over the years. Several large studies around the world also showed that engaging in physical exercise on cognitive stimulation help improve cognition in seniors (see Chapter 23). While this approach has gained an unprecedented popularity over the last few years, its efficacy to improve cognition in individuals already dealing with mild cognitive impairment (MCI) or people living with dementia (PLWD) remains to be convincingly demonstrated. Here we summarize findings from major studies that investigated whether physical exercise and multidomain interventions can help alleviate cognitive symptoms in people with MCI or dementia.

## Physical exercise in MCI and PLWD

Multiple studies have been published with various exercise interventions: aerobic exercise (including walking), resistance training, dance, and mind-body exercise. Both aerobic and resistance exercise have the potential to improve cognitive outcomes, supporting the notion that a multimodal exercise program might lead to larger gains. Most studies based their interventions on aerobic exercise and showed that aerobic exercise improved global mental functioning as well as memory in patients dealing with MCI. These studies support the conclusions from the fifth Canadian Consensus Conferences on the Diagnosis and Treatment of Dementia (CCCDTD5)[1], which recommend aerobic exercise to improve cognitive outcomes among people with MCI. For instance, in a meta-analysis, which includes multiple intervention studies with people diagnosed with Alzheimer's disease, those who completed an aerobic training program showed improvement in general mental status, which was not observed in those who did not train[2]. In another similar study, but including different types of dementia, both aerobic exercises alone, or combined with non-aerobic exercise

also showed positive effects on cognition in people living with dementia[3]. Thus, it seems that a fair component of aerobic exercise must be part of the intervention to lead to improvements in people living with dementia. This leads us to discuss the type of exercise or the composition of a multi-domain intervention program that would show the larger improvement in cognition.

With regards to non-aerobic or other types of exercise, studies suggest that Mind-Body Exercises (MBE) such as Tai Chi, yoga, dance, and Pilates, can help improve cognition in those with cognitive impairment. A meta-analysis also suggests that MBE positively impacts attention, short-term memory, executive function, which refers to a form of mental control by which we adapt [4] to novel situations. Together, these studies suggest that resistance training and MBE can improve cognition in older adults with MCI and people living with dementia.

## Multidomain intervention in MCI and PLWD

While some studies suggest that combining lifestyle management, exercise, cognitive stimulation, nutrition, and more, can improve cognition in healthy seniors or those at risk of dementia, the added benefit of these multidomain approaches for individuals with MCI and people living with dementia remains debatable. Some studies suggest that combining cognitive intervention with exercise, simultaneously, sequentially or using exergames (gamify exercises) can lead to cognitive improvement, with larger effect in simultaneous training[5]. This is in line with another study by Li et al.[6], showing that combining Tai Chi with cognitive intervention results in larger gains. More recently, a meta-analysis [7] based on 28 different studies comparing multidomain interventions to single-domain interventions, revealed significant improvement favouring multidomain interventions on global cognition, executive function, memory, and language. This study also emphasized that most studies used cognitive training, physical exercise, MBE, music, dietary supplement, social engagement, and education. More studies should be

conducted to better understand the contribution of different types and combinations of interventions, dose-response relations, sustainability of improvements over time, use of booster interventions, etc.

## Conclusion

In the absence of pharmaceutical treatments for cognitive impairment associated with MCI and people living with dementia, multidomain interventions with physical exercise of multiple types as the major component should be considered as effective and feasible secondary and tertiary approaches. In patients with MCI, aerobic exercise of at least moderate intensity should be part of a regular routine, ideally 10–15 minutes every day or at least 3–4 times a week. This can take the form of walking at a moderate speed or recumbent cycling if available. Resistance training

should also be part of a regular routine three to four times a week. Mind-body exercise like yoga and Tai Chi, as well as dancing will also likely lead to cognitive improvement and psychological benefits. Evidence suggests that a multidomain intervention should also include cognitive stimulation. This can be achieved using individual computer-based and group cognitive training, some of which have been validated in the scientific literature. Alternatively, increasing and maintaining cognitively stimulating activities like board games, volunteering, new learning and preferably a variety of new activities. The same recommendations apply to people living with dementia in order to help maintain cognitive functions longer and help manage behaviours, mood, and anxiety. All these activities could be performed with the carer or family members. This way, patients and relatives would benefit from the activities in addition to sharing enjoyable moments together.

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## Expert essay

# Nutritional interventions for people living with dementia

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**N**utrition is an essential component of the healthcare and wellbeing of people living with dementia. The brain relies on a constant supply of energy to function adequately and several nutrients are involved in tissue integrity (e.g., myelin sheath) and cerebral metabolism (e.g., synthesis of neurotransmitters). Older people living with dementia are at increased risk of weight loss and malnutrition due to various problems that develop during the course of the condition [1]. In the early stages of the condition, older adults may have difficulty shopping for food and preparing meals and lack the motivation to cook and eat. Changes in taste and smell (the latter more frequently observed) and depressive states have also been associated with reduced appetite [2]. In contrast, some people living with dementia develop an insatiable appetite or a craving for sweets.

As dementia progresses, individuals may become unable to recognize and communicate hunger and thirst. Behavioural issues such as confusion, agitation, anxiety and aggressivity may occur and perturb the mealtime experience. Hyperactivity (i.e., pacing, wandering) can also be observed, increasing energy requirements as a result of accrued energy expenditure. In advanced stages of the condition, physical weakness, loss of motor skills and distractibility make eating increasingly difficult. Patients lose the ability to use utensils or recognize foods, begin eating inedible items or reject food altogether [3, 4]. Dysphagia is often present in the latter stages of the condition, further challenging food intake, in addition to being an important risk factor for aspiration pneumonia, a common cause of mortality in people living with dementia [5].

## Maintaining and improving nutritional status

Maintaining and improving nutritional status is an integral part of the healthcare of a person living with dementia as weight loss and malnutrition have been associated with progression of the condition and cognitive decline [6]. Hence a vicious circle whereby dementia leads to a deterioration of the nutritional status, which in turn contributes to an acceleration of the condition. There is currently no indication

that energy and nutrient requirements of people living with dementia differ from those of the general older population. Diets rich in fruits, vegetables, whole grains, low-fat dairy products, and lean protein foods (i.e., legumes, fish) are nutrient rich and will support the cognitive function and general health of those living with dementia, whatever the stage of the condition [7]. More specific recommendations include limiting foods high in saturated fats (animal sources), salt and added sugars. Drinking plenty of water is also important as dehydration can increase confusion and the risk of delirium and can accentuate the symptoms of dementia. Based on current guidelines, supplementation of single nutrients (i.e., vitamins, minerals) is not recommended as standard of care for people living with dementia unless to correct a documented nutrient deficiency. However, oral nutritional supplements can be used to meet requirements and nutritional status as they have been found beneficial to increase body weight in individuals with dementia [8]. At this time, there is no evidence that nutrient supplementation can correct cognitive impairment or prevent cognitive decline [4].

Specific nutrition-related difficulties are known to develop as dementia evolves and should be addressed to ensure adequate oral intake and nutritional status [9][10]. Maintaining a regular meal schedule is encouraged, something usually facilitated by care partners and family members. For people with dementia who are living alone, who have lost their sense of hunger or have become forgetful, mealtimes can be prompted with an alarm clock or other signalling device. Planning and shopping for meals in advance will establish a routine around food and facilitate meal preparation. Individual meals and cooking instructions can be printed, and foods and ingredients required for the meals organized in a convenient and easily accessible manner. Furthermore, because people living with dementia may forget about the foods they have in their cupboards and refrigerator, checking and disposing of anything out of date should be done on a regular basis. With respect to the meals specifically, they should be planned considering the person's food preferences and habits, which may be influenced by cultural and religious traditions. Nutrition restrictions linked to specific medical conditions (i.e., diabetes, bowel disease) also need to be considered when planning the meals. The context of the meal

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experience is also important. As people living with dementia may be prone to confusion, meals should be consumed in a calm, peaceful environment. Loud noise coming from the radio, television or electronic devices should be discouraged in favour of relaxing or familiar music. Plates, tablecloths, and placemats should be simple in style and in contrasting colours to make it easier for the person to distinguish the food from the plate or table. Similarly, only the utensils needed for the meal should be provided to avoid confusion.

With the progression of the condition, people living with dementia often see a decrease in their appetite. In such instances, care should be taken that this is not as a result of a change in medication or dosage. Lack of physical activity will also decrease appetite; hence individuals should be encouraged to be physically active. Simple exercise such as walking and gardening have been shown to be beneficial. Poor appetite can also result from chewing problems, hence the importance of regularly ensuring optimal dental and oral health. For individuals with taste and smell impairment, strongly flavoured and aromatic food can stimulate appetite.

Similarly, eating in the company of others has been shown to increase food intake of older individuals and should be encouraged as much as possible. As motor impairment develops and feeding becomes increasingly difficult, foods may be served in bowls instead of plates and specially designed cups (i.e., with lids) and utensils (i.e., large handles) can be proposed. Likewise, meals can be adapted to include finger foods, meaning foods that can easily be eaten with the fingers (e.g., vegetables, sandwiches, fish sticks). Use of such foods have been shown to help maintain a person's independence during meals [3][4].

People living with dementia and those who care for them are faced with a wide range of challenges when it comes to nutrition health. The aim of the present article was to present some of the strategies that have been utilized in the effort to maintain adequate nutritional status and oral intake in patients with dementia. Useful resources supporting nutrition health have been developed and are available for patients living with dementia and their carers [11].

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## Conclusion

The key components required for all individuals to live as healthy a life as possible – exercise, nutrition, social stimulation, managing existing health conditions as well as having a “life’s purpose” – also apply to persons who have been diagnosed with dementia.

Brodaty et al's eloquently worded conclusion captures the essence of this chapter: “Nihilism, despair and inactivity have no place after a diagnosis of dementia...Those diagnosed with dementia deserve the opportunity to live positively, build on their assets and compensate for their disabilities using a rehabilitation framework.”

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# Chapter 16

## Interventions for the carers

*Claire Webster, José A. Morais*

### Key points

- Feelings of powerlessness, high levels of stress, and role conflict among family members are commonly experienced by informal carers. System navigation is key to reducing carer strain.
- Creating a compassionate workplace culture is essential to the future of homecare and carers. Caregiving is not a one-size-fits-all solution and therefore, a variety of supports should be considered.
- Psychoeducational interventions, encompassing a tailored person-centred approach, are recommended to address the specific training and support needs expressed by carers to fully understand the condition and to try to prevent some of the negative impacts of this role.
- Positive psychology is the study of the conditions and processes that contribute to optimal development and functioning of individuals, groups, and institutions. It can assist informal carers acquire the necessary strategies to maintain a sense of well-being and optimism while caring for a person living with dementia.
- The rise of tele-interventions and web-based psychoeducational training in recent years have proven to be a constructive way to support and educate people living with dementia and their carers due to convenience, ease of access, affordability, flexibility of timings, decreased need to travel, as well as reducing social isolation and increasing camaraderie among participants.
- In-home respite services are underused by carers because of feeling guilty about leaving the person living with dementia, worries about the safety and quality, not accepting their own need for a temporary break, or by the affordability of and the difficult access to the respite service.
- Many factors influence the bereavement experience for family carers and supportive psychosocial interventions should be offered to assist them in navigating their grief and managing their depressive symptoms after the death of the person they cared for.



## General background

Caring for a person living with dementia can last many years and much has been written about the negative effects that caregiving can have on the physical and mental health of carers, especially when they lack the necessary education, information, resources, and support. This chapter showcases how various psychosocial and psycho-educational interventions – including positive psychology, in-home respite, bereavement support and meditation – can help carers and persons living with dementia navigate their journey. Dementia is an ever-evolving illness, and the education and support provided to carers must keep pace. Exploring the multitude of available interventions described herein will undoubtedly provide valued strategies and direction along the care path.

This chapter is framed by a beautiful quote from Zelda Freitas in the first essay. Hers is both a personal and professional testimony of her role as a social worker and carer to both of her parents who have dementia. She underlines viable ways to attain balance under very trying circumstances yet recognises that *"Carers are the keepers of dignity and personhood of those living with dementia. Carers need to reap the positive benefits of caring and try to find moments of joy, laughter, and expression of love, as dementia can fade away these privileged moments on the caregiving journey."*

In her essay, Veronique Dubé discusses the important role that psychoeducation, from a person-centred and multi-component approach involving contact and validation by healthcare providers, can play in ensuring the proper education and training of carers so that they develop the necessary skills to take the best care possible of the person living with dementia – whether it be face-to-face training or web-based interventions. *"The training and support needs of carers are constantly changing throughout the person living with dementia's care path. Psychoeducational interventions, particularly tailored ones, and multicomponent interventions have been shown to have a better effect,"* explains Dubé.

Two essays in this chapter offer optimistic approaches to address carer stress and anxiety. In his essay, Pascal Antoine presents us with the concept of positive psychology" which he defines as the study of the conditions and processes that contribute to optimal development and functioning of individuals, groups, and institutions. *"To better prevent a downward spiral of the carer's health, it is necessary, in addition to protective measures against stress, to know how to support the psychological well-being of caregivers and allow them to maintain or even develop personal resources,"* writes Antoine. The benefits of meditation are

outlined in an essay by Sacha Haudry and Gaël Chételat as a promising approach to reduce depression, stress, anxiety, burden and enhance quality of life for carers.

Most people living with dementia and their carers would prefer to stay at home for as long as possible and avoid transitioning to a residential care facility. A key component to ensuring this objective is to provide the carer with much needed in-home respite, which unfortunately, is often not easily accessible or not welcomed by the carer themselves. In her essay, Sophie Vandepitte describes the many benefits and barriers to in-home respite services. *"There is clearly a need for support to alleviate the degree of exhaustion of the informal carer and to delay institutionalisation. However, to be successful these supportive services need to be as flexible as possible and suited to the specific needs of families."*

Mina and Kalpana Chandra present us with their comprehensive tele-intervention programme, launched in the wake of the COVID-19 pandemic to circumvent the effects of lockdowns and disruptions and provide continuity of care to people living with dementia and their carers. This includes a wide variety of virtual offerings such as cognitive stimulation therapy, supportive psychotherapy, grief therapy, strategies for carers, mindfulness, and yoga.

Another important psychosocial intervention is helping carers come to grips with the full spectrum of the bereavement process. This is often overlooked and can have significant emotional implications following the death of a family member. In her essay, Shelley Peacock advocates for the importance of providing as much support as possible, not only after the death of a loved one but during the illness as well.

Informal carers who responded to our survey indicated that stress was a very common factor while trying to cope with their caring responsibilities: 54% of them said they felt stress either often or all of the time, 39% said they felt stress some of the time, while only 8% of informal carers said they rarely or never felt stress.

Meanwhile, the vast majority of informal carers – 70% – responded "no" when asked whether they had been offered professional support for themselves. There was a notable gap in answers between respondents from lower- and higher-income countries, with only 22% of informal carers in lower-income countries saying they had been offered professional support, compared to 33% in higher-income countries – although the need for more support for carers is evident across the board.

## Expert essay

# Navigating the carer journey as a daughter and social worker

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## Introduction

The increase in life expectancy as well as the chronic nature of certain illnesses have prompted a growing need for more widespread support for people living with dementia. It is well established that family and friends already assume a large part of the responsibility, providing more than 80% of the care required by the elderly [1]. Their availability is a primary factor in a person's ability to remain in their own home for as long as possible. Carers are defined as family members or friends who provide care to persons with physical, cognitive, or mental health conditions, loss of autonomy, chronic or life limiting illness or disability [2]. Working carers, many of whom with a full-time job, make up approximately 56% of the carer population with many working in health and social services [3]. Years of limited home care funding, early discharges, reduced hospital stays, virtual care, and limited availability of residential housing has increased escalated care needs[4].

This essay will reflect on lessons learned at the intersection of paid and unpaid caring, as well as will impart my reflections on my experiences as a carer to my parents.

## Professional experience helped me adjust to an ever-changing carer journey

I'd like to start with a little about my own journey. I am a social worker and have spent a good part of my career aiding and supporting families and individuals living with a loss of autonomy, many of whom diagnosed with dementia. I am also a family carer. I am the primary carer within a circle of carers comprised of my siblings, with additional support from our partners and children. I have helped families who struggled with caring for their father, like mine. He was diagnosed with vascular dementia eight years ago. Other families have been faced with the physical and cognitive decline of their mother, like mine. She'd acted as dad's primary carer until about four years ago. Both now require full-time care and monitoring 24 hours a day. Both remain at home, a personal choice they conveyed, as their illnesses evolve, and their health worsens. Both are in their early 90s. After what started off as the typically slow and episodic pace of becoming a carer after an initial diagnosis, my family and I now face the wider breadth of demanding long-term care that also requires participation from public and private home care support.

Unable to separate my professional from my personal life, I have come to appreciate the expertise I've acquired – including empathy, good listening skills, problem solving,

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crisis intervention, among others. These have benefitted me greatly. In fact, health care navigation and advocacy have become invaluable skills.

Knowing the lay of the land, in this case, the healthcare system, is an invaluable asset and my first-hand knowledge proved useful to my family's situation. System navigation is key to reducing carer stress. Identifying the available resources made it easier to put needed services in place as well as educating my siblings about the condition through our local Alzheimer's Society and other community resources. Over the years, we have all learned how crucial it is to maintain a calm living environment and adhere to routines. It has taken years to get to that equilibrium. Multiple carers (some of whom may not seem familiar) can be very disruptive for everyone as it involves many people coming in and out of the home. This can contribute to increased insecurity and confusion for the person living with dementia. The nature of dementia is inherently unpredictable, and a calm environment can be threatened with volatility at any moment. For carers, this translates to an ongoing and impending sense of stress that a crisis could be near. The pandemic certainly amplified this.

Carers are the keepers of dignity and personhood for people living with dementia. When those we are caring for are sometimes treated as an illness rather than a whole person, this necessarily adds to carer strain. Common feelings of powerlessness, high levels of stress, and role conflict [5] are experienced by all carers. While the rhetoric around caregiving is to view them as partners in care, it is not always the reality. This is a major challenge in the current healthcare system.

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**“ Carers are the keepers of dignity and personhood for people living with dementia. When those we are caring for are sometimes treated as an illness rather than a whole person, this necessarily adds to carer strain.**

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## Share the care: Sibling cooperation

One of the benefits of being a carer in my situation is our family network. We have, since the start of our sibling journey, shared the care. Having spoken to many carers over the years, I realise how fortunate that there is four of us. Carers who must face caregiving alone, in conjunction with work and family responsibilities, may be confronted with heightened stress levels, and increased risks to their own health. It does indeed take a village.

Little is known about the framework of family and sibling collaboration, and how they assist one another. Caregiving outside of the carer/care recipient dyad is not well

understood [6]. It is through family care and cooperation that we have been able to maintain my parents in their own home for as long as we have. This has not always been easy. We have also been faced with our own challenges as well as differences of opinion, values, and beliefs, not to mention unique life stressors.

As professionals, we are accustomed to identifying one primary carer. In all likelihood, having one main contact person makes communication easier. That said, we need to recognise and encourage a broader care network. It is crucial to support all family members throughout the trajectory of care, which necessarily comprises multiple and compound losses [6], ongoing changes and continual planning needs.

## Finding the help – seeking out services and supports

When my father was diagnosed, my experience was much like most families. His family doctor evaluated the “patient” and then offered little follow-up support. Could this be because I worked “in the system”? Soon after the appointment, I was assigned the task of telling my father that he could no longer drive. I had to take away his car and his keys. I have had this conversation many times in my role as a social worker, but as a daughter, it was devastating. That is when the magnitude of becoming a carer and what lay ahead on this journey became real. I understood that I was not my parents' social worker, but first and foremost daughter who found herself on the receiving end of social services.

Aware of the services available, I quickly referred my siblings to carer dementia workshops, support resources and available documentation. I shared with them that being informed about the illness, how to cope with the upcoming changes as well as the need for emotional support was essential. I knew that though we fully supported each other, we also needed the guidance of external resources for the difficult road ahead.

In these conversations, I also had to persuade them of the necessity for respite and the benefits of day centres. This insight was well received as my parents respected the fact that I worked “in the system”. This implicit trust carried us through many anxious discussions about what was in their best interest. I sought to put into practice what I instructed other carers to do. I realised that this was the right approach.

Given the nature of my profession, I also possessed the health literacy to speak to health care providers, and I always appreciated how incredibly hard they worked providing care to people in their homes. I knew how to advocate for the best care that could be provided in the best way possible way. This included reducing the numbers of different people coming into the house, asking for respite hours, and developing a care plan that suited varying needs.

I appreciate that growing old at home is the best choice for my parents – an opportunity that not everyone gets. Increased government funding for increased homecare would allow those to age in place.

## Family resilience

My career has also led me through hallways of palliative care, and I have advocated for more community care over the years, I am aware of what ambiguous loss and grief looks like as we bear witness to the functional and cognitive decline of strong and resilient individuals who have played a central role in all our lives. Carers need professionals to acknowledge this grief. The emotional pain is real, and we must allow space for it.

Family caregiving tests relationships, between those being cared for and those providing the care. Using open communication to acknowledge that as individuals, we confront caregiving differently as well as recognize that we all have the capacity to learn new skills. Further, it is important to recognise the existing gaps in the system, inequities, and vulnerabilities that many families endure. In this view, carers need concerted efforts from professionals to help them maintain hope.

## Achieving work-life balance

In the literature, I am referred to as a double-duty carer [7] as I am a paid healthcare professional who simultaneously provides unpaid elder care in the community.

Balancing expected and unexpected events, along with a career and family that requires my full attention, has its challenges. I have always been capable of sustaining a very good work-life balance, but caregiving has pushed my capacity to maintain this balance. As working carers, we are constantly adjusting and making accommodations in the effort to maintain a steady foothold in all aspects of our lives as we risk experiencing compassion fatigue and neglecting self-care. It can also trigger feelings of guilt and anxiousness, feelings known all too well to carers.

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I have had the privilege in working in an environment that allowed some flexibility, and where caregiving was not stigmatised. The support of managers, colleagues, and teams are key for family members to continue to respond to the dual responsibilities of caregiving and their work. Creating a compassionate workplace culture is key to the future of homecare and carers. Caregiving is not a one-size-fits-all solution and therefore, a variety of supports should be considered. Flexibility whenever possible, resources in the workplace for supporting carers such as information sessions on aspects of care, resources, and a care navigator available to staff, self-care activities made available at lunch, among others, can go a long way in staff retention and showing meaningful appreciation towards employees and their well-being. Work flexibility is a must for carers to be able to balance all the demands on their time, both emotionally and physically.

## Conclusion

More and more healthcare professionals will become carers. Understanding this experience as a lived experience will enrich their practice and position them to provide better support for carers. Looking after someone living with dementia is a commitment that may last many years [8]. Understanding the intersection of work and family life as well as the need for having workplace programmes and policies in place will contribute substantially to mitigating the consequences to carers and their work-life balance.

Outcomes for carers are optimised when they are tailored to their unique caregiving situations by competent and caring professionals. Carers can benefit from building their support networks, exploring shared care within a variety of care resources and seek out means to cope with the stressors associated with caregiving. Just as important, they need to reap the positive benefits of caring and try to find moments of joy, laughter, and expressions of love, as dementia can fade away these privileged moments on the caregiving journey.

## Expert essay

# Psychoeducational interventions: effective and relevant interventions to support carers

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Caring for a person living with dementia has a significant impact on the carer. Although the positive impacts of caring for a family member (such as feeling useful or giving meaning to one's life) have been documented, more often than not the scientific literature has reported on the negative impacts on the physical and mental health of these carers including stress, fatigue, burden, depression, insomnia, use of medication, and poor health habits. In addition, we know that the role has many consequences on the personal, family, social and professional lives of carers (for example, reduced leisure activities, isolation, early retirement, and financial vulnerability). Given these impacts, it is hardly surprising that in its latest global action plan, the World Health Organization has made support for carers of people living with dementia one of its top public health priorities.

In recent years, several studies have examined the needs of carers of people living with dementia. Although they identified several, such as needs for information, training, support, respite care, and recognition, the preferred avenue seems to be a person-centred approach. Such an approach makes it possible to explore unique needs, reassess them, and plan the required support in partnership with the carer. A person-centred approach with a carer is even more essential considering the wide range of needs and the extended period of assistance, which often leads to the emergence of new needs. In a mixed-method systematic review, Bressan et al[1], proposed four themes for carers' needs: (1) being supported, (2) receiving and accessing information, (3) being trained and educated on how to care for people as their dementia changes, and (4) finding a balance. Accordingly, carers expressed their desire for training and support. They want to learn how to care for the person living with dementia and, in particular, develop an understanding of the condition and how it impacts the individual. They also want to develop skills related to caring for the person living with dementia and know how to maintain their abilities. On the other hand, carers also have their own needs: they want to learn how to set limits and manage their stress, as well as know more about sources of assistance (for example, available services, respite care, and financial assistance). It should

be noted that these often-interrelated needs may differ from one carer to the other and are subject to change throughout the caregiving process.

Psychoeducational interventions have been developed and evaluated to address more specifically the training and support needs expressed by carers of people living with dementia and to try to prevent some of the negative impacts of this role. In general, psychoeducational interventions are structured, and include an informational or educational component (for example, regarding the condition or the available services) along with a support component, most often with the goal of helping carers apply what they have learned (such as communication strategies with a person living with dementia) [2]. For instance, interventions may include written material (readings) and audio and/or video materials, as well as exercises or role-playing; they may be delivered or supported by a health care professional; and they may allow for discussions among the participating carers (such as a peer-to-peer discussion group). These interventions can be provided to either an individual or a group. They can be delivered in person, on the internet (synchronous or asynchronous delivery), or through some other method (over the phone or a mobile app). Some interventions may combine various approaches. Lastly, the psychoeducational interventions identified in the scientific literature vary significantly in length (e.g., one to two hours), frequency (e.g., weekly, monthly), and be given over various extended periods of time (e.g., weeks, months), and dosage [3][4][5][6][7]. However, the heterogeneous nature of these psychoeducational interventions makes them difficult to compare.

In addition, compared to face-to-face psychoeducational interventions, web-based interventions have certain advantages for carers, particularly in terms of their flexibility and accessibility. Web-based psychoeducational interventions appear to be particularly appreciated by carers who are actively employed, who have busy schedules due to their multiple roles, or who must travel a considerable distance to reach a service point [8][9]. This type of intervention also proved beneficial during the COVID-19 pandemic, when services for carers were limited due to lockdowns and social

distancing measures. Nevertheless, web-based psychoeducational interventions can complement other approaches. In this sense, some carers prefer the contact and discussions that face-to-face interventions provide, and they appreciate being able to get out of the house, since they are often held there by the intense nature of their role, which sometimes requires a continuous presence (24 hours/day). In addition, with some carers, digital literacy may be an issue. This also highlights the importance of a carer-centred approach.

Both face-to-face and web-based psychoeducational interventions have positive impacts on health outcomes and on the various quality-of-life indicators of carers of people living with dementia. In general, psychoeducational interventions have demonstrated significant effects on these carers in terms of improved knowledge; reduced stress, anxiety, and depression; and an improved sense of self-efficacy [10][11]. Some studies also tend to show potential effects of these interventions not only on the carers but also on the people living with dementia, notably on their quality of life or neuropsychiatric symptoms.

At the time of writing, it is still difficult to determine the optimal components, duration, and dosage of a psychoeducational intervention, but it appears that carers of people living with dementia value interventions that are tailored to their needs and care paths. Psychoeducational interventions that provide contact with a health professional are also appreciated for the advice, validation, feedback, and emotional

support that this professional can provide. More specifically with respect to web-based interventions, addressing issues around data security and privacy is essential if carers are to accept these interventions. Similarly, the interventions must be designed to simplify the browsing experience and help carers find the information they consider relevant.

In summary, the training and support needs of carers are constantly changing throughout the people living with dementia's care path. Psychoeducational interventions, particularly tailored ones, and multicomponent interventions have been shown to have a better effect. In this vein, there is a need for studies comparing the efficacy and cost-effectiveness of various intervention modalities. Lastly, although these psychoeducational interventions seem to be gaining ground in industrialised countries where the role of the carer is increasingly recognised, accessibility remains an issue elsewhere. This type of intervention should also be evaluated in other health systems, as disparities persist in support being provided to carers in various parts of the world. For example, it is important to examine how these psychoeducational interventions can support carers where the phenomenon of family caregiving – which is still mostly associated with women (the person living with dementia's wife, daughter, or daughter-in-law) – is not necessarily perceived as separate from other social roles. It appears essential to adapt and evaluate these interventions to different cultural and socioeconomic contexts.

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## Expert essay

# An overview of positive psychology and its relevance for carers

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Since the publication of the carer stress model [1], caregiving has effectively been regarded as a source of stress and the carer identified as a key player who is just as susceptible to the home support setting of the person living with the condition. Psychosocial support programmes are largely based on this conceptualisation and have focused on the vulnerability of carers. Meta-analyses and critical reviews suggest that the impact of these programmes on health indicators is effective but relatively limited [2], suggesting that they should be combined with other approaches. In addition, these supports tend to be time- and resource-intensive, making their availability somewhat difficult to a large population of carers.

It is certainly important to decrease the burden, reduce negative emotions, and prevent the onset of depressive disorders, but a focus on the vulnerabilities of the carer tends to sideline the positive aspects of the relationship between the carer and their family member. To better prevent a downward spiral of the carer's health, it is necessary, in addition to protective measures against stress, to know how to support their psychological well-being and allow them to maintain or even develop personal resources[3].

## Key principles of positive psychology

Carrying out controlled interventions to promote well-being and mental health has been a priority of positive psychology. Positive psychology is the study of the conditions and processes that contribute to optimal development and functioning of individuals, groups, and institutions. These interventions promote development of the individual's skills and resources while preventing the emergence of psychological disorders[4]. Optimal adaptation to life events (such as becoming a carer) requires self-regulatory strategies that engage the properties of positive emotions. According to the *Broaden-and-Build* model [5], negative emotions reduce the repertory of thoughts and actions and restrict the range of reactions to known experiences only. On the other hand, positive emotions broaden an individual's range of attention as well as their repertory of thoughts and actions. New perspectives and the innovative actions that stem from them are resources that can be implemented in the face of life

challenges. *Positive reappraisal*, which consists of considering negative events by analysing their positive components, makes it possible to trigger a positive feeling and prevent the incidence of affective disorders. Positive emotions can counter negative emotions by an *undoing effect*. Meta-analyses of positive psychology interventions have shown effects such as reduced depression or negative feelings, an increase in well-being or of positive feelings and life satisfaction [6], as well as improved physical and mental health.

## Positive psychology interventions to improve well-being in carers

Among carers, a growing body of research highlights the unique role that positive thinking and emotions play on their mental and physical health. In elderly women who were followed-up for two years, half of whom were carers, positive emotions are a predictor of lesser frailty[7]. The distress of carers can be understood as an imbalance between, on the one hand, an increase in negative emotions maintained by ruminations and, on the other hand, a reduction in positive emotions linked to the decrease in activities[8]. The number of activities has a direct and decisive influence on the positive emotions of carers, and life satisfaction is a powerful moderator of the perception of difficulties. These results suggest supporting carers' involvement in activities that contribute to their life satisfaction to protect their mental health. For this notion, the positive aspects of support are now well documented [9] and there are even dedicated measures. Helping the carer to provide meaning to their daily life and to apply their strengths to concrete actions can be an effective strategy.



**Helping the carer to provide meaning to their daily life and to apply their strengths to concrete actions can be an effective strategy.**

It is possible to draw inspiration from the many positive psychology interventions in individuals or couples in the general population, as well as interventions for people with mental or physical difficulties. Among the latter, one intervention focuses on skills to increase the frequency of positive emotions to better cope with the stress associated with caring for someone with dementia [10]. After being used in many clinical settings, its feasibility and acceptability have been successfully tested with family carers of people living with frontotemporal dementia. This multicomponent intervention (that is, based on several positive aspects) of six sessions is grounded on the teaching and daily implementation of activities allowing the development of eight emotion-regulation skills and the increase of positive emotions: noticing and getting the most out of positive events, striving to have an appreciative demeanour, training mindfulness skills, developing a positive evaluation, focusing on personal strengths, setting achievable goals, and engaging in acts of kindness. More recently, the benefits of this intervention were made available to 86 carers of people living with a neurodegenerative disease. During each individual online session, concepts were presented and discussed and daily practice exercises are provided: for example, writing down three things that went well, writing one thing for which one is grateful, practicing mindful breathing, being fully engaged in the present by doing one thing at a time, thinking about something negative that has happened and positively reassessing one's reactions, setting an achievable goal related to one's personal strengths and striving to achieve it, or performing small acts of kindness. In the immediate post-care period, and compared to

carers on the waiting list, there was a greater improvement in positive emotions and perception of the positive aspects of support among carers who underwent the intervention. The authors highlighted an improvement in mental and physical health, and it is the increase in positive emotions that would have mediated the effect of this intervention on depression.

## Future perspectives on positive psychology interventions for carers

The literature shows that a generic intervention, designed for deployment in multiple health settings, allows for clinical improvement of the participants. To optimise this efficiency, interventions will be developed that are specifically based on the experience of carers and that take into account three dimensions: the maintenance or restoration of well-being that the carer tends to neglect so as to prioritise the well-being of their family member [11], preservation of the quality of the singular bond between the carer and the person living with the condition, and identification and development of positive aspects related to caregiving situations. Multicomponent interventions, oriented toward concrete activities that are easy to introduce into a busy daily life, will have to be devised, depending on the stage of caregiving. The prospects generated by these first experiences are promising, and they will require training professionals in these approaches to allow implementation of a positive intervention in the field and complementation of existing interventions.

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## Expert essay

# The value of in-home respite care services for people with dementia and their informal carers

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## The need for in-home respite services

Informal care is a cornerstone in today's long-term care for people living with dementia. Indeed, in recent years, healthcare systems have increasingly relied on informal carers, partially because community-based informal care is considered a favourable financial solution compared to professional and especially institutional care, but also because community-based care is preferred over institutional care by the people with dementia themselves[1]. Although the latter positively influences their quality of life, informal carers often experience substantial negative health consequences from providing large amounts of care for many years[2]. In response, several supportive programmes for carers have been developed worldwide to alleviate their burden[3]. As such, in-home respite care – that allows carers to take a temporary break from caregiving while the person with dementia remains home – was often appointed as a promising strategy to alleviate carers' strain and enable them to continue to provide care[4]. However, when the informal carer needs multiple days of rest to recharge or meet other obligations, they most often must rely on temporary residential services or private agencies. Besides the problem that private services are very expensive and not widely available, they have an advantage over temporary institutional services because the people living with dementia can remain in their trusted environment. As such, two displacements and a disruption from daily routines, which often results in a temporary increase of behavioural problems of the person with dementia and additional stress for the family upon arrival home, can be avoided.

## The benefits and barriers to use in-home respite services

Substantial qualitative and, to a lesser extent, quantitative research concluded that carers are generally very satisfied with respite care. They describe benefits such as lower perceived burden, being able to perform tasks, lower stress, and that the possibility of escaping from their duties enables them to continue in their role. Some studies have concluded that in-home respite is the preferred type [5], and that carers use their respite time to catch up with routine tasks, to

attend to their own health (for example, surgery requiring the informal carer to be admitted to hospital), to attend to work obligations, to perform domestic tasks or chores, and, less frequently, for social activities[4]. Moreover, in-home respite users expressed their hope that the service would become widely available as it helps them to keep their family member at home. However, although many carers express an unmet need for respite services and multiple benefits, there is a clear underuse. This is often caused by the carer feeling guilty about leaving the person, worries about safety and quality, not accepting their own need for a temporary break, or by the affordability of and the difficult access to the respite service[6].

## The recent evidence on the impact and economic value of an in-home respite care programme

Because evidence about the effectiveness and cost-effectiveness of in-home respite care services was found to be rare, a comparative study to investigate effectiveness and cost-effectiveness of a specific in-home respite care programme to support informal carers of people living with dementia was conducted. The in-home respite service under investigation – offered by a Belgian non-profit organisation called Baluchon Alzheimer – allowed carers to take a break from caregiving for at least five days while a trained professional took over care responsibilities for the person with dementia at their home[7].

Shortly after the in-home respite period, the informal carers reported lower role strain, a decreased burden on social and family life, and a reduced desire to institutionalise the person with dementia in the next six months. After six months, the positive effect on their desire to institutionalise the person (known as a valid predictor of actual institutionalisation) with dementia remained[7].

The health-economic evaluation of this in-home respite care service indicated that the programme is likely to be a cost-effective approach compared to standard community-based dementia care only, from both the third-party payer perspective and the extended healthcare payer perspective[8].

## The future ahead

There is clearly a need for support to alleviate the level of exhaustion of the informal carer and to delay institutionalisation. Based on both qualitative and quantitative evidence, in-home respite services have the potential to address this need. However, to be successful, these supportive services need to be as flexible as possible and suited to the specific needs of families. Today, in-home respite services for a restricted number of hours are offered by multiple social care organisations on weekdays or nights, while round-the-clock 24-hour services for multiple days are not widely available nor easily accessible. As a result, informal carers often feel forced to admit the person living with dementia into a temporary residential institution or pay a high price for private services. Also, general service knowledge and the degree of professional referral based on identified needs should be improved. Finally, mutual trust and communication between

client and provider is key, and especially efforts to comfort informal carers about the quality and safety is of utter importance.

Based on the conducted comparative study and from a health-economic viewpoint, round-the-clock 24-hour in-home respite services can be designated as 'good value for money' and should be considered by policy makers for reimbursement and implementation. However, the impact on the healthcare budget and overcoming barriers needs to be considered. From a more policy-oriented viewpoint, these types of services fit within a government's vision of long-term care and correspond to the societal preference for community-based care. Even more so, use of this service could help reinforce sustainability of long-term dementia care. Meanwhile, respite service providers and policy makers need to develop strategies to improve the delivery of these services.

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## Expert essay

# Meditation to improve mental health in carers of people living with dementia: preliminary but promising evidence

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**M**editation is a generic term encompassing various forms of mental training – such as mindfulness meditation or loving-kindness and compassion meditation. Meditation involves complex emotional and attentional regulatory strategies developed for various ends, including the cultivation of well-being and emotional balance[1]. Mindfulness meditation is a practice that involves paying attention in a particular way: on purpose, in the present moment, and non-judgmentally. Loving-kindness and compassion meditation focuses on cultivating compassion for self and others[1][2]. Several mindfulness-based therapy programmes have been developed for healthcare. The most used in research are the Mindfulness-Based Stress Reduction (MBSR) program, and its adaptation for the prevention of recurrent depression the Mindfulness-Based cognitive Therapy (MBCT), which are secular eight-week standardised programmes developed by Dr Jon Kabat-Zinn[3].

Over the past 15 years, there has been an exponential increase in the number of studies on meditation due to increasing evidence of its positive effect in reducing depressive and anxiety symptoms as well as decreasing stress, improving wellbeing and quality of life[2][4][5][6][7]. Moreover, research has shown that long-term mindfulness practitioners have larger grey matter volume or attenuated atrophy in areas of the brain related to attention, introspection and memory, such as the hippocampus[4]. Meditation intervention is considered a promising approach to help prevent dementia, due to its potential to reduce the main risk factors of dementia in late life including depression, stress, anxiety as well as sleep disorders. Meditation studies in people diagnosed with Alzheimer's disease dementia are however very sparse to date, due to the difficulty in adapting the intervention for people living with dementia while accounting for their cognitive, and sometimes also behavioural, changes.

Meditation practice may also benefit informal carers of people living with dementia, defined as a close relative or friend who cares them. Family carers in general report significantly more psychological health problems, and have

higher levels of depression and stress, and lower levels of self-efficacy and subjective wellbeing than non-carer populations. Furthermore, informal carers are also affected by caregiver burden, which is conceptualised as “the extent to which carers perceived their emotional or physical health, social life, and financial status as suffering as a result of caring for their relative”[8]. Carers are also at risk for cardiovascular diseases and showed an increased prevalence of depressive and anxiety symptoms as well as suicide[5][6]. Informal dementia carers (iDC), in particular, are found to be significantly more stressed than non-dementia carers and to suffer more serious depressive symptoms and physical problems[5]. As such, meditation interventions could be very helpful in reducing these symptoms in informal dementia carers, thereby improving care, and delaying institutionalisation, for the ill family relative[5].

## Effects of meditation interventions in dementia carers: results from clinical trials

Studies that have assessed the impact of meditation training in dementia carers used various meditation approaches, including adapted mindfulness-based stress reduction (MBSR) or mindfulness-based cognitive therapy (MBCT) programmes (most frequently), transcendental meditation or Kirtan Kriya (less frequent) or compassion meditation (rarer)[2][4][6][7][9]. In most cases, MBSR/MBCT protocols were adapted by shortening the duration and number of sessions to enhance adherence for time-poor family carers[2][4][6][7][9]. Across studies, intervention effects were assessed on several distinct health outcomes, most frequently on self-reported assessments of depression, stress, burden, quality of life and anxiety[2][4][6][7][9]. Studies described below include both longitudinal clinical trials comparing data in informal dementia carers before and after a meditation intervention, and cross-sectional comparisons of data in informal dementia carers after a meditation training versus after another intervention or informal dementia carers who'd had no intervention. Among these studies, about 2/3 are randomised controlled trials (RCT)[2][4][6][7][9].

Meditation intervention in informal dementia carers were revealed to be feasible and show high overall acceptability with low attrition rates (from 0 to 33% across studies)[2][4][6][7].

Among the multitude of significant effects reported, the most evidence supported the effectiveness of meditation intervention in reducing depression[2][4][6][7][9]. A possible mechanism is that mindfulness can help carers observe their thoughts and feelings from a distance, without judging them to be good or bad, but simply accepting what they are, thus minimising their ruminations and depressive symptoms[10].

Several studies have also shown a reduction of stress and carer burden through meditation practice in dementia carers[2][4][6]. Indeed, 10 studies have shown reduced stress (eight randomised controlled trials) and eight detailed a reduction in burden (four randomised controlled trials). In contrast, very few studies reported no effect of meditation on these health outcomes[2][6][9].

Some studies have assessed the impact of meditation interventions on anxiety, and/or quality of life (9 and 10 studies, respectively) and findings are more conflicting. Six studies (four randomised controlled trials) showed a positive effect, that is, reduced anxiety and improved quality of life[2][4][6], while four studies for anxiety (one randomised controlled trial) and five studies for quality of life (two randomised controlled trials) showed no significant effect of meditation on these health outcomes[7][10].

Studies including other outcomes, such as those related to the brain, are rarer. One study indicated increased connectivity in the meditation group between the dorsolateral prefrontal cortex network and a network thought to be involved in emotion regulation[11]. Another study reported both decreased and increased regional glucose metabolism measured with FDG-PET in brain areas involved in response inhibition and task switching; skills that informal dementia carers need to use on a daily basis[2]. One study also reported that meditation improved diurnal cortisol slope, a physiological measure of stress, in internally directed cognition, suggesting normalisation of HPA axis (hypothalamic-pituitary-adrenal) function in this at-risk population[2][4][9]. Finally, some studies also investigated cognition and they usually showed a positive effect of meditation on memory and attention in internally directed cognition[2][4][6][7][9].

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Other non-pharmacological approaches have been assessed in dementia carers, including psychoeducation, psychotherapy, and multicomponent intervention, showing overall small to moderate effects on dementia carer burden, depression, and general health. There are discrepant findings on whether meditation is more effective than these other approaches. Thus, studies comparing meditation to an active control showed more conflicting findings than compared to a passive control. Moreover, in two reviews[2][6] meditation was shown to be more effective than other interventions on stress (7 studies), depression (4), anxiety (1), quality of life (1) and burden (1) while one meta-analysis found that meditation was superior than other interventions only in depression, while being less effective than acceptance and commitment therapy and behavioural activation[9]. Moreover, other studies showed no evidence of differences between the interventions[2][6].

The greatest evidence for a positive effect of meditation is on depression, significant but less evidence on stress, anxiety, carer burden and quality of life, and sparser evidence still on other outcomes such as brain integrity, cortisol level and cognition. Despite being overall encouraging, these findings should be interpreted with caution. While a majority of studies are randomised controlled trials, they are most often judged to have moderate to high risk of bias, have a small sample size (22 studies with  $n < 40$  carers), include a very limited number of outcomes, use subjective (self-reported) outcome measures, only short-term programmes were assessed, and blinding of participants is not possible given the nature of the intervention.

## Future directions

Future research should aim to assess a more thorough combination of measures, including more objective measures, such as physiological, cognitive and brain health outcomes. Assessment of both short-term and long-term effects are necessary to appraise possible sustained effects of meditation. Studies have started to evaluate the impact of meditation interventions delivered remotely (using phone, internet, or applications). While interesting given the practical challenges for internally directed cognition in attending face-to-face sessions, effectiveness and acceptability would have to be reviewed with caution as the in-person interactions with the meditation teacher might be a relevant component of the intervention. Additionally, adverse effects of meditation interventions in internally directed cognition still need to be investigated.

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## Expert essay

# Tele-interventions in dementia care: lessons from the COVID-19 pandemic

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## Introduction

The onset of the COVID-19 pandemic was accompanied by lockdowns and disruptions in service delivery, especially for high-risk groups such as people living with dementia[1]. These unplanned upheavals provided an opportunity for expanding dementia care services for them and their carers by incorporating virtual platforms. Accordingly, virtual or tele-interventions were developed and implemented for these individuals and their carers when referred from primary care services (Chandra K) for treatment in the Centre of Excellence in Mental Health at our institute. A summary is presented below.

## Classification of tele-interventions in dementia care

Dementia care tele interventions can be broadly classified as

1. Individual vs group interventions
2. People living with dementia centric interventions vs carer centric interventions

## Types of tele-interventions in dementia care

Virtual tele-interventions were developed to ensure continuity of care for people living with dementia and carers already enrolled in individual or group therapy.

Hindi versions, culturally validated for north Indian population, had already been developed at our institute for many evidence-based dementia specific interventions prior to the COVID-19 pandemic. Manuals were created for each session of the virtual versions of these therapies. The structured interventions offered included live sessions with a trained therapist, sharing of animations, audio recordings and video recordings. The platforms utilised for virtual therapies were telephone calls, Zoom, Google Meet and WhatsApp sharing/ video calling.

All people living with dementia were staying in the community with their families, as is the norm in the South Asian cultural context. One familial carer was involved as co-therapist for the virtual sessions and trained prior to the onset of therapy with a booster focused session prior to each session with people living with dementia.

With the initial positive feedback from therapists and clients about feasibility, acceptability and effectiveness, virtual options were subsequently offered to people living with dementia carers as standard of care along with pharmacotherapy.

The various interventions offered were as follows (Figure 1):

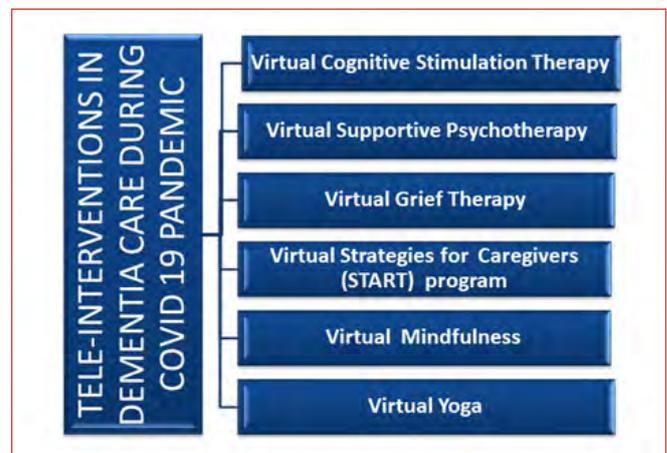


Figure 1. Tele-interventions in Dementia Care during COVID-19 Pandemic: ABVIMS-RMLH Experience

- **Virtual Cognitive Stimulation Therapy (vCST):** This was comprised of 14 sessions focusing on various cognitive domains[2]. A vCST manual was prepared and considered the potential translation of sessions to virtual platform with a remote therapist providing guidance through each session. The person living with dementia and carer were informed in advance about the requirements for the next session, such as stationery and

colouring pens for drawing childhood related events for the session entitled “Childhood”, different food items for tasting for the session entitled “Food”.

- **Supportive psychotherapy for people living with dementia and carers:** [3] People living with dementia were distressed by the COVID-19 pandemic and its ensuing lockdowns, continuous need for precautions such as masks and sanitisers, lockdown related issues like difficulty accessing medical facilities, sudden unemployment of offspring, among others. Virtual supportive psychotherapy sessions with trained therapists allowed them to vent, receive reassurance and learn relaxation techniques.
- **Grief therapy for people living with dementia and carers:** [4] Many people living with dementia and carers lost significant others to COVID-19 including family members, close friends, and neighbours, some of whom they had not seen since the start of the pandemic due to travel restrictions. The limitations imposed on attending funerals and memorial services resulted in many individuals unable to get closure for their grief. Individual and group virtual grief therapy with a trained therapist was offered to people living with dementia and carers to address the issues of grief, loneliness, guilt, and regret associated with the death of loved ones and missing last rites.
- **Virtual Strategies for Caregivers programme (vSTART):** [5] This manualised eight-session programme aims to empower carers of people living with dementia by demonstrating determinants of behaviour and strategies to address problem behaviour, thought and mood. The vSTART programme was offered to carers as complementary sessions to the vCST programme.
- **Mindfulness:** This concept has been successfully used in dementia to address depression, anxiety, and insomnia. [6,7] A mindfulness module, comprising of thought awareness, body scan, loving, kindness, compassion, and gratitude exercises, had already been created for depressed diabetics at our centre with a written script, audio recording in Hindi and English and animation videos[8]. The same modules were shared with people living with dementia and carers on WhatsApp with a therapist providing guidance about the process before the session and being available for queries and feedback after the session.
- **Yoga intervention:** Yoga has been used as an adjunct intervention in people living with dementia for addressing cognitive symptoms, neuropsychiatric symptoms, activities of daily living and quality of life[9]. People living with dementia were facilitated through a yoga programme by sharing practice videos created by the Centre Council for Yoga and Naturopathy on WhatsApp[10].

## Initial feedback

The tele-interventions generated favourable feedback regarding convenience, ease of access, affordability (all sessions were free of charge), timing flexibility, decreased need to travel and other logistics. Involving a family carer virtually as co-therapist helped in skill building as compared to conventional in-person sessions which certain carers could never attend. Both people living with dementia and their carers reported reduced social isolation and increased camaraderie after attending group therapy sessions, especially during lockdowns.

## Challenges

There were several challenges in the expansion of tele-interventions for dementia care. These included issues relating to a lack of logistics and infrastructure to support virtual connectivity especially in lower- and middle-income countries/ low-income countries (LMICs/LICs). At the same time, the target population may have low levels of digital literacy and awareness or may not accept tele-interventions as valid interventions.

People living with dementia and carers interested in virtual therapy had no access to virtual dementia specific intervention platforms. In contrast, service providers faced difficulty in reaching out to people living with dementia /carers for tele-interventions especially during lockdowns which was addressed through virtual awareness drives disseminated on social media and through word of mouth.

## Possibilities

There is a huge treatment gap in dementia care in large parts of the world, including India and other LMICs/LICs. Tele-interventions can provide affordable and accessible dementia-specific interventions in regions of the world having moderate to high internet connectivity and at least mobile phone device availability.

## Conclusion

COVID-19 provided the impetus to expand the use of tele-medicine in dementia care. Tele-interventions can provide affordable and accessible culturally validated care packages for people living with dementia and their carers. Tele-interventions can reduce cost, decrease the burden on tertiary care facilities and enhance health equity for these individuals. At the same time, capacity building of researchers and students is required by training them for virtual interventions with periodic fidelity assessments.

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PART I

PART II

PART III

PART IV

PART V

PART VI

PART VII

PART VIII

## Expert essay

# The need for psychosocial bereavement interventions for family carers of people with dementia

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The experiences and consequences of family carers when providing care to a relative with dementia has been well-researched, albeit less so for end-of-life and post-death bereavement periods[1]. Moreover, effective psychosocial interventions have been developed and implemented to support these carers while tending to a relative with dementia [2], yet they are also in need of supportive psychosocial interventions once the active caregiving ceases upon the death of their family member. Researchers are beginning to examine the bereavement period and develop psychosocial interventions to support carers who have experienced the death of their relative with dementia; however, far more remains to be done.

## The bereavement experience

Many factors influence the bereavement experience for family carers, including, but not limited to the carer's: gender or age; socioeconomic status; relationship to their relative with dementia; length of time caregiving; pre-death grieving; or the location of death (for example, at home in the community, in a long-term care home, or in hospital) [3]. Research that examines the experience of bereavement for family carers of people living with dementia largely focuses on two main areas: (a) grief and (b) depressive symptoms.

The multiplicity of losses, before, during end of life, and after the death of their relative has been acknowledged as characteristic of caregiving in dementia because of the progressive nature of the condition and how it psychologically "steals" the person away[4]. As a result, the experience of grief begins before the physical death of their relative with dementia and extends well into the period of bereavement [3]. Peacock, Hammond-Collins and Forbes [5] found that bereaved family carers experienced post-death grief that changed over time, first in relation to grieving the relative they cared for to eventually grieving who the person was before dementia changed them (for example, their parent while they were growing up or the person they married). It is important to note that grief is a normal and expected

reaction to the death of a relative; still additional work is required to identify those carers who experience a complicated grief process that requires support[6].

There is ample evidence that indicates bereaved family carers of a relative with dementia experience depressive symptoms [4] that are often closely intertwined to post-death grief[6]. Some studies indicate when bereaved carers are compared to non-carer groups that they experience significant depressive symptoms that can last months or years after the death of their relative [7]; while other studies have found that bereaved family carers experience minimal depressive symptoms [8]. Presentation of depressive symptoms is immensely complex, and it is probable that multiple trajectories and responses to a relative's death exist (and that go beyond the scope of this essay). It is evident that carers of a relative with dementia do not have uniform emotional responses to bereavement.

Given the significance of the experiences of grief and depressive symptoms in the bereavement period, psychosocial interventions for family carers need to address these consequences. Supportive psychosocial interventions may assist bereaved carers to navigate their grief and manage their depressive symptoms. Of note, it may be beneficial to initiate bereavement interventions prior to a relative's death and continue thereafter to enhance positive outcomes in the bereavement experience[4]. While no doubt psychosocial bereavement interventions exist, there is a lack of rigorously evaluated interventions available in the research literature[9].

## Example of a bereavement intervention

The *Reclaiming Yourself* tool[10] was developed with bereaved carers to address the gap in bereavement support for spousal carers of people with dementia[11]. The *Reclaiming Yourself* tool is a self-directed writing-based psychosocial intervention, designed to encourage and guide users to reflect on their past, present, and future experiences by engaging in exercises focused on (a) *Deep Grieving*, (b) *Embracing Self*, and

(c) *Moving Forward*. The tool is structured to aid spousal carers to work through many of their complex feelings and help them navigate their bereavement. Indeed, during a pilot of the tool, spousal carers shared that the tool provided a way to express their complex emotions and facilitated reflection to make meaning of their post-death grief [11]. Extending the use of the tool within a bereavement support group setting might also be beneficial as this would provide another way for them to grapple with their grief with others who have had a similar experience.

## Looking ahead

Once a relative with dementia passes away, the carer in question will need support. The various caring trajectories create unique bereavement experiences. For instance, a spouse and an adult child will necessarily be impacted differently. Thus, different psychosocial interventions to address each one and aid carers in navigating their bereavement are required.

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That said, future research is necessary to better understand the full scope of bereavement to further develop these interventions and address the diverse contexts family carers find themselves in. This could range from relatives with young-onset dementia or those who live in long-term care facilities. What fundamentally matters are that these interventions be empirically evaluated for their impact on articulating positive outcomes in bereavement. This would allow carers to benefit from strategies aimed at: understanding their grief; managing their emotions associated with depressive symptoms; thinking ahead to the future as their role as carer has ended; returning to previous relationships; reflecting on the *story* of their carer journey; and finally connecting to the memories of their relative – both before and after dementia became part of their lives.

## Conclusion

Understanding how to navigate the journey of looking after a person living with dementia while ensuring one's own health and well-being is a very complex matter. As the condition evolves, so does the person with dementia's dependence on the carer to meet their daily needs. This often means the carer has less time to devote to their own. Feelings of guilt, sadness, anger, and grief are intrinsically tied to the emotional rollercoaster that carers are on, and these are heavy burdens to carry on a regular basis. Thus, it is essential that clinicians and other healthcare providers incorporate psychosocial and psychoeducational interventions, including home care support and respite, from the moment a diagnosis is rendered. Most importantly, these interventions should take a person-centred approach that respects, among others, the individual's needs, beliefs, culture, family and work obligations, financial capacity, and health literacy.

In order to ensure a person living with dementia's highest quality of care and safety, carers need and deserve to have all the necessary resources made available to them in terms of services, education, training, and support. Consider this intertwined and irrefutable reality: There is no current cure for dementia and most people are being cared for at home. Governments around the world must take a much closer look at possible methods and means to offer carers additional help, so they may ensure a dignified level of care. Some initial progress has been made with pilot face-to-face and web-based psychoeducational interventions as described in this chapter, but more work is needed to continue these types of initiatives to ward off harmful reactions and bolster feelings of self-sufficiency over the long run.

# **Part V**

Current and future  
pharmacological  
interventions in dementia

# Chapter 17

## Symptomatic drugs

*Serge Gauthier, Pedro Rosa-Neto*

### Key points

- Better symptomatic medications remain an unmet need in dementia.
- No new drug has been introduced in the last 20 years to alleviate the symptoms of dementia.
- There are various drug classes available to treat some, but not all, of the symptoms associated with the various dementias.
- The strongest available evidence is for acetylcholinesterase inhibitors (donepezil, rivastigmine, galantamine) and for NMDA-receptor partial antagonist memantine.
- There is equivocal evidence for benefit from antidepressants.
- There is weak evidence of benefit for some antipsychotics, and their use must be weighed against possible harm.



## General background

The drugs currently available to treat many of the symptoms associated with dementia are working through increasing levels of activity of some brain neurotransmitters such as acetylcholine, serotonin, and noradrenaline, or through reducing activity of other neurotransmitters such as glutamate and dopamine. A list of the most commonly used drugs is found in Table 1. These interventions have been recommended by numerous clinical consensus meetings[1–5].

Table 1

| Examples of current symptomatic drugs by category   |
|---|
| Acetylcholine enhancement through acetylcholinesterase inhibition: donepezil, rivastigmine, galantamine |
| Glutamate NMDA receptors modulation: memantine  |
| Serotonin Selective Reuptake Inhibitors: citalopram, escitalopram, sertraline                           |
| Selective Noradrenaline Reuptake Inhibitor: venlafaxine, desvenlafaxine                                 |
| Dopamine antagonists: risperidone, aripiprazole, olanzapine   |

The side effects of these drugs are well known, and their medical and economic impact has been demonstrated. Some of these drugs are available for medical conditions other than dementia (such as depression and psychosis), and some were developed primarily for Alzheimer's disease, such as the acetylcholinesterase inhibitors [AChE(-)] (Figure 1) and memantine (Figure 2). The efficacy and safety of these drugs has been studied through randomised clinical trials (RCTs) with different doses of the active drug compared to placebo or to another drug (usually a standard-of-care, for example, a drug already in use). This type of RCT is called a *parallel design* RCT.

Figure 1 represents the fibres that produce acetylcholine in the brain overlaid in a Magnetic Resonance Imaging. Red indicates normal brain concentrations of acetylcholine (top). Reduced brain levels of acetylcholine present in Alzheimer's disease (middle) are rectified by the administration of cholinesterase inhibitors (bottom). Cholinesterase inhibitors work by reducing its natural degradation in the brain by the enzyme acetyl cholinesterase.

Figure 2 represents brain connections that produce glutamate in the brain overlaid in a Magnetic Resonance Imaging (MRI). Purple and green indicate normal activity of glutamate (top). In patients with dementia, glutamate

### Cholinergic deficits in Alzheimer's disease

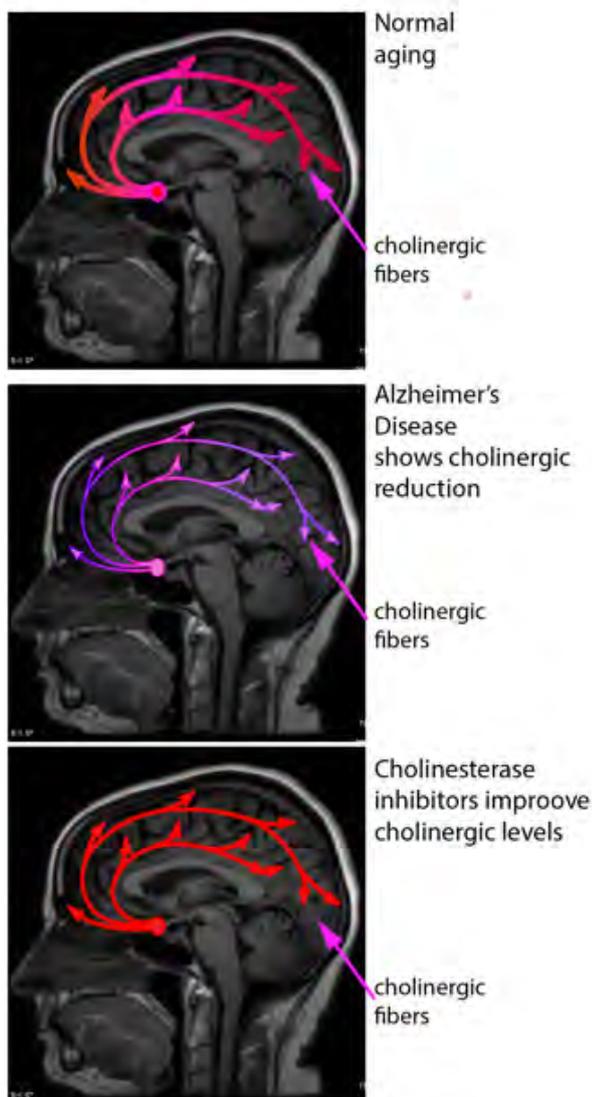


Figure 1

becomes overactive in the brain (middle). Memantine rectifies glutamate overactivity by mitigating excessive glutamate actions in a specific site called N-methyl-D-aspartic acid or N-methyl-D-aspartate receptor (bottom). The result is an improvement of the abnormal glutamate activity in the brain present in Alzheimer's disease.

Memantine is a low- to moderate-affinity not competitive N-methyl-D-aspartic acid (NMDA) receptor antagonist that has been approved for use in the treatment of moderate to advanced dementia. Memantine compensates abnormal glutamate neurotransmission rather than slowing down or reversing Alzheimer's disease pathophysiology[1].

One particular issue encountered in the treatment of symptoms associated with dementia is that they often improve on their own over time. This is particularly true for neuropsychiatric symptoms (NPS) such as depression.

### Glutamate overactivity in Alzheimer's disease

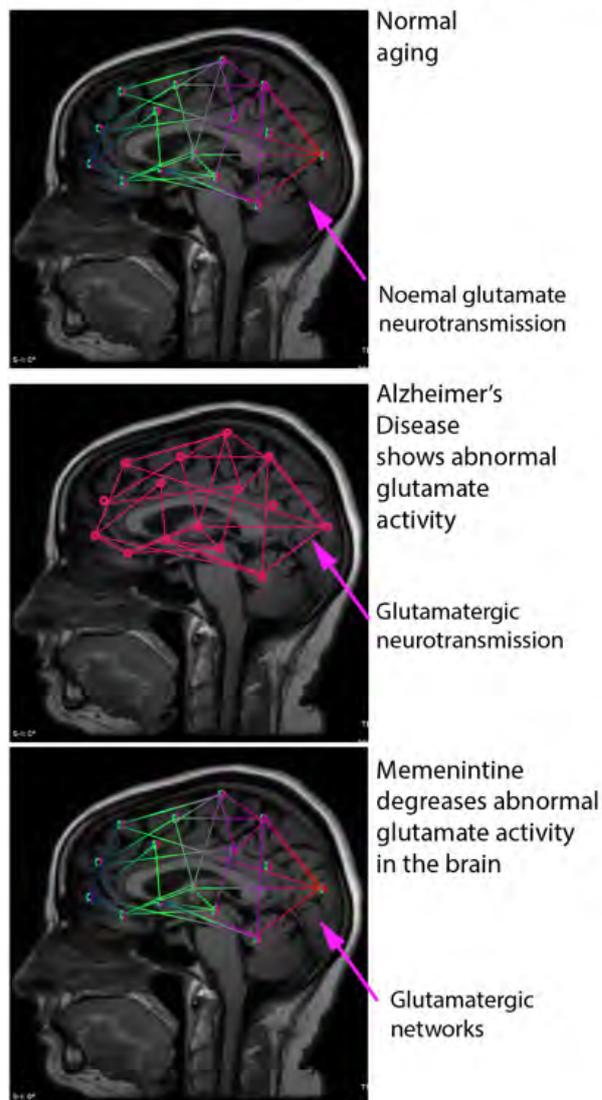


Figure 2

The other issue is that some NPS such as agitation may be caused by factors other than dementia, such as pain. These issues are discussed in the essays by Drs Herrmann and Ballard. We are still learning how best to prove the efficacy of medications for specific symptoms, such as apathy, requiring research diagnostic criteria for testing the right drug for the right symptom.

Another issue is whether a combination of symptomatic drugs is more useful in treating symptoms associated with dementia. It is logical based on the experience gained with other common conditions ranging from diabetes to arterial hypertension, bipolar disorders, and schizophrenia. But attempts to demonstrate synergism (interaction between two drugs that causes the total effect of the drugs to be greater than the sum of the individual effects of each drug) have proven difficult so far, possibly because of a reluctance to use a *factorial design* for a RCT where placebo/

placebo is compared to drug 1/placebo, drug 2/placebo, and drug1/drug 2. We do have some evidence for additive benefit from RCTs where memantine or placebo is added to donepezil, using the *add-on design*[5].

It is also important to personalise dementia symptomatic therapeutics considering patient's comorbidities and their respective therapies. Effects on cardiac function, drug elimination, and other interactions should be assessed case by case.

The development of AchE(-) as specific treatment for dementias such as Alzheimer's disease, Parkinson's disease dementia and dementia with Lewy bodies is of great interest, as summarised in the essay by Dubois. Acetylcholine enhancement was modelled on the successful strategy of dopamine enhancement for Parkinson's disease. Although the effect size or visible clinical improvement from neurotransmitter enhancement is not as striking in dementia as it is in Parkinson's disease, there are clear benefits noticed by the person living with dementia, their families, and their doctors that justify their use. Side effects are predictable and easy to manage by dose reduction or

slower titration. This being said, there is a trend to reduce the number of drugs given to elderly persons and it is appropriate to question the benefit of all drugs as the dementia progresses through moderate and advanced stages. Discontinuation protocols have been proposed to establish if AchE(-) are still useful after prolonged use.

Survey results among people living with dementia for prescription of AchE(-) and/or memantine at the time of disclosure of diagnosis indicate a discrepancy between lower- and higher-income countries (65% versus 47% as far as responses from people with dementia, 70% versus 59% as far as informal carers answered), possibly explained by a more reserved approach to the use of such drugs in higher-income countries, with a higher percentage of persons being referred to their Alzheimer or dementia association before prescribing these symptomatic drugs.

The present pharmacological armamentarium for dementia symptoms has remained the same for nearly three decades and urgently needs innovations to alleviate the cognitive and behavioural symptoms associated with dementia.

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## Expert essay

# Are cholinesterase inhibitors clinically useful and safe in the treatment of dementia?

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**T**he cholinergic adventure. Everything started with the discovery of a significant decrease in cholinergic innervation (nerve terminals using acetylcholine) of the cerebral cortex of people with Alzheimer's disease[1]. This was partially explained by a reduction of more than 75% of cholinergic neurons in the Nucleus Basalis of Meynert[2]. The link between the acetylcholine neurotransmitter and memory was already known at that time: the experimental blocking of acetylcholine receptors by scopolamine induces deep disturbances in tests exploring memory in animals. In humans, atropine, a drug that also blocks acetylcholine receptors, was known to promote the onset of a confusional state. Two American researchers, David Drachman and Jane Leavitt, showed in 1974 that the administration in humans of a cholinergic antagonist resulted in cognitive symptoms fairly comparable to those observed in elderly subjects or in persons with Alzheimer's disease[3]. Based on these neuropathological and clinical pharmacological arguments, "the cholinergic hypothesis of Alzheimer's disease" was put forward: cognitive symptoms associated with the condition result from dysfunction of the cholinergic system, and increasing cholinergic activity by pharmacological means would improve symptoms. This very reductive approach found its basis by an analogy to the dopaminergic deficit of Parkinson's disease: the hope was to duplicate with acetylcholine enhancement in the cognitive domain, the improvement observed on the motor deficits of parkinsonian patients after the normalisation of dopaminergic transmission using levodopa.

On November 13, 1986, this hope was reinforced by the publication of an article by William Summers and colleagues in the prestigious New England Journal of Medicine[4], where the authors reported a dramatic effect of oral intake of tetrahydroaminoacridine or tacrine (THA), a molecule that prevents the degradation of acetylcholine by blocking the enzyme acetylcholinesterase. The class of drugs that block this enzyme, acetylcholinesterase inhibitors or AchE(-) do increase the concentration of acetylcholine in the synaptic cleft and thus prolong its duration of action, especially in the

brain. The publication by Summers was widely discussed, gave support to the cholinergic hypothesis, and stimulated research on this drug class.

*The AchE(-) currently in use.* There are three AchE(-) that have been approved by regulatory agencies such as the US Food and Drug Administration (FDA) and the European Medicines Agency (EMA). They are used in more than 60 countries for the treatment of mild-to-advanced stages of Alzheimer's disease. These are donepezil, rivastigmine, and galantamine:[5]

- *Donepezil* is a selective, reversible inhibitor, with a half-life of 70 hours, allowing only one dose per day. The medication is available in 5 and 10 mg tablets. Treatment is usually initiated at the dose of 5 mg daily for 1 month, to be increased to 10 mg thereafter. At the 10 mg dose, there may be an improvement in cognition and function. Side effects are mainly gastrointestinal and cardiovascular[6].
- *Rivastigmine* was initially available in oral form. Treatment is initiated at 1.5 mg twice a day and gradually increases to 6 mg twice a day. Side effects, linked to cholinergic action, can be reduced by the use of the transdermal patch[7].
- *Galantamine* is a selective, competitive, and rapidly reversible inhibitor, also acting on nicotinic receptors[8]. It is usually initiated at the dose of 4 mg twice a day to be gradually increased to 12 mg twice a day. Side effects are comparable to the other AchE(-).

Of note, Tacrine, the first AchE(-) approved for the treatment of Alzheimer's disease in 1993 in some countries, was discontinued due to a high incidence of side effects, including hepatotoxicity[9].

*The balance sheet for benefits versus risks.* In general, the therapeutic effects of donepezil, rivastigmine, and galantamine are fairly comparable. Their effectiveness is considered modest

and temporary and needs to be regularly re-evaluated. That said, all AchE(-) drugs have demonstrated symptomatic benefits in rigorous double-blind placebo-controlled randomised clinical trials (RCTs). Effects on cognition have been demonstrated using the Alzheimer's Disease Assessment Scale–Cognitive Subscale (ADAS-Cog), a composite scale which evaluates performance in several domains (verbal episodic memory, naming, comprehension of orders, word recognition, orientation, praxis) and on activities of daily living, particularly in initiation and planning of instrumental activities. The clinical impression is that of a modest but global attentional and cognitive awakening effect that impacts the various domains studied more than a specific effect on a given domain. Based on the study populations where most of these RCTs took place, these drugs are authorized primarily in mild to advanced stages of dementia.

Stimulation of the cholinergic receptors is also noted at the level of the peripheral nervous system, which is at the origin of many of the side effects: slowing of the heart rate and syncope, and increase of intestinal peristalsis, responsible for diarrhoea and/or nausea that can lead to anorexia and long-term weight loss. These side effects justify prescribing these drugs in progressive doses, checking for the absence of cardiac contraindications with an electrocardiogram in case of unexplained syncope, and limiting their prescription in much older people.

The benefit/risk ratio is, however, still being debated, which explains why some countries, notably France, have chosen not to allow their reimbursement by the public health sector. Other countries or jurisdictions request that their benefit be regularly reviewed to maintain their renewal. That said, with

careful control of the conditions of their prescription, these drugs can have a significant beneficial effect, and I consider that there is a lost opportunity to help in not proposing such drugs to people with Alzheimer's disease. The symptomatic effect of these drugs is at times confirmed by the observation of clinical worsening after washout observed in clinical trials or in clinical practice when stopped abruptly. In addition, follow-up analyses of treated patients suggest the existence of a long-term stabilising effect that may reduce the rate of institutionalisation (DOMINO study). [10] These data are consistent with clinical impression and are supported by a 43% reduction in hippocampal atrophy in patients treated with donepezil in a double-blind placebo-controlled RCT [11].

Evidence of a comparable reduction of acetylcholine levels in the cerebral cortex of patients with Parkinson's disease dementia (PDD) or with dementia with Lewy bodies (DLB) explains the positive results in RCTs with AchE(-) performed in these conditions. The effect seen clinically is at times larger than in Alzheimer's disease, possibly due to the fact that there are significantly fewer lesions of cortical neurons in PDD and DLB, which make the correction of the cholinergic deficit more clinically effective. Based on these positive results, AchE(-) have been approved for use in PDD and DLB in many jurisdictions.

To conclude, AchE(-), although derived from different chemical structures, have in common to be reversible enzyme inhibitors, to have a globally comparable efficacy, a same indication for use in mild to advanced stages of Alzheimer's disease, and have a superposable profile of side effects.

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## Expert essay

# Why is it so hard to demonstrate benefit from antidepressant drugs in dementia?

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Depressive symptoms and syndromes in Alzheimer's disease and other dementias are common, serious problems that impair quality of life for both the people living with dementia and carers, and are associated with other adverse outcomes including increased risk of mortality and increased risk of institutionalisation. They were also among the first neuropsychiatric symptoms (NPS) to be studied systematically, by examining prevalence, neuropathological and neuroimaging correlates, and treatment. Beginning with the first randomised placebo-controlled trial (RCT) of an antidepressant for depression in patients with Alzheimer's disease in 1989, a problematic signal was already detected. In that study by Reifler et al [1] imipramine, a tricyclic antidepressant, was compared to placebo in 28 patients with at least mild to moderate depressive symptoms as rated by the Hamilton Depression Rating Scale. Results clearly demonstrated a significant improvement in depressive symptoms over the course of the study, with both imipramine and placebo treated patients improving in exactly the same way. By the time my research group reviewed the RCT literature in 2007, there were already five of 13 published RCTs that we could include in a meta-analysis, suggesting that antidepressants (including tricyclic antidepressants and selective serotonin reuptake inhibitors) were better than placebo for both response and remission, with numbers needed to treat that would have been similar to those of antidepressant use in cognitively normal elderly patients[2]. Unfortunately, shortly after this publication, two of the largest and most rigorous studies of antidepressant use in Alzheimer patients were published with sertraline and mirtazapine, once again demonstrating that depressive symptoms appeared highly treatable, but that there was no significant difference in response rates between antidepressant and placebo treated patients[3,4]. In the latest Cochrane Review from 2018, 10 studies with over 1,500 patients could be included, and the authors concluded that antidepressants demonstrated "little or no effect"[5]. So, after 30 years, dozens of studies, and thousands of patients, it is important to think about why it has been so hard to demonstrate antidepressant efficacy.

*Depression in Alzheimer's disease (DAD) is not similar to Major Depressive Disorder (MDD):* Just because depression in Alzheimer's disease can present with depressed mood and

anhedonia, this doesn't mean that it shares the same biological substrate as MDD. While some studies have suggested similar neuroimaging correlates, there are also differences in neuropathological correlates including Aβ and tau accumulation as well as white matter vascular changes[6]. Thus even though the phenomenology of DAD and MDD overlap, they are not the same, with more irritability and less pervasiveness of symptomatology in DAD. This has led to the proposal for specific diagnostic criteria for DAD[7]. Perhaps most problematic in terms of the differences which might impact clinical trial outcome, the course of DAD might be different for many patients. While inconsistent, many studies have shown that DAD is not persistent and might remit spontaneously after several months[6].

*DAD is not depression – it's apathy:* Recent research has suggested that while there is overlap of symptoms and correlates, apathy syndromes in Alzheimer's disease are very common, and have very different biological correlates and even worse effects on clinical outcomes compared to depression[8]. Apathy in Alzheimer's disease might also be worsened by some antidepressants like SSRIs, and by contrast, might respond to different pharmacological interventions like psychostimulants[9].

*DAD responds strongly to psychosocial interventions:* While more high-quality RCTs are required, it has been demonstrated that many types of non-pharmacological interventions can improve depressive symptoms and syndromes in DAD[10]. Many authors of the negative antidepressant RCTs refer to this possibility, especially since most of the pharmacological trials for NPS now include non-pharmacological interventions for the caregiver, while the patient in a clinical trial benefits from the Hawthorne effect and increased stimulation.

This discussion focused on the challenge of demonstrating efficacy of antidepressants in patients with DAD but could just as easily have applied to studies of pharmacological interventions of agitation, aggression, psychosis, and other NPS in dementia, which have also struggled to demonstrate benefit beyond placebo. However, the search for the most effective treatments for DAD must persist as

it has been clearly shown that improvement in depressive symptoms benefits not only the patient, but also the carer. Future research must pay particular attention to the potential adverse effects of antidepressants in this elderly patient

population, including effects on cognition, gait and stability, cardiac effects, and hyponatremia. Finally, while it is still possible that pharmacological interventions will be proven to be helpful for DAD.

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## Expert essay

# Do we need antipsychotics in dementia care?

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The use of antipsychotics for the treatment of neuropsychiatric symptoms (NPS) such as agitation, aggression, and psychosis in people with Alzheimer's disease and other dementias remains controversial. While NPS are almost universal over the course of dementia and can result in significant distress and major detrimental impacts for both those living with dementia and their carers, many would argue that the adverse effects of antipsychotics are worse than the symptoms for which they are prescribed.

So firstly, what is the evidence for the benefits and harms of antipsychotics in the treatment of NPS in people living with dementia? A number of systematic reviews have analysed the clinical effectiveness of antipsychotics in people living with dementia, most focusing on all or a sub-set of the 18 placebo-controlled randomised clinical trials (RCTs) of atypical antipsychotics, conducted over 10–13 weeks. Many of these trials have not been published in full and the evidence base is best understood for risperidone, with five fully published good quality RCTs including more than 1,500 participants[1,2]. A meta-analysis of the efficacy results indicated a small, but significant advantage for risperidone in the treatment of aggression on the BEHAVE-AD rating scale ( $-1.5$  points 95% confidence interval  $-2.05$  to  $-0.95$ ) at 2 mg risperidone. Effectiveness is even more limited for the treatment of psychosis, with no benefit at 2 mg and a Cohen's *d* effect size of less than 0.2 (below the usual threshold for a small effect size) at a 1 mg dose. For both the treatment of aggression and psychosis this in the context of a high placebo response rate, indicating that probably only about 10% of participants directly benefited from risperidone treatment[1,2]. The evidence is less complete but indicates a similar level of benefit for olanzapine, aripiprazole, and potentially for brexpiprazole [3] based on more recently emerging data. The clinical trial evidence, however, suggests that quetiapine does not confer benefits in the treatment of agitation, aggression, or psychosis in persons with Alzheimer's disease[4].

The modest clinical benefits must be balanced against the risk of potential harms. A systematic review of 15 RCTs of antipsychotics in persons with Alzheimer's identified a significant 1.5-fold increase in mortality compared to placebo over 10–13 weeks[5]. A subsequent 12-month double blind RCT examined antipsychotic discontinuation in people with

Alzheimer's disease, with follow-up of participants for up to five years, reported a similar 1.8-fold increase in mortality risk for people continuing to take antipsychotics, highlighting a sustained risk of increased mortality with ongoing prescriptions[6]. Meta-analyses of RCTs have also established a number of other adverse events associated with antipsychotic prescriptions in persons with Alzheimer's, including a three-fold increased risk of cerebrovascular events, an increased frequency of extrapyramidal symptoms, sedation, prolonged Q-Tc interval, infections, abnormal gait, and accelerated cognitive decline[1,2].

When considering the modest benefits and substantial risks of antipsychotics in persons living with dementia, it is clear that probably only a small minority of people have sufficiently severe or distressing symptoms that the potential benefits of treatment may outweigh the risks. Policy and clinical practice have changed significantly in the past decade, leading to significant reductions in antipsychotic prescriptions in many countries. However, 15–20% of persons living with dementia living in nursing homes are still being prescribed antipsychotics[7], and there is some concern of possible increasing prescription rates during the COVID-19 pandemic.

While I would not argue that antipsychotic treatments have no place in the treatment of NPS, I do still feel that the frequency of usage is too high and does not currently provide the optimal benefits to our patients. One important consideration is whether a pharmacological treatment is needed at all – whether monitoring without specific treatment or first line non-pharmacological approaches may be the best option for many persons with mild or moderate NPS. The high placebo response rates in clinical trials (45% v 55% for risperidone) suggests to me that benefit is often related to clinical practice, including clinical review, treatment of comorbidity, and improved social interaction, and that we can provide these elements of clinical management whether or not a pharmacological treatment is prescribed. Non-pharmacological treatments, such as personalised activities or personalised exercise are straightforward and effective (Cohen's *d* standardized effect size  $>0.4$ )[8], and could be used much more widely in clinical practice. There is also recourse to more detailed non-pharmacological approaches when simple first line approaches have not been effective.

We should also be mindful of pain, which is a common underlying cause of agitation in people living with dementia. For example, RCT evidence from a trial in 352 nursing home residents with dementia indicated that analgesics conferred significant benefit in the treatment of agitation compared to placebo, and that the magnitude of benefit compared favourably to treatment with antipsychotics in previous trials[9].

Currently there are no direct alternatives to atypical antipsychotics, although emerging evidence does highlight the potential value of citalopram as a potential alternative[10]. There are now a number of emerging treatments, such as pimavanserin [11] for psychosis, and a number of compounds targeting a variety of novel mechanisms in clinical trials for the treatment of both agitation and psychosis,

respectively. For the first time I am therefore hopeful that we will have a better armoury of pharmacological treatments of dementia-associated NPS in the next three to four years.

However, considering where we stand at the moment, the evidence strongly suggests that we should continue to use antipsychotic drugs very judiciously for the treatment of NPS in persons living with dementia, probably limited to situations with severe distress or tangible risk to the person with dementia or others. My personal view is that we should be aiming to reduce antipsychotic prescribing by a further 75% in order to give our patients the best treatment and care. A combination of good clinical practice, problem solving, support to people living with dementia and their carers, evidence-based non-pharmacological treatments, and improved pain management will give favourable outcomes to the majority of people living with dementia experiencing NPS.

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## Conclusion

The introduction to this chapter outlines the modes of action for the various drugs utilised to treat symptoms associated with dementia and describes the study designs that have been used to document their efficacy and safety.

The three essays in the chapter deal with evidence about the risks versus benefits of acetylcholinesterase inhibitors (Dubois), of antidepressants (Herrmann), and of antipsychotics (Ballard). Clinicians need to be aware of these data in order to give people living with dementia and their families the facts that will allow them to make informed decisions about the best use of these drugs.

Medicine is still an art as much as a science, and listening carefully to people living with dementia and their families will help focus on the most troublesome symptoms at a given stage of their condition. After trying non-pharmacological approaches, selecting the best drug for the target symptom should be followed by careful reassessment of clinical benefit versus side effects. Some drugs, such as antipsychotics, need to be discontinued relatively quickly (weeks), some later (months), such as antidepressants, whereas AchE(-) and memantine are often used for years.

# Chapter 18

## Disease-modifying drugs

*Pedro Rosa-Neto, Serge Gauthier*

### Key points

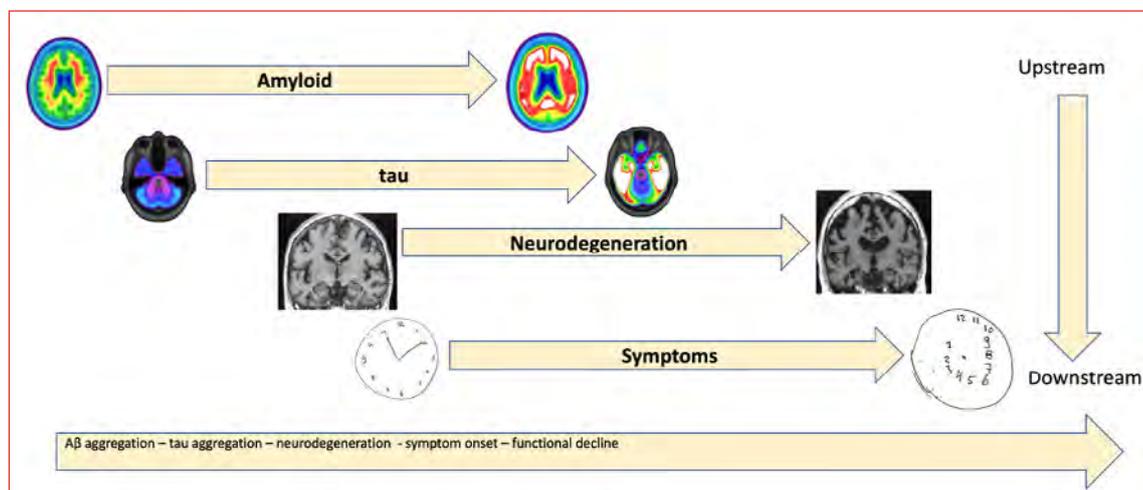
- It is still early days for the approval of drugs such as monoclonal antibodies against amyloid- $\beta$  for clinical use in early Alzheimer's disease, but healthcare systems world-wide need to prepare for their use.
- Earlier and more accurate diagnosis of dementia will be a positive outcome of the availability of such drugs.
- Demonstration of slowing down of clinical progression will require comprehensive clinical assessments.
- Evidence of drug efficacy may be supported by biomarkers.
- The extensive technology required for monoclonal antibodies administration currently limits their access globally, but emerging technologies such as plasma biomarkers and subcutaneous administration may facilitate global use.



## General background

There has been a sustained interest in developing drugs that can modify pathophysiological factors in the various dementias. In the case of Alzheimer's disease, a pathological cascade of amyloid- $\beta$  deposition, tau-hyperphosphorylation and neuro-fibrillary tangle formation, inflammation, synaptic and cell loss has been well documented, and could precede the emergence of clinical symptoms by many years.

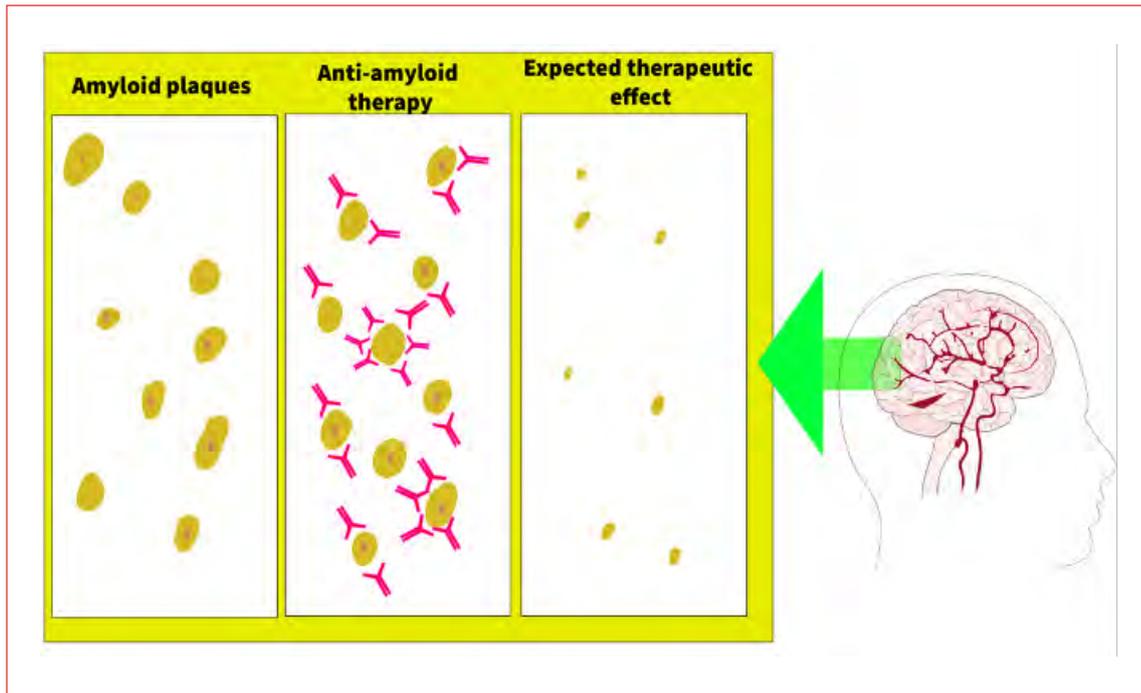
Figure 1



**Figure 1. Pathological cascade in Alzheimer's disease** This schematic representation summarises the cascade of pathophysiological events leading to Alzheimer's disease. This hypothesis proposes that the formation of amyloid aggregates triggers a cascade of downstream events causing tau aggregation and neurodegeneration, which ultimately leads to cognitive and functional decline. It has been proposed that interventions in the upstream events ( $A\beta$  or tau aggregation) are necessary to mitigate downstream deleterious events leading to dementia.

The best results so far have been in reducing the amyloid- $\beta$  brain levels in persons in the early stages of Alzheimer's Disease (AD) using monoclonal antibodies (mAbs). Figure 2 illustrates where they act on the amyloid- $\beta$  protein.

Figure 2



**Figure 2. Mode of action of monoclonal antibodies against Amyloid- $\beta$  Plaques** present in the brain of Alzheimer's patients (left panel) are cleared by the actions of monoclonal antibodies (centre panel) leading to amyloid clearance (right panel). The mechanisms by which the clearance occurs involves vascular and inflammatory responses.

As listed in Table 1, many mAbs have been tested over the past decade and much has been learned over their ability to reduce the amyloid- $\beta$  brain levels when they are administered in high enough doses and for long enough time, but with the risk of brain swelling (ARIA-E) or haemorrhage (ARIA-H) as the amyloid- $\beta$  is cleared off the blood vessels. The biggest issue right now is how much clinical benefit is demonstrable considering costs and risks: stabilisation of the condition for a treatment started in early Alzheimer would pay off years later with delays in progression to moderate and advanced stages.

Table 1

| List of monoclonal antibodies tested in Alzheimer's disease |
|---|
| Babineuzumab  |
| Solanezumab   |
| Gantenerumab  |
| Aducanumab  |
| Donanemab   |
| Lecanemab   |

The two essays in this chapter deal more in depth with the regulatory and practical use issues associated with the use of mAbs.

## Expert essay

# Anti-amyloid monoclonal antibodies for the treatment of Alzheimer's Disease

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Monoclonal antibodies (mAbs) have emerged as the most promising disease-modifying treatments (DMTs) for Alzheimer's disease (AD)[1]. Aducanumab has been approved by the United States Food and Drug Administration (FDA) making it the first new treatment for the treatment of Alzheimer approved since 2003 and the first DMT ever approved for the treatment of Alzheimer's disease [2].

Monoclonal antibodies are a new type of passive immunotherapy involving intravenous or sub-cutaneous administration of externally developed antibodies that are directed at epitopes on fibrillar amyloid- $\beta$  in plaques. The plaque burden is visualized in the brain by amyloid positron emission tomography (PET) and a reduction in plaque burden following the therapeutic intervention has been demonstrated on amyloid-PET using aducanumab [3] and others mAbs. The major therapeutic effect of mAbs is thought to be mediated by activated microglia engulfing and removing fibrillar amyloid- $\beta$ . In addition, antibodies may interfere with aggregation of amyloid- $\beta$  species into higher order molecular assemblies leading to plaque formation [4].

Aducanumab was approved using the accelerated approval regulatory pathway based on removal of amyloid- $\beta$  plaques as demonstrated by amyloid-PET [5]. This pathway requires a therapeutic impact on a biomarker considered reasonably likely to predict clinical benefit and is used when the clinical benefit of the therapy has not been fully demonstrated. A confirmatory trial of aducanumab is required to demonstrate clinical benefit. If no effectiveness is demonstrated or other problems arise, approval can be rescinded.

Several mAbs are positioned to be approved in the wake of aducanumab. Donanemab[6] and lecanemab[7] are mAbs whose sponsors will likely apply to the FDA for approval using the accelerated pathway. Gantenerumab will complete assessment in clinical trials in 2022 [8], and if positive, i.e. demonstrating a clinically meaningful drug-placebo difference, a more conventional application pathway for approval based on established clinical benefit with support from biomarker changes may be pursued.

MABs are administered as infusions (aducanumab, donanemab, lecanemab) or as subcutaneous injections (gantenerumab). Each of these drugs has a different titration schedule with lecanemab administered every other week and not requiring titration; other agents are administered monthly and require several titration steps of various lengths.

The major side effect of mAbs are amyloid-related imaging abnormalities (ARIA)[9]. ARIA is thought to represent the leakage of fluid into the brain through blood vessels (ARIA-E) made more permeable by removal of amyloid- $\beta$  from the vessel wall. In some cases, microhemorrhages occur in this setting (ARIA-H). Patients must be monitored with periodic magnetic resonance imaging (MRI) during the mAbs titration periods. When ARIA is observed, if it is symptomatic or if it is of moderate to severe intensity on the MRI (with or without symptoms), therapy is interrupted, monthly MRIs are obtained, and therapy is reinitiated only if the ARIA-E resolves or ARIA-H stabilizes [10]. If more than 10 microhemorrhages occur following the initiation of therapy or MRI reveals new superficial siderosis or a macrohemorrhage, treatment is permanently stopped.

Approximately 75% of ARIA events have no associated symptoms [9]. The most common symptoms of symptomatic ARIA are headache, confusion, nausea, visual changes, and gait disturbances. In rare cases, ARIA has resulted in severe symptoms including seizures, status epilepticus, and death.

ARIA occurs disproportionately in individuals with the apolipoprotein E genotype. In trials of aducanumab, approximately 20% of persons without the APOE4 gene exhibited ARIA, 36% of those with one copy of the APOE4 gene had ARIA, and 66% of those with two copies of the APOE4 gene developed ARIA [11].

Most ARIA occurs within the first eight treatments with aducanumab during the titration period, and other mAbs may have a similar pattern of a predominance of ARIA occurrence early in the treatment course.

ARIA has been observed in clinical trials of all mAbs associated with plaque reduction. ARIA may reflect the successful engagement of the antibody with amyloid- $\beta$  in the blood vessels [12]. Monoclonal antibodies not directed at fibrillar amyloid- $\beta$  have not produced ARIA, have not lowered amyloid- $\beta$  plaques, and have not been associated with clinical benefit.

It is uncertain if the therapeutic response seen in patients who have amyloid- $\beta$  plaque reduction with mAbs is a result of lowering the plaques, reflects engagement of other aggregated amyloid- $\beta$  species that may be neurotoxic, or is based on a secondary impact on hyperphosphorylated tau (p-tau) and neurofibrillary tangles formation following amyloid- $\beta$  plaque removal. Cerebrospinal fluid (CSF) collected in trials of mAbs reveal reduced levels of p-tau and total tau whereas tau PET studies provide evidence of reduced neurofibrillary tangle formation. These and other downstream biological events may account for or contribute to the observed clinical changes.

Currently, mAbs require an extensive advanced medical infrastructure to be safely administered. This includes amyloid-PET or resources for documenting abnormal CSF amyloid- $\beta$  levels [10]. In addition, patients must have baseline MRIs that show no vascular changes that would suggest an elevated vulnerability to ARIA, and patients must have MRI for routine monitoring for ARIA early in the treatment period. Patients must have rapid access to MRI if symptoms occur that are consistent with ARIA and require at least temporary interruption of therapy. Patients receiving mAbs administered by infusion must be proximate to infusion centres or other infusion venues. Patients treated with mAbs administered subcutaneously must have access to proper training of carers for administration or the availability of home nursing services to provide regular subcutaneous treatments. Testing for the APOE genotype is recommended for informed use of aducanumab and may be necessary for safe use of other mAbs. Genotyping is not available globally. Finally, mAbs are currently being assessed in patients with mild cognitive impairment or mild dementia due to Alzheimer's disease and there is a global shortage of practitioners with skills to assess and diagnose early Alzheimer's.

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The extensive technology required for mAb administration currently limits their access globally. Most medical centres in middle- and lower-income countries will not have the resources required for safe administration of mAbs. These limitations may be addressed by emerging technologies. Progress is being made in the development of plasma biomarkers that may allow the use of mAbs more widely. Plasma p-tau levels and plasma amyloid- $\beta$  42/40 ratios correlate with brain amyloid- $\beta$  and may eventually be regarded as sufficient to identify a patient as having a brain amyloid- $\beta$  burden warranting mAbs treatment without requiring confirmation by amyloid-PET or CSF studies [13]. Subcutaneous administration of mAbs makes it possible to deliver mAbs at home without the requirement for an infusion centre. As more is learned about ARIA, it may be possible to reduce the amount of scanning with MRI or to identify biomarkers indicative of ARIA risk or occurrence without use of MRI. Progress in these aspects of Alzheimer care will facilitate the global utilization of mAbs.

The approval of mAbs using the accelerate pathway based on changes in amyloid-PET considered reasonably likely to predict a therapeutic benefit encourages the development of other anti-amyloid approaches that may be more amenable to global use. In addition, approval of the first DMT may result in more interest in investing (from private or governmental entities) in research for Alzheimer therapeutics that will lead to treatments targeting other biological changes of Alzheimer's disease such as tau hyperphosphorylation, neurofibrillary tangle formation, inflammation, or synaptic dysfunction.

The approval of aducanumab and the emergence of other mAbs reflect progress in Alzheimer's research involving the basic understanding of Alzheimer's disease, its biomarkers, and improved development programs for new therapies [14]. Further progress and a commitment to global equity for Alzheimer's disease therapies can lead to new therapeutics that will be accessible to patients worldwide.

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## Expert essay

# How can healthcare systems cope with a new generation of drugs that require biological diagnosis and regular injections?

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We are on the verge of a new era of treating Alzheimer's disease. After more than 20 years of having only symptomatic relief to offer to our patients, the accelerated approval of Aduhelm on June 7, 2021, opened the door to other monoclonal antibodies (mAbs) to follow, requesting accelerated and full approval in the years to come. Following that, there may be anti-sense oligonucleotide approaches, requiring intrathecal administration, or even gene therapy requiring even more invasive technology. Aside from these compounds, several small molecules appear on the horizon that will be far less invasive to administer. How the actual mix will ultimately look cannot be predicted yet, but the landscape will change definitively [1].

In the short term, as indicated in the essay written by Jeff Cummings in this chapter, mAbs require an extensive advanced medical infrastructure to be safely administered. This includes PET or CSF lumbar puncture to show abnormal amyloid- $\beta$  levels, baseline MRIs that show no vascular changes, and follow up MRIs for routine monitoring for ARIA early in the treatment period [2]. Patients receiving mAbs administered by infusion must be proximate to infusion centres or other infusion venues. Patients treated with mAbs administered subcutaneously must have access to proper training of carers for administration or the availability of home nursing services to provide regular subcutaneous treatments. Testing for the APOE genotype is recommended for informed use of aducanumab and may be necessary for safe use of other mAbs.

The healthcare challenges associated with the availability of mAbs in addition to the costs of these drugs[3], are many. A partial list can be seen in Table 1.

Table 1

| Challenges to access disease-modifying drugs in Alzheimer's disease                     |
|---|
| Global shortage of skilled clinicians to diagnose Alzheimer's Disease in an early stage |
| Limited access to MRI facilities  |
| Limited access to PET facilities  |
| Limited acceptance of CSF tapping   |
| Limited presence of qualified labs to perform CSF analysis                              |
| Limited availability of APOE testing  |
| Limited services for infusions  |

One can safely state that there is a global shortage of skilled physicians knowledgeable enough to diagnose Alzheimer's disease early and differentiate it from other forms of cognitive or behavioural decline, who know to how perform cognitive testing themselves, use validated screening tests and understand how to interpret the findings of ancillary investigations. Before, there was very little interest in dementia among neurologists: it takes time to do a serious cognitive work up and there was little to offer in terms of treatment. Other specialists have taken over and most of the care for people living with dementia around the world is provided by geriatricians, geriatric psychiatrists, general practitioners, and even internal medicine specialists. As it is neurologists who will be most likely to be the ones to initiate and monitor mAbs therapy, we need to ensure they are well educated and trained to specialize in dementia diagnosis and care. This has to be a collaborative effort between various

organisations like the European and American Academies of Neurology, together with all the national associations, International Psychogeriatric Association, Alzheimer Association, Alzheimer Europe and ADI.

Increased access to MRI and PET facilities will be needed, and while this seems to be mostly the case in lower- and middle-income countries, even in the EU and USA there are huge local differences. Training of radiologists in evaluating scans of eligible patients and in recognizing and rating ARIA appropriately will become of utmost importance, requiring efforts from the (inter)national radiology associations. Training nuclear medicine physicians to properly judge amyloid PET scans will be needed. To complicate matters even more, reimbursement for PET ligands to perform amyloid PET is highly variable globally [4]. The same goes for laboratory facilities to analyse CSF for Alzheimer's disease biomarkers and blood for APOE testing. On the horizon the attractive alternative of blood tests for amyloid- $\beta$  and p-tau is luring, but the real challenge here will be to validate these in clinical settings and then to make them available globally and to have standard cutoffs [5]. Finally, infusion centres will need to

be created, as was the case when new therapies for Multiple Sclerosis became available, but given the frequency of the infusions, monthly or even biweekly, this needs to be organized to be given at home subsequently, which will increase the need for specialized nurses and other staff.

Given all these challenges it is evident that the availability of the various mAbs for eligible patients, will be strongly dependent on the local organization of healthcare, reimbursement of care, availability of ligands and of the drugs. For some countries and regions, it will take many years to prepare the healthcare system to be ready to diagnose and treat the increasing number of patients who will qualify to receive these treatments. Other countries may be closer to implementation. These issues are pressing, and governments around the world need to start preparing their healthcare systems now. The World Dementia Council has drawn attention to this in its Dementia Landscape Project on health system readiness [6]. Let us hope this call to action will resound globally, in order to offer all Alzheimer's patients worldwide the opportunity to be treated with the disease-modifying drugs of the future.

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## Conclusion

These essays and published evidence support the fact that DMT for Alzheimer's disease will be available in the near future. Although it is still early days in the approval process of mAbs for clinical use, healthcare systems world-wide need to prepare for their optimal use. At the very least, we need to improve our diagnostic accuracy, particularly when symptoms are still mild and people are independent in their daily life. We can also improve our assessment of the disease clinical stage, carefully considering cognitive, functional, mood and behavioural symptoms.

The final goal is a personalised treatment approach where a person with mild symptoms is fully characterised biologically for which pathological factors are at play at a given time in the course of their disease, and the appropriate drugs are used. It may turn out that a sequence of treatment is better than a combination, such as amyloid- $\beta$  therapy followed by anti-tau therapy. Another hope is that blood biomarkers such as ptau-181 and Neurofilament light chain protein (NfL) will be indicators of response to treatment, as explored in the 2021 edition of the World Alzheimer Report.

Cautious optimism is thus appropriate in the field of DMT for Alzheimer's disease. Lessons learned in how to find them and demonstrate efficacy may speed up therapeutic research in other causes of dementias.

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# **Part VI**

## Special Considerations

# Chapter 19

## Special care needs for people with specific types of dementia

*Pedro Rosa-Neto, Serge Gauthier*

### Key points

- Education regarding the progressive nature and milestones of atypical dementias is fundamental for optimising care planning.
- Advice regarding aids and treatment strategies must be tailored to the individual, their condition (type and severity) and environment (social and physical), ideally with the involvement of a multidisciplinary clinical and/or long-term care support team.
- Young onset dementias (before age 65) occur while the person is still likely engaged in professional activities, forcing unplanned retirement, and causing financial concerns.
- Dementias where there is early and prominent visual impairment may benefit from registration as partially sighted or blind, which may facilitate access to relevant care and support services and financial and legal benefits.
- Referral to a speech-language pathologist and use of augmentative and alternative communication devices may help persons with early and prominent language impairment.
- Some types of dementia include early symptoms related to physical impairment (parkinsonism, frailty) requiring special care such as physiotherapy.



## General background

Why do we need this chapter? The short answer is that there are differences in the initial symptoms and their progression through mild, moderate, and later stages amongst different causes of dementia. Special care needs for some of these dementias have been identified by experienced clinicians and are described in the following twelve essays.

Dementia is the final manifestation of progressive brain diseases that develop years before the onset of symptoms. Dementias associated with age 64+ typically begin as insidious difficulty in retaining new information, followed by decreasing ability to judge, reason, plan, communicate and move. An 'atypical' dementia is when symptoms start either before age 65 or when symptoms other than forgetfulness constitute the most noticeable feature of the condition at the onset.

In atypical dementias, communicating the diagnosis and informing about upcoming milestones (stages) to carers and family members is of utmost importance. Frequently cultural perspectives and misconceptions might undesirably interfere with management of the person living with dementia's care. In this context, educational materials, website links, and in-person or web sessions play an important role in informing persons living with dementia and families about the nature of the atypical dementia,

perspectives regarding experimental therapies and the upcoming decisions related to the progression of the condition. In hereditary forms of the condition, genetic counselling and molecular diagnosis play an important role given the higher frequency of genetic alterations associated with atypical dementias.

To facilitate management of the affairs of the person living with dementia, one should encourage the early designation of a healthcare and financial power of attorney for managing upcoming therapeutic and financial decisions in anticipation of capacity decline. Such individuals could elaborate decisions such as where to live safely, participation in experimental therapies, assisted end of life and other relevant decisions. Assistance to family members and care partners should be integrally included as prescription of care.

The management challenges of atypical dementias depend on the complexities associated with the coexistence of motor, sensory, behavioural and communication symptoms, which translate into autonomy loss and safety concerns. As functional decline might occur more rapidly in these individuals, driving capacity and autonomy to manage medications should be assessed early in the course of the condition. As atypical dementias are frequently

associated with locomotion issues and gait difficulties or Rapid Eye Movements (REM) sleep behavioural disorder, persons living with such dementias are at higher risks of falls. Behavioural changes such as irritability, anxiety or hallucinations are frequent medical challenges faced in early stages of these disorders.

To address all the complexities associated with atypical clinical presentations, the prescription of care for an atypical dementia involves a multidisciplinary team featuring physiotherapists, nurses, social workers, psychologists, genetic counsellors, occupational therapists, support groups and educators.

Apart from traditional assistive devices (such as wheeled walkers) or home adaptations (such as grab bars, toilet risers, alarms) the rapid diffusion of home intelligent devices radically expands the possibilities to intervene in atypical dementias. Emerging technologies assist persons with communication disorders. Virtual reality brings the promise of innovations in non-pharmacological therapies for these individuals.

Support groups are important, particularly for young persons living with dementia. Socioeconomic factors complicate management as frequently the person living with dementia's income constitutes an important source revenue of a family with young children. Furthermore, these support groups engage and bring awareness to

persons living with dementia and to carers about scientific advances related to atypical dementias, and the availability of clinical trials. Due to their reduced prevalence, the management of atypical dementias are most often restricted to specialised tertiary centres.

The following essays summarise post-diagnosis approach including nonpharmacologic therapies, safety surveillance, carer support, mobilisation of community resources, and advance care planning.

The first one by Chertkow is about 'typical Alzheimer's disease' between ages of 65 and 84. It provides a review of good clinical practice applicable to all types of dementia. Then comes specific atypical syndromes with special care considerations for conditions with early and predominant visual impairment, speech difficulties, neuropsychiatric symptoms, parkinsonism. Alcohol-related dementia and Alzheimer's disease associated with Down's syndrome deserve their own essays. We then have a special look at young onset dementias (<65) and very late onset dementias (≥85) which differ in aetiology and management.

As you read through these essays, you will find common themes: the importance of clinicians and long-term care teams sharing information with the persons living with dementia and their carers to the best of their knowledge and ability, treating current symptoms with all resources available, and planning ahead for later stages.

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## Expert essay

## Alzheimer's disease

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Since Alzheimer's disease (AD) is the most common diagnosis attached to dementia in memory clinics, we are thus speaking here of the care of most persons living with dementia (PLWD). This subject has been reported on many times and should be part of the core teaching to clinicians around the world[1] (Chapter 22 of this report).

Who will care for the PLWD? Most can be cared for by their family physician. At the same time, individual family physicians in certain jurisdictions are challenged by particular barriers to care such as financial remuneration, lack of necessary time for the visits, and expertise. The management is complex, because AD is progressive and evolves over a five-to-ten-year period and the management needs also change during this time[2]. Carers and PLWD should be followed regularly for support and for dealing with new issues as they arise. Increasing cognitive, functional, and behavioural deficits are to be expected over time, and trials of medications will need to be monitored. Core knowledge and skills (and the time to devote to care of a person with a chronic illness) are essential on the part of the physician. Referral to a specialist is needed if there are particular diagnostic and management issues such as a genetics clinic in the event of strong family history of early or young onset dementia.

Support and education of PLWD and carers is essential: they should be informed of the diagnosis and counselled about it. Disclosure of the dementia diagnosis is an important element of care and should be carried out incorporating the individual PLWD perspective and wishes [3]. Anxiety is often reduced by a clear discussion of the diagnosis. Diagnosis disclosure is itself a complex procedure requiring sensitivity [1].

The PLWD and carers should be informed that there is generally a "typical" course of events, but there can also be considerable heterogeneity [4]. It is thus possible that the progression of symptoms is quick, or to have a long (years) plateau. A treatment plan with definite goals should be drawn up and continually updated.

Issues to be reviewed with the PLWD and carers on an ongoing basis include:

- Safely risks – particularly driving, but also management of finances and medication. Persons with mild AD are particularly prone to on-line and

phone scams. Non-compliance with medication use is always an emergent issue, and the need to involve family members to monitor medications as the illness progresses must be continually updated. Wandering is a safety risk at later stages.

- Driving capacity is another issue that requires continual updating. Persons with mild dementia need to be evaluated on an individual basis for their ability to drive. Impairment of multiple instrumental activities of daily living (ability to handle finances, medication, telephone, travel) or impairment of any basic activities of daily living (hygiene, etc.) occur in a moderate or advanced stages of dementia and are not compatible with safe driving. Formal driving assessment may be needed. PLWD and carers need to be informed that cessation of driving is almost inevitable in dementia.
- Arranging advance planning documents such as wills and power of attorney. Discussion of these documents should begin as soon as the diagnosis is disclosed, because decisions need to be made before the PLWD loses the legal capacity required to declare his or her wishes on the matter.
- Monitoring nutrition over time. Weight loss has a bad prognosis, and the PLWD can forget to eat properly.
- Management of functional problems as they arise (e.g., incontinence).
- Management of neuropsychiatric symptoms (NPS) as they emerge
- Management of co-morbidities. We know that poorly controlled diabetes and hypertension will exacerbate cognitive decline. At the same time, the PLWD role in self-management of a chronic disease such as diabetes, will need to be adjusted. Furthermore, we know that concurrent use of medications with anticholinergic properties (such as oxybutynin for bladder function), and certain medications will need to be reassessed in light of a diagnosis of AD.

Carers need to be monitored for evidence of burnout and stress [5], and they should be encouraged to contact agencies that can provide additional support, including local government public health offices, Alzheimer Societies, local agencies and community-based resources depending on the geographic location.

The appropriate treatment with non-pharmacological interventions in mild and moderate AD has been a topic of many reviews and papers. Individual exercise programs appear to have a positive impact on functional performance of people living with dementia [6]. Loneliness and depression will generally have a negative impact on all geriatric patients, thus social support and encouragement for persons with AD is recommended [7]. On the other hand, there is limited evidence at this time that cognitive training or cognitive rehabilitation improves or maintains cognitive and functional performance in people with mild to moderate dementia [1,8].

In terms of pharmacological agents, symptomatic therapy with cholinesterase inhibitors (donepezil, galantamine, rivastigmine) remains the main treatment option as it has been for twenty years [9]. PLWD and carers should be told that these medications help with their symptoms but do not stop the condition itself, and that there is limited benefit seen in 25% of individuals. The benefit for most patients

is modest [10,11]. The PLWD should be monitored after three and six months to assess the benefit of the medication. Side effects (particularly gastrointestinal) should be monitored. Memantine is a viable alternative choice for individuals with moderate dementia, and a combination of memantine with a cholinesterase inhibitor seems to provide an additive benefit [12].

NPS have their own symptomatic treatments, using medications with variable efficacy [13, 14]. Non-pharmacological therapies to reduce anxiety and agitation should be used in tandem with pharmacological approaches.

There are currently numerous disease-modifying therapies for AD in randomised clinical trials. The lack of an effective disease-modifying therapy for AD, more than 100 years after its discovery, remains a major gap in modern medicine, thus PLWD and carers should be encouraged to participate in observational and therapeutic research.

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## Expert essay

# Posterior cortical atrophy

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**P**osterior cortical atrophy (PCA) is a neurodegenerative syndrome characterized by predominant and progressive loss of higher order visual and other posterior cortical functions consistent with parieto-occipital and occipito-temporal involvement, despite relatively preserved memory, language, and insight. PCA tends to have a young onset presentation, typically around 50–65 years, being underpinned by Alzheimer's disease (AD) pathology. Core features of PCA include space and object misperception, features of Balint's and Gerstmann's syndrome, apraxia, environmental agnosia, diminished reading and face perception and visual field defects (Table 1[1]).

Table 1

| Clinical features   |
|---|
| Space and/or object perception difficulties   |
| Simultanagnosia, optic ataxia, and oculomotor apraxia   |
| Dyscalculia, dysgraphia, left-right confusion, finger agnosia                                       |
| Constructional, dressing, and/or limb apraxia   |
| Environmental agnosia   |
| Reading difficulties  |
| Face perception difficulties  |
| Relatively spared anterograde memory, speech, non-visual language, executive function and behaviour |

Early PCA symptoms include difficulties with driving, reading, dressing, and orientating to familiar environments. PCA symptoms often carry significant implications for autonomy and personhood; feelings of disempowerment and depression may arise in individuals unable to use a telephone or remote control despite spared insight[2].

## Common misconceptions and clarifying needs

Consistent with individuals with other young onset and atypical forms of dementia, people with PCA have often experienced a lengthy period of uncertainty before diagnosis

(Table 2[3]). Stress associated with this often-convoluted diagnostic journey may be exacerbated by challenges regarding employment, finances and changing family roles and the need to frequently re-explain PCA owing to limited public and professional awareness[2].

Table 2

| Diagnostic red flags                                       |
|--|
| Repeated appointments with eye specialists                 |
| Repeatedly changing prescription of glasses                |
| Misdiagnosed with ocular condition                         |
| May undergo unnecessary surgeries (e.g., cataract removal) |
| May be diagnosed as having a functional disorder           |

Factors complicating PCA diagnosis may cause continuing frustrations and undermine subsequent support provision. For example, the easy misattribution of PCA cortical visual problems as eyesight rather than 'brainsight' issues may prompt support designed to assist with sensory but not concurrent cognitive decline. A related misperception limiting the effectiveness of post-diagnostic support is the notion that PCA is solely a 'visual dementia'. Perceptual ('what?') and spatial ('where?', 'how?') changes may manifest not only through disturbed visual, but also auditory and somatosensory functions[3][4][5] visual imagery and spatial concepts like left and right[1]. Awareness of non-visual deficits is critical to design, tailor and communicate support strategies with, for and to the individual with PCA and their care partner.

Those caring for a person living with PCA may be surprised by variations in visual functions, from inconsistent visual field testing to dissociations between single word and space perception[3][6]. Variable field deficits can result in apparently implausible difficulties with misperceiving objects presented in clear view (albeit in inferior peripheral vision) despite better perception of objects presented at a distance, or misreading newspaper headlines despite better reading of small print. These inconsistencies challenge not only

understanding of symptoms, but also confidence in carrying out superficially simple tasks which have become more effortful and unreliable.

## Post-diagnostic support, information, and management

Prominent visual, motor, language and other symptoms carry particular implications for self-care, social and leisure activities for persons living with PCA and their carers and support needs (Table 3). Most persons living with PCA will not be safe to drive, with consequent ramifications regarding dependency. Providing tailored information, advice and support regarding PCA symptoms and everyday difficulties, time-sensitive aids and adaptations to manage symptoms, and psychosocial interventions may improve functional status and wellbeing.

Table 3

| Considerations  |
|---|
| A key priority is discussion of driving safety; most individuals will not be safe to drive  |
| Occupational and daily routines may be severely impacted by progressive cortical visual loss, despite relatively preserved memory, language and insight |
| Individuals may have a high risk of becoming lost   |
| Individuals may be eligible to register as severely sight impaired or blind, even despite normal visual acuity  |
| As PCA progresses, most individuals will become functionally blind leading to a high risk of falls  |

Registration as partially-sighted or blind may facilitate access to relevant care and support services and financial and legal benefits[3]. Access to information and advice reflecting lived experiences of PCA is critical given limited public and professional awareness[2]. Co-developed resources include the Stages of PCA, describing symptom progression, public engagement, and professional development materials to improve recognition and management of PCA symptoms.

## Pharmacological approaches

In principle, most individuals with PCA caused by AD should benefit from symptomatic or eventual disease-modifying treatments for 'typical' AD. In practice, few existing pharmacological therapies have been directly examined in PCA, and the inclusion or exclusion of PCA participants into conventional trials remains somewhat inconsistent.

Clinical benefit of cholinesterase inhibitors for PCA has been reported. While there have been no pharmacological trials in relation to management of PCA motor symptoms,

expert review of corticobasal syndrome found limited support for pharmacological management of tremor, levodopa for rigidity and bradykinesia, and botulinum toxin injections managing dystonic spasms and pain[7]. Standard pharmacologic treatments may be considered for patients with persistent low mood or anxiety and recommending treatments for parkinsonism, seizures or myoclonus may be appropriate for individual patients[3].

## Non-pharmacological approaches

### Aids and adaptations

As with all dementias, advice regarding aids and strategies must be tailored to the individual, their condition (type and severity) and environment (social and physical), ideally with the involvement of a multidisciplinary clinical and/or support team. Practical tips for patients with PCA and their families have been collated based on occupational therapy and neurological practice (Table 4). Several compensatory approaches have been developed to mitigate PCA symptoms, particularly space/object perception, alexia, and environmental agnosia. Evidence of reducing visual clutter, increasing spacing and maximizing contrast supporting visual functions in PCA participants has informed the development of computer-based reading aids[6,8] and environmental adaptations comprising visual cues and lighting interventions to support navigation and walking[9,10]. Occupational therapists, speech and language therapists and physiotherapists may promote functional status and communication through compensatory approaches, communication skills training and managing falls[3][7].

### Advice, social context, and peer-to-peer support

Beyond the individual, support and advice must be tailored to setting and context. Persons living with PCA face numerous barriers to service use and participation, with general dementia group activities often inappropriate due to age and/or symptom profiles, and psychosocial therapies relying on visual formats (e.g., reminiscence photographs) or advising against inclusion of people with visual impairment (e.g., cognitive stimulation therapy). During the COVID-19 pandemic, mask wearing, digital/video-based communication and social distancing posed particular challenges to those with praxic, proprioceptive, face, object and space perception and mobility difficulties.

Home-based interviews and observations with persons living with PCA and their care partners highlight the challenges and importance of maintaining ongoing engagement in daily activities which are both 'fun' (e.g., adapted artistic and music-related activities) as well as 'functional' (e.g., household chores and personal care). Findings also suggest the enduring importance of enabling persons living with PCA to continue to contribute to everyday life and to provide

Table 4

| Non-pharmacological treatment  |
|--|
| Individuals may benefit from referral to an occupational therapist, ideally with experience in supporting individuals with cortical visual loss, to develop compensatory strategies to support functional status and promote participation in meaningful activities (e.g. utilising voice-activated music listening devices)   |
| There is evidence that reducing clutter may promote reading function[6,8]. Professional recommendations include simplifying the environment (e.g. removing clutter and unused objects), though with sensitivity to the potential emotional impact of removing objects which relate to an individuals' identity and personhood (e.g. books for a previously avid reader, tools for a former handyman)                                     |
| There is evidence that strategic use of contrast, minimizing lighting variability and shadows may facilitate visually-guided navigation and walking[9,10]. Shared strategies from individuals include brightly coloured stickers to make parts of garments or buttons on gadgets more visually salient and motion-sensor lights or nightlights to support wayfinding to the bathroom   |
| Use of a white cane or Sunflower lanyard may be helpful, particularly to encourage awareness of the individual's support needs among others in public places   |
| While equipment designed for those with low vision might be appropriate beyond the white cane (for example, talking watch, typoscope, audiobooks), careful appreciation of concurrent non-visual symptoms is required. Diminished praxis skills and non-visual spatial awareness subsequently accompanied by declining memory and executive functioning pose substantial challenges to the adoption of generic assistive technology[3–5] |

care and support for others, as well as receiving support for themselves – e.g., via long-established family or work roles – and a particular impact on identity given relatively intact long-term memory[3].

Given the symptoms, typically young onset presentation and context, syndrome-specific peer-to-peer support may be especially valuable for persons living with PCA.

Syndrome-specific groups may provide opportunities for advocacy and sharing of strategies. Tailored peer support is available through formal multicomponent (mixed peer and professional) support services (e.g., Rare Dementia Support, Colorado PCA Support) and informal peer-led social media groups.

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## Expert essay

# Primary progressive aphasia

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Primary progressive aphasia (PPA) is a heterogeneous neurodegenerative disorder mostly due to Alzheimer's disease (AD) or Frontotemporal lobe degeneration (FTLD) [1]. PPA is characterized by progressive, distinctive language impairments, relatively isolated for at least two years, with significant communicative skill disruption and functional impact in daily living activities involving communication functions [2]. In accord to different, well described, unique clinical profiles and underlying brain regional neuropathological changes, patients can present difficulties in speech production, lexical retrieval (word-finding), sentence repetition, or single word comprehension [3]. Syntax and grammar can also be selectively involved. Language impairments are obvious in oral production and comprehension, and parallel deficits in writing and reading. As the condition progresses, other cognitive, motor, and behavioural deficits become more prominent, but language usually remains the most affected domain, and early or end-stage mutism is not rare [4].

Using language to communicate is a unique human being skill. Not surprisingly, PPA affects dramatically patients' quality of life and is often associated with profound psychological distress and isolation. Moreover, compared to typical dementias, PPA tends to present earlier in life, often before age 65, when patients are still likely engaged in professional activities, forcing unplanned retirement, and causing financial concerns.

Consequently, persons living with PPA need special care and support once the diagnosis has been made and throughout the progression of the condition. Similar to other dementia types, social isolation must be avoided, persons should be encouraged to continue pleasant and cognitively stimulating activities and remain physically active. Cerebrovascular risk factors must be rigorously controlled. Incipient neuropsychiatric symptoms of depression or anxiety must be recognized and addressed appropriately. A prompt referral to a social worker must be done for assessment of needs, advice concerning power of attorney and other legal arrangements, and psychological support. Establishing a link with a local or national support group or association of aphasic patients should also be proposed to empower patients and caregivers. Participating in ongoing research activities on neurodegenerative aphasia in tertiary care centres, if available, could

help the person living with dementia (PLWD) to keep the control over the condition and reduce hopeless feelings. For example, some centres offer a structured aerobic physical training program to persons living with PPA with the hope to improve cognitive (namely executive) functioning and quality of life.

Nevertheless, PPA is a progressive and ultimately fatal condition, and, as opposed to post-stroke aphasia, PLWD must expect variable but ineluctable deterioration in language abilities over the following months to years. There is still no cure or effective medical treatment for PPA. PPA due to AD is generally treated with cholinesterase inhibitors and/or memantine but efficacy is limited and improving in communication has been rarely observed.

With progression of the condition, persons living with PPA may need an augmentative and alternative communication device, that is a tablet or laptop that helps someone with a speech or language impairment to communicate. Some rehabilitation institutes give access to such compensatory technological devices and offer training on complementary nonverbal communication strategies. Educating carers to become competent communication mediators is also an effective strategy to promote functional communication for persons living with PPA [5].

In recent years, many research efforts have been devoted promoting language recovery in neurodegenerative aphasia by adopting behavioural (language) therapies, similarly to speech-language pathologist (SLP) interventions commonly used in post-stroke aphasic syndromes. Studies have focussed mainly on naming impairment (word-finding difficulties) which is the most frequent deficit in persons with PPA (but definitively not the only one). Naming therapies have been largely based on lexical retrieval strategies consisting of overtrained phonological and semantic stimulation and self-cueing approaches to promote word access. Different paradigms in PPA treatment and dosage parameters in terms of treatment frequency and duration have also been compared. Supervised weekly or biweekly training sessions are generally accompanied by unsupervised daily homework. Results are generally positive, with significant improvement observed in trained items and some generalization also found

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in untrained items. Training-induced improvement may persist at 12 months post-therapy and has been associated to positive self-assessment of change [6,7,8].

In addition to classic language therapies, alternative non-invasive brain stimulation methods have been investigated to promote language remediation in PPA. These neuromodulatory procedures include transcranial direct current stimulation (tDCS) and transcranial magnetic stimulation (TMS), which apply respectively a weak electric current and a magnetic field to the brain. They have been shown to provoke persisting electrical changes (i.e., cerebral excitability) and enhance plasticity in targeted cortical brain regions. These techniques have been tested in association with language therapies in a few persons living with PPA with positive results, over and above the improvement observed with behavioural interventions alone [9].

Despite these positive and promising results from research studies, such language and neuromodulatory interventions have not yet been translated into routine clinical practice.

Maybe because these studies have been conducted on a small number of selected (mostly highly motivated Caucasians) but heterogeneous (with respect to condition characteristics) participants, or because of the high demands in terms of PLWD and therapist engagement and costs they require, and lack of general accessibility, especially, but not only, in lower- and middle-income countries. Moreover, these approaches have been conducted only in the early to moderate stages of condition, and unfortunately, they cannot modify the progression of the condition.

Therefore, even if SLP is recognized to be the cornerstone of PPA care, actually a very small number of persons living with PPA are regularly followed by a language therapist, and almost exclusively on a private care basis. Lack of public resources, limited insurance reimbursement for therapies, only partial PPA disease awareness by physicians, and limited expertise in neurodegenerative aphasia treatments make integrated care approach in PPA still an unmet need.

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## Expert essay

# Frontotemporal dementia and behavioural variant Alzheimer's disease

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The behavioural variant of frontotemporal dementia (bvFTD) is the most common syndromic presentation of frontotemporal dementia. As the name indicates, it is characterised primarily by early and marked changes in behaviour and personality. The current consensus diagnostic criteria identified six core features characteristic of the condition, five of which are related to changes in some aspects of behaviour (disinhibition, apathy, loss of empathy, perseverative or stereotypical behaviour, dietary changes or hyperoral behaviours) with the last criterion focusing on the presence of isolated executive deficits in the context of reasonably preserved other cognitive functions[1]. Presence of at least three of these core features is needed to meet a diagnosis of bvFTD, ranging from possible, probable, or definite, based on the presence/absence of additional structural or functional brain changes on neuroimaging, pathological confirmation or the presence of a genetic abnormality known to be causative for the condition. Pathologically, bvFTD is predominantly associated with the presence of abnormal deposition in the brain of either the tau protein or of tar-DNA binding-protein 43 (TDP-43), with a small proportion exhibiting fused in sarcoma (FUS) pathology. To complicate the matter further, in cases with underlying tau pathology, abnormal tau protein deposition can be in the form of either 3-repeat tau (also known as Pick's disease) or 4-repeat tau, which is associated with corticobasal degeneration or progressive supranuclear palsy pathology[2]. Importantly, the clinical profile of bvFTD appears unrelated to its underlying pathology. In other words, it is almost impossible to determine the underlying pathological type in individuals diagnosed with bvFTD based solely on their clinical profile. Indeed, clinical phenomenology appears to be related to the location and severity of the pathological changes rather than the type of pathology.

Clinical presentations mimicking bvFTD but with underlying Alzheimer pathology have also been reported. These have been variously labelled frontal variant Alzheimer's disease (AD), dysexecutive AD and, more recently, behavioural variant AD (bvAD)[3]. Compared with bvFTD, the behavioural changes in these behavioural presentations with underlying

AD pathology tend to be milder in severity, although the cognitive deficits may be more pronounced, particularly in the domain of executive functions, and often with concomitant episodic memory deficits. Other differences are present, for example, on structural brain imaging, a mix of anterior (dorsolateral, orbitofrontal) and posterior (temporal, parietal) atrophy changes have been reported in bvAD. In bvFTD, the typical pattern of brain atrophy tends to involve predominantly orbitofrontal and frontomedial regions and the insula, as well as the thalamus[4]. As indicated above, bvFTD and bvAD belong to two very different diseases with different pathomechanisms. From a clinical perspective, however, the distinction between bvFTD and bvAD is challenging in the absence of biomarkers or genetic investigations.

Because of their marked behavioural changes and impact on interpersonal relationships and social behaviours, bvFTD and bvAD have special care needs. From a management and care viewpoint, distinction between these two presentations is important as they will, in part, require different approaches. No disease-modifying treatments or cures currently exist for bvFTD. While a number of clinical trials are currently under way, these are predominantly focusing on the genetic forms of the condition, which account for only 20–30% of all cases of bvFTD. The outcomes of these trials remain some years away and may not necessarily be applicable to the sporadic, non-genetic, form of the condition. At the current time, pharmacological management of bvFTD is therefore primarily symptomatic, targeting behavioural features such as apathy, disinhibition, or other challenging behaviours. Use of selective serotonin reuptake inhibitors or of antipsychotics, however, appear to have limited benefits. Drugs used in typical AD, such as cholinesterase inhibitors or NMDA receptor antagonists have shown no benefits in this population. Small trials of intranasal oxytocin for the management of social behaviour disturbance have shown promise but will need replication on a larger scale[6]. In contrast, by the very nature of the underlying pathological process, bvAD cases are likely to show some benefits from the established AD drugs that have been available in the past two decades. Whether patients presenting with

bvAD, rather than the typical amnesic presentation of AD will qualify for the recent FDA approved aducanumab, a monoclonal antibody targeting amyloid-beta deposition remains uncertain[7].

Despite their different aetiologies, bvFTD and bvAD are likely to draw similar benefits from non-pharmacological interventions targeting behavioural difficulties, such as agitation, repetitive behaviours, or apathy, given their overlap in clinical features. In general, these interventions aim to reduce the behaviour of concern and variously combine direct patient interventions, carer education and support, as well as environmental modifications. The Tailored Activity Program is such an intervention, which targets a specific undesired behaviour to re-orient it into an activity that is relevant and meaningful to the person living with dementia (PLWD)[8]. Positive Behaviour Support approach is another option where carers are trained to recognise the behaviours of concern (e.g., aggression) and identify their purpose, with the view to modify the environment or how the carer responds to the behaviour. Existing evidence indicates that these approaches will result in a reduction in the frequency and severity of the behaviour as well as a reduction

in the level of stress experienced by carers[9]. An additional downstream benefit of these interventions is to enhance quality of life of the PLWD and their family, maximise functional independence, thereby reducing the needs for supported accommodations or nursing home placements. Importantly, because of their flexibility, these non-pharmacological approaches may be applied at all levels of severity.

Undoubtedly, accurate, and early, diagnosis of bvFTD has improved markedly over the past 20 years, with a related progress in management of the condition, interventions and understanding of the related pathologies. Nevertheless, the challenge remains in distinguishing bvFTD from bvAD, a syndrome with similar clinical features but with an altogether different aetiology, an important endeavour given the need for targeted medications, even these are currently missing. In addition, appropriate management of the behavioural changes characteristic of these syndromes require special care. Importantly, evidence has shown that targeted approaches focusing on specific behaviours will be of benefit to patients and families, regardless of their underlying causes.

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## Expert essay

# Corticobasal syndrome and corticobasal degeneration

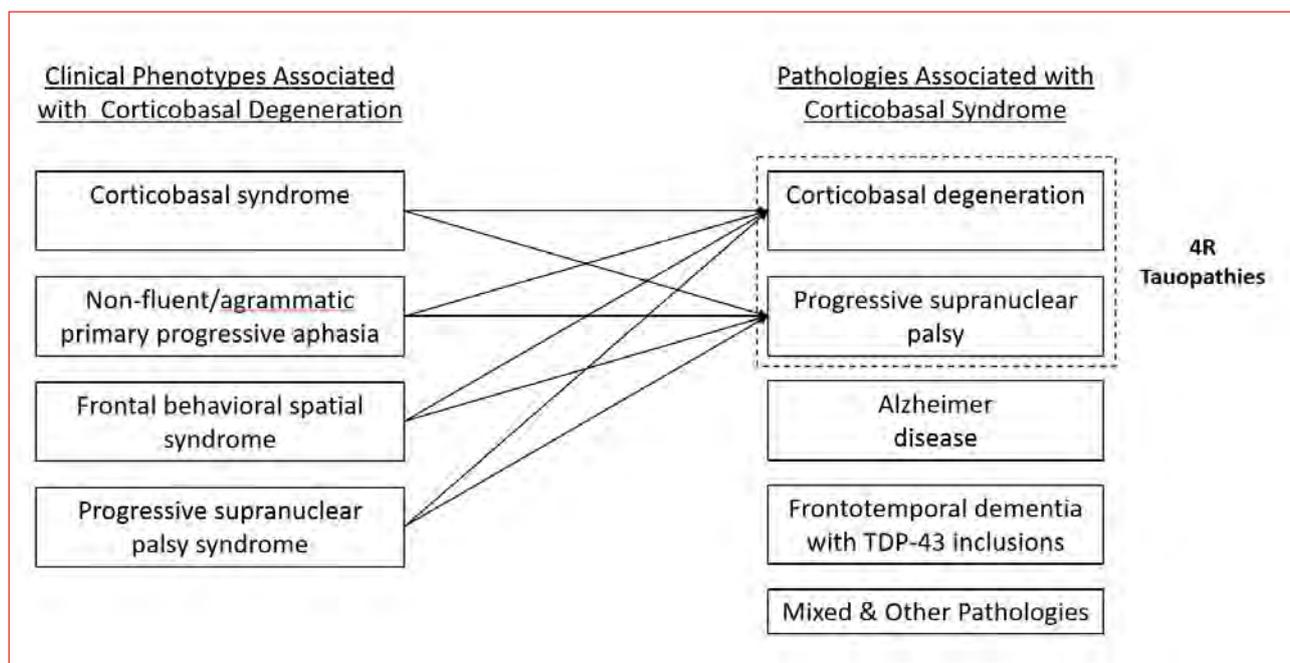
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**C**orticobasal degeneration (CBD) is a primary 4R-tauopathy characterized by astroglial plaques and tau-positive neuronal and oligodendroglial inclusions. Other 4R-tauopathies include progressive supranuclear palsy (PSP), globular glial tauopathy, and argyrophilic grain disease [1]. These neurodegenerations have overlapping clinical presentations, often causing confusion early in the diagnostic process. One presentation of CBD is corticobasal syndrome (CBS). The CBS clinical phenotype is typically asymmetric and includes motor features (limb rigidity or akinesia, dystonia, myoclonus) and higher cortical features (orobuccal or limb apraxia, cortical sensory deficit, alien limb phenomena) [2]. When initially described, it was thought that the CBS syndrome was pathognomonic for CBD pathology. Subsequently it became clear that CBS is only one presenting phenotype of CBD pathology. Other

presentations associated with CBD pathology include a non-fluent/agrammatic primary progressive aphasia, frontal behavioural-spatial syndrome, and PSP syndrome (Richardson syndrome) (2). Similarly, individuals with a CBS clinical phenotype can have pathologies other than CBD. The most common pathologies associated with CBS are CBD, Alzheimer's disease (AD), PSP, and frontotemporal lobar degeneration with TDP inclusions [3]. There is particular overlap in the clinical presentations of CBD and PSP; each clinical phenotype associated with CBD is also a phenotype of PSP (Figure) [4].

This heterogeneity in clinical presentations and pathology underscores the first special care need for persons living with CBS and CBD – getting the right diagnosis and receiving an explanation of associated vocabulary and diagnostic



*Legend: Corticobasal degeneration pathology is associated with multiple clinical phenotypes, including corticobasal syndrome, nonfluent/agrammatic primary progressive aphasia, frontal behavioural-spatial syndrome, and PSP syndrome (Richardson syndrome). These phenotypes are also associated with progressive supranuclear palsy pathology. Corticobasal degeneration and progressive supranuclear palsy are both categorized as 4R-tauopathies. Corticobasal syndrome is also associated with other pathologies, including Alzheimer's disease and frontotemporal dementia with TDP-43 inclusions.*

challenges. There are often delays in the diagnosis of atypical parkinsonism, including CBD [5]. This can contribute to person living with dementia (PLWD) and family frustrations, expense from seeking additional opinions and evaluations, and treatment delays. Once a clinician makes a diagnosis of CBS or suspected CBD (CBD can only be diagnosed definitively via autopsy/pathology), it is critical to educate individuals living with the condition and their families regarding the challenges relating to vocabulary and overlapping clinical-pathological syndromes. This education helps PLWD and families better understand their condition and the diagnostic delays. Understanding the heterogeneity can also help people living with dementia connect to advocacy organizations and resources. Persons living with CBS and suspected CBD are supported by organizations associated with 4R-tauopathies (e.g., PSP), frontotemporal dementia, and AD.

Education about CBS and CBD should include the limitations of current diagnostic strategies. At present, there are no clinically available biomarkers to confirm underlying 4R tauopathy pathology. Whereas tau-positron emission tomography (PET) may signal AD-related tau pathology, current tau tracers have much milder signals in suspected CBD and PSP [6]. Use of AD biomarkers (e.g., cerebrospinal fluid assays, amyloid PET) may help identify cases of CBS relating to AD rather than CBD. Identification of the pathology underlying CBS presentations has limited clinical implications currently, as there are no disease-modifying therapies for either the 4R-tauopathies or AD. Should disease-modifying treatments (e.g., targeting tau) become available, identifying an individual's underlying pathology will be critical.

Current treatment for CBS and suspected CBD remains symptom-based. For parkinsonian motor features in CBS, clinicians should prescribe levodopa preparations (levodopa combined with a peripheral dopa-decarboxylase inhibitor, e.g., carbidopa or benserazide) [7]. Efficacy is assessed after one month. Individuals with CBS typically have a modest levodopa response at best, even at high doses. In the presence of painful focal dystonia, botulinum toxin injections are another pharmacologic option. When myoclonus is present and disruptive (e.g., interfering with feeding or dressing), clinicians may try pharmacologic options such as clonazepam, levetiracetam, or valproic acid [8]. It should be noted that none of these approaches has specific approval from drug regulatory bodies (e.g., the Food and Drug Administration in the US).

Pharmacologic options generally have limited benefits, so a particular care need in CBS is connection to rehabilitation specialists at diagnosis and throughout the disease course [7]. Physical therapists help individuals with CBS with

strategies relating to gait, postural stability, and transfers (e.g., sit-stand). Occupational therapists identify optimal assist devices (e.g., walker, wheelchair), assess for orthotics (e.g., splints/braces) in the context of dystonia or contractures, and provide non-pharmacologic strategies for managing deficits relating to impaired extra-ocular movements or apraxia-related disability. Speech and language pathology assessments are needed for the language impairments seen in CBD (apraxia of speech, progressive non-fluent aphasia), described in greater depth in the section on Special Care Needs in Primary Progressive Aphasia. Speech and language pathologists are also critical for strategies to manage the dysphagia that is a common contributor to death in CBS and suspected CBD.

Special care needs also include treatment of CBS- and CBD-related symptoms that affect quality of life and be amenable to pharmacologic and non-pharmacologic interventions, such as constipation, urinary dysfunction, sleep disturbance, sialorrhea, and behavioural disturbances (e.g., apathy, depression, pseudo-bulbar affect) [7]. There are not good pharmacologic options for the cognitive impairments seen in suspected CBD, but cholinesterase inhibitors may be tried if amnesic deficits are present [7]. Where available, neuro-ophthalmologists can advise on pragmatic interventions for oculomotor disturbances, similar to PSP.

Palliative care is also critical in the context of CBS and suspected CBD. Palliative care is used in the setting of life-threatening illnesses, with a goal of identifying and treating physical, psychosocial, or spiritual concerns in order to improve the PLWD and family's quality of life [9]. In the setting of CBS and suspected CBD, this includes early advance care planning, discussions of expected prognosis to inform future planning, treatment of bothersome symptoms, connecting PLWD and families to resources (e.g., advocacy and support organizations), and providing carer support and counselling. Hospice is a type of palliative care initiated towards the end of life, often when an individual is expected to live 6 months or less. Hospice care, which may occur at home or in external facilities, provides end-of-life support to people living with CBS/CBD and their families including resources (e.g., hospital beds), counselling regarding the end of life, and symptom palliation (e.g., pain).

Thus, special care needs start with accurate diagnosis and education in CBS and suspected CBD, continue with symptomatic treatment with a focus on rehabilitation strategies, and continue through the end of life, with support throughout targeting both the person living with CBS/CBD and their family.

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## Expert essay

# Progressive supranuclear palsy and related 4 repeat tauopathies

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**P**rogressive supranuclear palsy (PSP) and other four microtubule binding domain repeat tauopathies (4R tauopathies) such as corticobasal degeneration (CBD) have been traditionally considered to be a cause of atypical Parkinsonism, however over the past decade it has been increasingly recognized to encompass a spectrum of clinical phenotypes involving behavioural, language and a range of movement abnormalities. The classic movement disorder clinical phenotype, now referred to as Richardson's syndrome (PSP-RS), was first described in 1964 by Steele, Richardson and Olszewski. Since then, no effective treatments for this uniformly fatal disorder have been identified. Despite ongoing efforts in clinical trials, there are no FDA approved treatments that reverse, stop, or delay progression of PSP, and current management is focused on ameliorating symptoms, maintaining function, and maximizing quality of life. As the condition progresses, symptoms can arise in multiple domains, with motor features often prominent, and the many options that are available to manage these symptoms can easily be overlooked in the routine care of 4R tauopathy patients [1–6]. (Table 1).

## Current symptomatic management

### Motor symptoms

#### *Bradykinesia/rigidity*

In line with pathological evidence of neuronal loss in the substantia nigra, patients with 4R-tauopathy often show features of an akinetic-rigid parkinsonism, but the response to dopamine replacement is typically modest and short-lived, and a prominent and sustained response is exclusionary for a diagnosis of CBD. However, phenotypes of PSP with predominant parkinsonism (PSP-P) may show a more measurable and sustained benefit from levodopa, and a cautious dose-escalation trial, both for diagnostic and therapeutic considerations, unless limited by other symptomatology.

Early involvement of ancillary health fields such as physical therapy and occupational therapy is also recommended to preserve functional independence, and a randomised clinical

trial provided strong evidence for this approach by demonstrating functional clinically meaningful improvements on the PSP rating scale using an intensive, aerobic, multidisciplinary, motor-cognitive, and goal-based rehabilitation program in 24 patients with PSP-RS.

#### *Dysphagia*

Aspiration pneumonia is the leading cause of death in PSP-RS, and progressive dysphagia marks the final stages of condition in most 4R-tauopathies, which may be worsened if behavioural symptoms such as impulsive and rapid eating are present. Vigilance for swallowing symptoms is recommended even in early stages, and some authors recommend routine swallow evaluation every six months. A measured approach to dysphagia treatment should carefully weigh reduction in aspiration risk alongside considerations of hydration, quality of life, preferences for end-of-life care, and respect for familial and cultural values.

A referral to a Speech-Language Pathologist (SLP) for an instrumental swallow evaluation such as a modified barium swallow (MBS) exam or fiberoptic endoscopic evaluation of swallowing (FEES) can detect overt or silent aspiration, which can lead to compensatory modifications including change in bolus size, texture, and presentation rate; changes in head posture; education on safe swallowing strategies; tactile and/or verbal cuing; adaptations to mealtime equipment; and assisted hand feeding as indicated.

If dysphagia is accompanied by weight loss, referral to a dietitian can help ensure appropriate caloric and nutritional intake and offering high-calorie nutritional supplements and favourite foods are often successful strategies to maintain weight. Placement of a percutaneous endoscopic gastrostomy (PEG) tube is a challenging and an ethically fraught decision in neurodegenerative disease, and early discussion of this issue should guide later management. However, it should be stressed that the risk of aspiration remains after PEG placement, as it does not prevent the aspiration of gastric contents and saliva, nor does it preclude ongoing oral intake, and in the cases where dysphagia is accompanied by

severe akinetic rigidity, PEG placement can lead to prolongation of a very poor quality of life and a difficult decision as to when to withdraw feeding for patients' families. Comfort-based late-stage dysphagia management centres around the identification of feeding strategies for pleasure, accepting that aspiration may occur.

### **Dystonia**

Increased tone can be the most prominent feature of 4R-tauopathies, especially in corticobasal syndrome, where dystonia is typically asymmetric and may affect an upper/lower extremity or present as cervical dystonia or blepharospasm. Pain resulting from dystonia is sometimes considerable and disabling, and general pharmacologic and non-pharmacologic strategies to manage pain should be employed, in collaboration with a chronic pain or palliative care specialist when necessary.

Local paralysis of focal dystonic muscles by botulinum toxin (e.g., Botox) is the mainstay of treatment for dystonia, with resultant improvement in dystonic posturing and pain reported in a subset of patients.

### **Imbalance/falls**

Postural instability and falls are central to the diagnostic criteria for PSP-RS and decreased regional glucose metabolism during locomotion has been observed in subcortical and cortical locomotor centres in PSP, supporting dysfunction of these brain regions as central to the condition. In addition, 4R-tauopathy patients may also have axial rigidity, dystonia, visual impairment, and impulsivity, which can exacerbate imbalance and lead to a high fall risk early in the condition.

Frequent exercise with careful monitoring to avoid injury from falls, including treadmill exercise, is beneficial for preserving balance and reducing falls in PSP-RS. For patients with gait freezing, use of ancillary devices such as walker-mounted laser pointers, visual and rhythmic cues, and arc turning can be employed. In one case report, transcranial magnetic stimulation (TMS) reduced freezing and falling, however this is still considered experimental, and more work will be necessary to evaluate its potential clinical use.

Weighted walkers (such as the U-Step walker) in combination with physical therapy have been shown in case reports to prevent falls and preserve independence, and assistive devices such as wheelchairs and mobility scooters should be introduced before injurious falls become frequent. Also, given the high risk of injurious falls including bone fracture, age-appropriate bone density screening should be considered, with initiation of calcium, Vitamin D, and bisphosphonates if indicated.

### **Involuntary movements (tremor/myoclonus/pseudobulbar affect)**

Tremor in 4R-tauopathies can be resting, postural, kinetic, dystonic, or mixed, but tremor typically occurs much less frequently than in diseases such as idiopathic Parkinson's disease, and data on pharmacologic efficacy specifically for tremor in this population are limited. As with standard treatment of tremor, a careful review of medications for offending agents should be conducted prior to initiation of pharmacologic therapy.

Myoclonus, often triggered by motor or sensory stimulation, is commonly associated with CBS. Pharmacologic treatment strategies include levetiracetam and clonazepam, though levetiracetam is associated with worsening behavioural changes, and the use of benzodiazepines is limited by sedation and increased fall risk. Piracetam, gabapentin, and valproic acid have been proposed as second line agents, though the evidence base for use in this cohort is poor.

Pseudobulbar affect (PBA) is characterized by inappropriate, disproportionate, or uncontrollable laughing and/or crying, and the social impact and resultant embarrassment can lead to restriction of social activities and a lower quality of life. Dextromethorphan-quinidine is FDA approved to treat PBA in a number of neurologic conditions, and efficacy has been demonstrated in clinical trials in dementia, stroke, traumatic brain injury, and ALS.

### **Motor speech difficulty and voice disorders**

Motor speech difficulty is common in 4R-tauopathies and can present either as focal or mixed dysarthrias, apraxia of speech, or hypophonia. Patients with PSP-RS most frequently present with a mixed dysarthrophonia characterized by hypokinetic and spastic features, with ataxic speech being less common. In the non-fluent variant of primary progressive aphasia (nfvPPA), apraxia of speech and a heterogeneous range of dysarthrias is common.

Regardless, speech therapy is recommended with an SLP, giving early consideration to Augmentative and Alternative Communication (AAC) aids (e.g., low or high technology pictographic boards, voice banking, and speech generating devices). AAC is ideally implemented prior to the development of anarthria or significant cognitive impairments, involves the patient's communication partners, and adapts to the patient's motor, cognitive, visuospatial, and ecological needs over time.

For hypophonia, the Lee Silverman Voice Treatment (LSVT) program has been shown to reduce motor speech and voice symptoms in patients with PD and can be considered in this population with or without use of a personal voice amplifier.

## Sialorrhea

The mechanism of chronic excess saliva in 4R-tauopathies is unclear but may be a result of impaired oral salivary clearance due to orobuccal apraxia or dysphagia. Anticholinergic agents like glycopyrrolate produce less CNS toxicity than scopolamine, the use of which be avoided due to significant systemic adverse effects on cognition, gait, and balance. Botulinum toxin injection to the salivary glands can reduce saliva production but may worsen dysphagia. SLPs or occupational therapists can be helpful in implementing techniques such as biofeedback or automatic cuing, while a dentist can help ensure good oral hygiene.

## Visual impairment

Ocular motor impairments frequently accompanied by diplopia are a core feature of PSP-RS, but may be seen in other 4R-tauopathies as the condition progresses. Other symptoms such as square wave jerks, blepharospasm, eyelid apraxia, dry eye syndrome, reduced blink rate, and photosensitivity may be present, and the resultant visual impairment may contribute to falls and impact daily life by causing difficulty with reading, eating, and maintaining appropriate social eye contact.

Botulinum toxin has been FDA approved for the treatment of blepharospasm since 1989, and many studies have reported that approximately 90% of patients will see a clinical benefit with this approach.

Occupational therapists are often helpful in patients with visual impairment of any cause, and many creative strategies are available to improve visual function. Examples include the use of an eye patch to eliminate diplopia, ensuring appropriate home lighting, removing clutter, improving visual contrasts, and the use of tilted mirrors and assistive reading technology (e.g., bookstands, magnifying glasses, and audio books).

## Cognitive symptoms

### Executive dysfunction

Cognitive impairment can occur even in motor-predominant syndromes, and subtle changes in executive function can often be uncovered with careful questioning and formal neuropsychological testing. If significant executive dysfunction is present, a thorough safety screen should be conducted that includes an assessment for medication mismanagement, financial risk and scams, home safety in the kitchen (e.g., use of stove), driving risk, and unsecured firearms.

Management of executive dysfunction includes implementing strategies such as environmental modifications (e.g., structured routine, minimizing distractors, simplifying tasks) and compensatory technology (e.g., daily planners, mobile devices), which may be facilitated through a referral to an occupational therapist. General recommendations on lifestyle modifications for other dementias may apply in this population and are reasonable to consider.

### Aphasia

In patients with cortical language dysfunction, such as the agrammatism and loss of fluency seen in nfvPPA, ongoing management by an SLP is recommended. Standard SLP rehabilitative interventions initially target syntax, and, as the condition progresses, include reading, spelling, and word finding, and a "Life Participation" approach aims to maximize functional communication and participation in desired life activities. Given the high prevalence of hearing loss in elderly patients, and the association of hearing loss with dementia, an audiology screening should also be considered.

### Memory dysfunction

The role of medications such as the cholinesterase inhibitors (CIs) typically employed in Alzheimer's disease is controversial in 4R-tauopathies. Cholinergic neuron loss has been observed in post-mortem studies in PSP, so use of CIs in this population is biologically plausible, but in a randomised clinical trial of donepezil in 21 patients with PSP-RS, a small positive effect on memory was more than offset by a dose-limiting worsening of motor symptoms, leading the authors to recommend against the use in this cohort [7]. Additionally, in patients presenting with frontal lobe impairments, CIs can worsen behavioural symptoms.

## Behavioural symptoms

### Behavioural changes

Typical behavioural changes in 4R-tauopathies are impulsivity and apathy, but disruptive behavioural changes can be a presenting or late feature, and behavioural impairment is the defining feature of bvFTD presentations, with diagnostic criteria that include disinhibition, apathy, loss of sympathy/empathy, unusual compulsions, and hyper-orality (impulsive overeating). If present, these behaviours can cause substantial distress to the patient's family and loved ones, contributing to caregiver burden and burnout, and management of these behaviours is a frequent reason for referral to a cognitive and behavioural specialist. While evidence of serotonergic deficit has prompted the use of selective serotonin reuptake inhibitors (SSRIs) to blunt impulsive and sexual behaviours in this cohort, the centrepiece of treatment

for diverse behavioural symptoms is working with available caregivers to develop non-pharmacologic strategies to modify behaviour.

The DICE model of behavioural intervention is recommended, whereby a careful and structured investigation into root causes of problematic behaviour is followed by the development of an action plan, with subsequent re-evaluation after implementation [8]. The authors of the DICE model also recommend searching for preventable/treatable causes of distress including untreated medical or psychiatric comorbidities, untreated pain, poor sleep hygiene, boredom and lack of sensory stimulation, a confrontational or overly nuanced caregiver communication style, an unpredictable daily routine, or an uncomfortable environment (e.g., chaotic, poorly lit, lack of recreational choices). Additionally, the development of a Tailored Action Plan has been shown to reduce problematic behaviours in frontotemporal dementia.

### Agitation/aggression

Though agitation is infrequent and typically mild in 4R-tauopathies compared to other neurodegenerative diseases, when present aggression poses a substantial challenge to caregivers and providers. The core of management is in providing behavioural strategies to the caregiver for redirection and environmental modification as discussed above. Specific strategies for management of agitation include implementation of any of a number of safe and low-cost activities: (1) music therapy, (2) pet therapy, (3) aromatherapy, such as lemon balm or lavender oil, (4) massage or touch therapy, (5) initiation of regular physical activity such as walks or exercise training, (6) scheduling of favourite hobbies, (7) and person-centred communication skills training for caregivers.

Due to lack of clinical trials and low incidence of aggression in 4R-tauopathy, much of the rationale for pharmacologic management is necessarily extrapolated from other dementia cohorts. Similar to trial data on agitation in Alzheimer's disease, we see a modest positive effect with selective serotonin reuptake inhibitors such as citalopram. Anti-psychotics should be avoided or only used for short durations in crisis situations, especially given the FDA black box warning of increased mortality in elderly patients with dementia.

### Anxiety/depression

Frequent screening for mood symptoms is recommended in all 4R-tauopathy syndromes, as patients are at high risk of suicide, and serotonergic deficit may be amenable to treatment with an SSRI. Generally, SSRIs such as paroxetine should be avoided due to a larger anticholinergic effect, while citalopram, escitalopram, sertraline, and fluoxetine are commonly prescribed. Cognitive behavioural therapy

(CBT), either self-guided or provided by a licensed psychologist, may be an effective non-pharmacologic intervention for mood symptoms.

### Apathy

Loss of motivation is often an early and unrecognised feature of many neurodegenerative diseases, including 4R-tauopathies, and may be mistaken for depressed mood. Apathy can be difficult to treat, but general strategies include selecting an activating antidepressant such as venlafaxine, while avoiding SSRIs that may worsen apathy, e.g., citalopram and escitalopram.

### Other symptoms

#### Insomnia/fatigue

Unlike in Alzheimer's disease, wake-promoting neurons are generally preserved in 4R-tauopathies, and therefore sleep problems typically involve insomnia rather than hypersomnia. In PSP-RS, severe insomnia is a characteristic feature, but unfortunately evidence for effective therapeutics is limited, though an ongoing clinical trial in PSP-RS is assessing the efficacy of zolpidem and suvorexant versus placebo. Melatonin and trazodone are commonly prescribed, while benzodiazepines should be avoided.

#### Urinary control/constipation

Problems with urination in PSP-RS can include frequency, urgency, retention, and incontinence. Typical pharmacologic agents such as anticholinergics (e.g., oxybutynin) should be avoided due to side effects of cognitive impairment and increased risk of dementia, and  $\alpha$ 1-adrenoceptor antagonists (e.g., tamsulosin) are associated with orthostatic hypotension that could increase falls. Antispasmodics (e.g., tolterodine, trospium, solifenacin, darifenacin) are a reasonable alternative. Newer agents, such as mirabegron, have been proposed to lead to less cognitive impairment, though specific studies in 4R-tauopathies have not been conducted. Alternatives include the use of bladder training, pelvic floor exercises, and adult pads. Electrical stimulation therapies such as percutaneous tibial nerve stimulation (PTNS) and sacral neuromodulation therapy are occasionally employed. Botulinum toxin can also be effective, and referral to a urologist is recommended for assistance in management.

Constipation is a common problem, often exacerbated by decreased fluid intake if urinary symptoms or dysphagia are present. Increased fluids, a high fibre diet, and regular physical activity and exercise are the foundation of treatment. If needed, polyethylene glycol, senna, lactulose, and bisacodyl suppositories are available over the counter.

## General considerations

### Education/caregiver support

Many patients, caregivers, and providers are unfamiliar with 4R-tauopathies and their associated clinical syndromes, and education about the condition process can be a key therapeutic intervention, especially early in the course of the dementia. Several resources are available for high-quality information about many syndromes caused by 4R-tau including CurePSP[9], the Association for Frontotemporal Degeneration[10], the PSP Association ([pspassociation.org](http://pspassociation.org)), Rare Dementia Support[11], and the Alzheimer's Association[12]. Patients interested in observational research in the United States can be referred to the ALLFTD research consortium[13], while European and Canadian patients can be referred to the Genetic Frontotemporal Dementia Initiative ([genfi.org.uk](http://genfi.org.uk)).

Given the multi-factorial symptoms in 4R-tauopathies, caregiver burden is often high, so frequent screening for caregiver burnout and increasing caregiver support are key factors to successful management. Several resources are available through organizations such as the Family Caregiver Alliance[14], and options are available through social

media platforms for those living remotely or who prefer not to attend in person. We recommend a multi-disciplinary approach with a careful review of available resources and coping strategies at each visit.

### End of life planning

Due to the progressive nature of neurodegenerative disease, discussion of goals of care should happen as early as possible, especially as judgement and reasoning may be impaired in later stages. Advance care planning should involve clarifying any limitations on treatments, including artificial feeding, resuscitation, and intensive care interventions, which can be recorded in documents such as the Physicians Orders for Life-Sustaining Treatment (POLST) form. Financial and medical power of attorney forms should be completed, along with creation of a will or trusteeship, and an elder law attorney can be helpful if issues arise. Finally, early decisions on end of life, including preferred place of care, place of death (e.g., home, hospice, hospital), and funeral plans, can ensure a patient's wishes are respected until the end. Autopsy and brain donation are options that can provide definitive diagnosis and assist in research efforts to find disease-modifying treatments.

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Table 1. Symptomatic Management of PSP

| Symptom                            | Pharmacologic Management  | Non-Pharmacologic Management   |
|------------------------------------|---|--|
| <b>Motor symptoms</b>              |   |  |
| <b>Bradykinesia/<br/>Rigidity</b>  | <ul style="list-style-type: none"> <li>Levodopa (trial is recommended)</li> <li>Amantadine (second-line)</li> <li>Dopamine agonist (avoid)</li> </ul>   | <ul style="list-style-type: none"> <li>Physical/Occupational Therapy referral</li> </ul>   |
| <b>Dysphagia</b>                   |   | <ul style="list-style-type: none"> <li>Speech language pathologist referral</li> <li>Compensatory modifications</li> <li>Comfort feeding/PEG tube</li> </ul>   |
| <b>Dystonia</b>                    | <ul style="list-style-type: none"> <li>Botulinum toxin (first-line)</li> <li>GABA agonists (use with caution)</li> <li>Dopaminergic/anticholinergic agents (avoid)</li> </ul>                     | <ul style="list-style-type: none"> <li>Occupational Therapy referral</li> <li>Passive stretching</li> <li>Guided muscle relaxation</li> <li>Strengthen antagonist muscles</li> <li>Surgical consultation (severe cases)</li> </ul>   |
| <b>Gait Freezing</b>               | <ul style="list-style-type: none"> <li>Levodopa (trial is recommended)</li> </ul>   | <ul style="list-style-type: none"> <li>Walker-mounted laser pointers</li> <li>Visual and rhythmic cues</li> <li>Arc turning</li> </ul>   |
| <b>Hypophonia</b>                  | <ul style="list-style-type: none"> <li>Levodopa</li> </ul>  | <ul style="list-style-type: none"> <li>Lee Silverman Voice Treatment (BIG)</li> <li>Personal voice amplifier</li> </ul>  |
| <b>Imbalance/<br/>Falls</b>        | <ul style="list-style-type: none"> <li>Levodopa (trial is recommended)</li> <li>Vitamin D, calcium</li> <li>Bisphosphonates</li> </ul>  | <ul style="list-style-type: none"> <li>Physical/Occupational Therapy referral</li> <li>Frequent exercise (treadmill)</li> <li>Multicomponent physical activity programs</li> <li>Assistive devices</li> <li>Transcranial magnetic stimulation</li> <li>Bone density screening</li> </ul> |
| <b>Motor Speech<br/>Difficulty</b> |   | <ul style="list-style-type: none"> <li>Speech language pathologist referral</li> <li>MBS or FEES</li> <li>Augmentative and Alternative Communication devices</li> </ul>  |
| <b>Myoclonus</b>                   | <ul style="list-style-type: none"> <li>Levetiracetam (use with caution)</li> <li>Clonazepam (use with caution)</li> <li>Piracetam, gabapentin, and valproic acid (no evidence for use)</li> </ul> |  |
| <b>Pseudobulbar<br/>Affect</b>     | <ul style="list-style-type: none"> <li>Dextromethorphan-quinidine</li> </ul>  | <ul style="list-style-type: none"> <li>Pocket education cards</li> </ul>   |
| <b>Sialorrhea</b>                  | <ul style="list-style-type: none"> <li>Botulinum toxin (use with caution)</li> <li>Glycopyrrolate/scopolamine (avoid)</li> </ul>  | <ul style="list-style-type: none"> <li>Speech language pathologist referral</li> <li>Occupational Therapy referral</li> </ul>  |
| <b>Tremor</b>                      | <ul style="list-style-type: none"> <li>Levodopa (rest tremor)</li> <li>Botulinum toxin (severe cases)</li> </ul>  | <ul style="list-style-type: none"> <li>Adaptive devices (weighted silverware)</li> </ul>   |
| <b>Visual<br/>Impairment</b>       | <ul style="list-style-type: none"> <li>Artificial tears (dry eyes)</li> <li>Zolpidem (gaze palsy; typically not used)</li> <li>Botulinum toxin (blepharospasm, eyelid apraxia)</li> </ul>         | <ul style="list-style-type: none"> <li>Neuro-ophthomology referral (prisms)</li> <li>Occupational Therapy referral</li> <li>Eyelid crutches (poorly tolerated)</li> <li>Tinted glasses</li> </ul>  |
| <b>Weight Loss</b>                 |   | <ul style="list-style-type: none"> <li>High-calorie supplementation</li> <li>Favourite foods</li> </ul>  |
| <b>Cognitive symptoms</b>          |   |  |
| <b>Executive<br/>Dysfunction</b>   |   | <ul style="list-style-type: none"> <li>Safety screen</li> <li>Occupational Therapy referral</li> <li>Compensatory technology</li> <li>Cardiovascular exercise</li> <li>Heart-healthy diet</li> <li>Cognitive and Social Engagement</li> <li>Address sleep or mood difficulty</li> </ul>  |

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| Symptom                       | Pharmacologic Management  | Non-Pharmacologic Management   |
|-------------------------------|---|--|
| <b>Language</b>               |   | <ul style="list-style-type: none"> <li>• Speech language pathologist referral</li> <li>• Audiology screen</li> <li>• Augmentative and Alternative Communication devices</li> <li>• Compensatory communication techniques</li> </ul>  |
| <b>Memory</b>                 | <ul style="list-style-type: none"> <li>• Acetylcholinesterase inhibitors (avoid if motor or behavioral problems)</li> <li>• Memantine (avoid)</li> </ul>  | <ul style="list-style-type: none"> <li>• Compensatory technology</li> <li>• Establishment of a routine</li> <li>• Cardiovascular Exercise</li> <li>• Heart-healthy diet</li> <li>• Cognitive and Social Engagement</li> <li>• Address sleep or mood problems</li> </ul>  |
| <b>Behavioral symptoms</b>    |   |  |
| <b>Problematic Behaviours</b> | <ul style="list-style-type: none"> <li>• SSRIs (avoid paroxetine)</li> </ul>  | <ul style="list-style-type: none"> <li>• DICE model of behavioural intervention</li> <li>• Assess for untreated medical or psychiatric problems</li> <li>• Address untreated pain</li> <li>• Address sleep or mood problems</li> <li>• Environmental modification</li> <li>• Establishment of a routine/schedule</li> <li>• Increase Activity (physical activity and hobbies)</li> <li>• Cognitive and Social Engagement</li> <li>• Caregiver education and modelling</li> <li>• Tailored Activity Plan</li> </ul> |
| <b>Anxiety/ Depression</b>    | <ul style="list-style-type: none"> <li>• SSRIs (avoid paroxetine)</li> <li>• Bupropion (second-line)</li> <li>• TCAs (typically not used)</li> <li>• ECT (refractory cases)</li> </ul>  | <ul style="list-style-type: none"> <li>• Cognitive behavioural therapy (CBT)</li> <li>• Mindfulness yoga</li> <li>• Guided meditation</li> </ul>   |
| <b>Apathy/ Inertia</b>        | <ul style="list-style-type: none"> <li>• "Activating" antidepressants (venlafaxine)</li> <li>• Methylphenidate (use with caution)</li> <li>• Avoid SSRIs (may worsen apathy)</li> </ul>   | <ul style="list-style-type: none"> <li>• Regular exercise</li> <li>• Scheduled activities</li> </ul>   |
| <b>Agitation/ Aggression</b>  | <ul style="list-style-type: none"> <li>• SSRIs (e.g., citalopram)</li> <li>• Antipsychotics (avoid if possible)</li> <li>• Low-dose lithium (avoid if gait problems)</li> </ul>   | <ul style="list-style-type: none"> <li>• Music therapy</li> <li>• Pet Therapy</li> <li>• Aromatherapy</li> <li>• Massage/touch therapy</li> <li>• See Problematic Behaviours above</li> </ul>  |
| <b>Other symptoms</b>         |   |  |
| <b>Insomnia/ Fatigue</b>      | <ul style="list-style-type: none"> <li>• Melatonin</li> <li>• Suvorexant</li> <li>• Trazodone (use with caution)</li> <li>• Benzodiazepines (avoid if possible)</li> </ul>  | <ul style="list-style-type: none"> <li>• Regular physical exercise</li> <li>• Sleep hygiene</li> <li>• Screen for sleep disordered breathing</li> <li>• Establish a routine</li> <li>• Strategic napping</li> </ul>  |
| <b>Urinary Control</b>        | <ul style="list-style-type: none"> <li>• Mirabegron</li> <li>• Antispasmodics (tolterodine, trospium, solifenacin, darifenacin)</li> <li>• Anticholinergics (oxybutynin; avoid if possible)</li> <li>• Botulinum toxin</li> </ul> | <ul style="list-style-type: none"> <li>• Referral to Urology</li> <li>• Bladder training</li> <li>• Pelvic floor exercises</li> <li>• Electrical stimulation techniques</li> <li>• Adult pads</li> </ul>   |
| <b>Constipation</b>           | <ul style="list-style-type: none"> <li>• Polyethylene glycol, senna, lactulose</li> <li>• Bisacodyl suppository</li> </ul>  | <ul style="list-style-type: none"> <li>• Increase fluid intake</li> <li>• High-fiber diet</li> <li>• Regular physical activity</li> </ul>  |

## Expert essay

# Parkinson Disease Dementia

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**P**arkinson's disease (PD) is the second most common neurodegenerative disease after Alzheimer's disease. Although PD is defined as a movement disorder, dementia is a common complication, affecting up to a third of patients, and with a cumulative prevalence over 80% 20 years post diagnosis [1]. Parkinson Disease Dementia (PDD) is one of the most debilitating consequences of PD, associated with rapid functional decline, poor quality of life, high mortality, and greater caregiver burden [2]. There is significant variability in the timing of onset and rate of cognitive decline, in addition to heterogeneity in the cognitive profile of those affected. PDD shares many clinical and pathological features with dementia with Lewy bodies, and the two disorders are often combined as Lewy body dementias and share management strategies and challenges [2]. Thorough initial assessment including review of cognitive and psychiatric symptoms is essential to guide optimal treatment and follow up. Functional capacity and other non-motor symptoms as discussed below are also important. This allows the specific needs of the patients and their caregivers to be targeted with individualized care including medication, care packages and future planning [3]. Here we describe some of the major affected domains to be considered in the management of PDD.

## Motor symptoms

PDD usually occurs at an advanced stage of disease, where the pharmacotherapy may be less effective for motor symptoms, associated with increased adverse effects and greater medication resistance [4]. Non-pharmacological approaches such as physical, speech and occupational therapies may be of additional benefit here. Deep brain stimulation (DBS) can be a consideration for some patients, but severe cognitive impairment is a contraindication due to the potentially deleterious effects on cognition [2].

## Cognitive impairment

Disease-modifying treatments are not available for PD and thus there are no drugs available to prevent PDD. There is Level 1 evidence for cognitive effects of cholinesterase

inhibitors (CIs), particularly rivastigmine and donepezil, in PDD, whereas evidence for the use of memantine in PDD is mixed [5].

Mild cognitive impairment (MCI) is also common in Parkinson's disease and associated with a high risk of progression to dementia, with rates at 5 years of almost 60%. Effective treatments targeting this stage are of great importance with the potential to slow further symptomatic progression or modify the condition. However, relatively few RCTs have been conducted in this patient group and currently there is no evidence for treatment of MCI-PD.

Non-pharmacological approaches such as cognitive training, physical exercise and non-invasive brain stimulation have also been trialled in PDD with some short-term efficacy, particularly for executive function domains. However, findings are mixed and there are few well-designed trials [6,7]. Given the likely multifactorial aetiology underpinning the cognitive impairment in PDD, dual approaches combining pharmacological and non-pharmacological therapies may be most effective but more studies with this targeted approach are needed.

## Psychiatric symptoms

Neuropsychiatric symptoms such as depression, anxiety, psychosis, and apathy are very common in PD, and are particularly common in PDD. Robust evidence supports the use of antidepressants and cognitive behavioural therapy for affective symptoms in PD, but there are no studies in PDD specifically [8]. For psychosis associated with PD (PDP), initial management includes excluding delirium and other potentially exacerbating causes such as dopaminergic medications. Where visual hallucinations co-exist in PDD, rivastigmine is associated with benefits for both cognition and neuropsychiatric symptoms. While quetiapine is widely used in the treatment of PDP, little evidence supports this approach, whereas clozapine is most efficacious but is rarely used first-line due to the extensive monitoring necessitated by the risk of agranulocytosis. Again, no studies of antipsychotics exist in PDD. Use of any antipsychotic in PDD is associated with a high risk of side-effects and an increased

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mortality risk, and thus treatment decisions need to balance the risks and severity of symptoms, with pharmacotherapy not always indicated. Pimavanserin is a novel serotonin 2A (5-HT<sub>2A</sub>) receptor inverse agonist and antagonist approved by the FDA for treatment of psychosis in PD and a tolerable side-effect profile [9]. There is some evidence that the effect is particularly strong in patients with cognitive impairment and can prevent relapse in dementia-related psychosis [10]. There are also non-pharmacological strategies such as cognitive behavioural therapy, improving sleep hygiene and caregiver education that can be considered [2].

## Sleep behaviour disorders

Sleep disturbances are common in PDD and can include a spectrum of sleep disorders. There are few RCTs to guide management of sleep in PDD, but optimal treatments are tailored individually to the prominent symptomology and diagnosis. RBD is particularly common in PDD, here rivastigmine has been associated with a reduction in episodes and clonazepam and melatonin may be useful but RCTs are lacking to support this. The use of benzodiazepines is associated with increased risk of falls, delirium and cognitive deterioration and should be used with care [3].

## Autonomic symptoms

There are few clinical trials targeting the management of autonomic symptoms in PDD, but evidence can be extrapolated from PD and older adults. Dizziness and postural hypotension are particularly common in PD both directly as a consequence of the process of the condition and secondary to the medication used. This, in addition to gait disturbances,

can increase postural instability and risk of falls. As with constipation, initial considerations include dietary modifications, review of current medication and lifestyle changes [3].

## Frailty and sarcopenia

Frailty and sarcopenia are common in PD and associated with negative outcomes [11]. Management of comorbidities, multicomponent exercise, nutrition interventions and reducing polypharmacy can improve frailty and sarcopenia and reduce cognitive decline, hospital and nursing home admissions as well as mortality [11]. Physical exercise can improve quality of life and functional independence, depression, and cognition [2].

Nutrition in PDD is another important aspect to consider, chronic illness is often associated with increased energy demands which may require special care or supplementation. Furthermore, inherent complications such as dysphagia and other motor symptoms may necessitate texture modification of diet while some PD medications can be altered by foods. Dietician support should be provided to guide the necessary dietary changes and avoid nutritional insufficiency. Strategies to prevent falls are important, and thus multidomain and individualized interventions are required in persons living with PDD [2].

Finally, social issues, such as socioeconomic deprivation and social isolation are important issues to identify and manage. Unaddressed, these issues are associated with poor adherence to treatments, increased adverse events, malnutrition, higher incidence of depression and falls. Psychosocial interventions with group activities have the potential to improve social integration in PDD.

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## Expert essay

# Dementia with Lewy Bodies

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Lewy body dementia is characterised by abnormal deposits of the protein alpha-synuclein in the brain. It is the second most common cause of neurodegenerative dementia following Alzheimer's disease [1], and includes two related disorders, dementia with Lewy bodies (DLB), and Parkinson's disease dementia (PDD). Diagnosis of DLB is based on a set of consensus criteria including core clinical features and indicative biomarkers [2], and accounts for 4–8% of dementia patients in clinic-based studies [3]. Post-diagnosis management and support are crucial, as DLB is a complex condition which significantly affects both persons living with dementia (PLWD) and family carers.

Cognitive symptoms are a central feature of DLB. These often disproportionately affect executive, visuo-perceptual and visuo-spatial functions. Marked unpredictable fluctuations in cognitive performance also occur frequently, often with significant variability in attention and functional abilities over the day. Memory impairments generally emerge later in the course of the condition. Recently published, evidence-based guidelines give clear recommendations regarding medication provision [4]. Oral or transdermal cholinesterase inhibitors are generally indicated with the choice influenced by ease of administration, and the side effect profile. Memantine can be prescribed where cholinesterase inhibitors are poorly tolerated or contra-indicated. It may sometimes also be used in combination with cholinesterase inhibitors, but the benefits of this need further study.

Non-pharmacological approaches are important alongside medication and may be particularly valuable in countries where cost or availability limit medication options. Strategies include cognitive stimulation, memory aids, increased social interaction and stimulation, and exercise. There is, however, a lack of DLB specific studies of non-pharmacological interventions, and there is thus a clear and urgent need for future research to build this evidence [5]. Not only can non-pharmacological strategies alleviate many difficulties, but they may also relieve carers' feelings of helplessness through providing opportunities to support the care-recipient.

## Visual hallucinations

Persons with DLB present with a variety of neuropsychiatric symptoms, most notably hallucinations. These are typically visual but can occur in other sensory modalities. Over the course of the condition, approximately 70% of people with DLB experience complex visual hallucinations (VH) [6]. These are generally well-formed and recurrent, often involve people or animals, and may be distressing. The cultural meanings attached to VH may make people reluctant to disclose them, and sensitive questioning (including with a caregiver or informant) is important. Understanding can be improved through psychoeducation. Frequency can be reduced with environmental adaptations such as good lighting, plain furnishings, and the reorganisation of furniture or other items that trigger misperceptions. Where hallucinations are regarded as benign or even comforting, they may not require pharmacologic treatment. Explanations concerning impaired visual processing may be reassuring. Other neuropsychiatric symptoms include delusional beliefs. These may respond to antipsychotics although a very cautious approach is needed, with regular review needed due to a high risk of sensitivity in DLB. There is no evidence to favour any individual anti-psychotic drug in DLB although atypical antipsychotic formulations appear to have the least side-effects. Other neuropsychiatric symptoms include apathy, depression, and anxiety. These may respond positively to environmental and social stimulation including music [7].

## Sleep disturbances

Sleep is significantly impacted in DLB. Disorders include REM sleep behaviour disorder (RBD) in which dream re-enactments occur causing movements and vocalisations. Symptoms of RBD often appear many years before cognitive dysfunction [8]. Falling out of bed and injuries to bed partners may occur and treatment with clonazepam and/or melatonin can be effective. Support strategies include placing the bed on the floor, removing or padding potentially hazardous objects to reduce injuries and encouraging a bedpartner to sleep separately if appropriate. Other sleep disturbances

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include excessive daytime sleepiness, difficulties wakening, insomnia, and restless leg syndrome. Evaluation by a sleep specialist and polysomnography can help with identification and treatment. Management strategies include promoting sleep hygiene, regular exercise, avoidance of caffeine stimulants and alcohol in the evening, establishing regular sleep patterns with restricted daytime naps, and comfortable bedding and room temperature.

## Parkinsonism

Parkinsonian motor symptoms frequently feature in DLB. These may include tremor, muscle rigidity (stiffness), slowness of movement, loss of spontaneous voluntary movement and impaired balance. As DLB progresses, the severity and type of these show significant individual variation. Strengthening and flexibility exercises and gait training can be beneficial, as can safety-proofing the home environment to reduce the falls risk. Motor symptoms may be treated with levodopa medications used for Parkinson's disease; however, improvements can be accompanied by worsening cognitive symptoms, particularly hallucinations, making disease management difficult. Finding a knowledgeable clinician able to balance this complex medication side effect profile is challenging and it is important to discuss treatment priorities with the patient and family.

## Autonomic dysfunction

The autonomic nervous system can also become significantly impaired, resulting in symptoms such as orthostatic hypotension, syncope, falls, gastrointestinal changes, and urinary and bowel problems [4]. Regular review of physical symptoms, referral to therapists and continence advisors

may improve quality of life and the ability to maintain social interactions. Psychoeducation can help people understand the multi-system presentation of DLB.

## Helping carers

Carers of persons with DLB experience poorer quality of life due to the complex and variable nature of symptoms [9]. Although widely recognised as important, the provision of individualised, tailored psychoeducation and emotional support for people supporting a family member is often lacking. Notable needs include understanding symptomology, and psychological support to manage hallucinations, cognitive fluctuations, sleep disturbance and apathy, symptoms that can cause significant caregiver stress. For example, carers can significantly reduce conflict by adapting their responses to hallucinations, or delusions and avoiding challenging or correcting the person with DLB. Psychoeducation can improve understanding where cognitive fluctuations are perceived as lack of co-operation or dis-interest. Carers can also benefit from counselling and/or psychotherapeutic interventions to help manage their own mental health needs. Psychosocial groups and/or couple interventions specific to the needs of those with DLB may also be beneficial for identifying practical solutions to day-to-day frustrations and obtaining emotional support from similarly placed peers and should be explored [10].

Further approaches to care management to support people with DLB are freely available online [11], such as this resource developed by the UK National Institute for Health funded Diamond Lewy programme and designed to assist clinicians and raise awareness.

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## Expert essay

## Alcohol-related dementia

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With the number of cases of dementia steadily on the rise due to population aging, researchers have focused on modifiable factors to prevent the future onset of the condition. Alcohol use has been identified as a risk factor for dementia and cognitive decline. Its excessive use is associated with a wide range of physical, psychological, and social consequences. Alcohol consumption triggers a neuroinflammatory response which, if prolonged, can lead to substantial volume loss in both grey and white matter associated with characteristic cognitive deficits, and, in extreme cases, with dementia.

Autopsy evaluations and in vivo neuroimaging of the brains of diagnosed human alcoholics have revealed that 78% of this population exhibits some degree of brain pathology. Human studies using brain imaging or examining brains after death have found that alcoholics have smaller brains, particularly frontal cortical regions, and white matter brain regions that represent the wiring connecting the brain [1]. There are conflicting data on whether moderate alcohol intake or intake of particular alcoholic beverages is related to a decreased risk of dementia.

Furthermore, definitions of “light”, “moderate”, and “heavy” drinking have varied widely among studies of older adults’ alcohol consumption and cognitive function outcomes. However, the qualitative analysis indicated that the protective effects only exist for wine consumption (up to four glasses daily). In general, it appears that the benefit is less in those individuals carrying the APOE ε4 allele. As alcohol level increases, the age at incident moderate cognitive impairment decreases, especially among those with at least one APOE ε4 allele. The main element favouring wine lies in its flavonoid content and its antioxidant activity, but the increase in wine consumption is associated with factors that, in turn, promote the onset of dementia, such as hypertension and diabetes. Furthermore, heavy drinking is associated with increased haemorrhagic stroke risk, and there is some consensus about this relation in relevant reports.

Understanding how medical comorbidities, such as hypertension and liver disease, interplay is also limited. Memory, executive function, and visuospatial ability may be affected, with general intelligence, declarative memory, language skills, and motor and perceptual abilities less impaired [2].

Alcohol-related dementia (ARD) has received little recognition as a distinct clinical entity, predominantly due to doubts regarding the etiopathogenesis and lack of pathophysiological profile typical for ARD.

The 5<sup>th</sup> edition of the *Diagnosis and Statistical Manual of Mental Disorders (DSM-5)* recognizes that the cognitive deficits seen with chronic excessive alcohol use are on a spectrum and include major or mild alcohol-induced neurocognitive disorders [3]. Oslin and colleagues proposed the broader diagnostic scheme and criteria for ARD [4]. According to these researchers, diagnosis of *probable ARD* is indicated when clinical symptoms of dementia are observed in the context of a significant history of alcohol use. Symptoms must persist for 60 days after cessation of alcohol use. The criteria exclude dementia secondary to focal vascular lesions and head trauma, cases with multi-risk factors and multiple brain infarctions, and those that occur after 10 years’ abstinence from alcohol use.

The incidence and prevalence of ARD varies across studies. The correlation between the amount and duration of alcohol consumption and the occurrence of ARD is not well established: this is due to different types and strengths of liquor available across the countries, varying definitions of leisure drinking and pathological drinking, different cultural beliefs, and different definitions of a standard drink. Researchers found that men who drank heavily (defined as >36 g/day; equivalent to >2 or 3 drinks/day) experienced a more rapid decline over 10 years in global cognition, memory, and executive function than those with light to moderate consumption (defined as <20 g/day) [5]. Older drinkers show greater alcohol-related cognitive changes and are less likely to recover function once they cease drinking, even after drinking history is controlled for [6].

Particular caution is needed among individuals with mild cognitive impairment (MCI) who continue to drink alcohol. Since alcohol-related MCI and dementia can persist after cessation of drinking, these conditions can be difficult to diagnose and they could also confound the course of other neurodegenerative diseases, including Alzheimer’s and vascular dementia. Light-to-moderate drinking compared with non-drinking has been associated with an increased risk of conversion from MCI to AD. MCI consumers of more than

14.0 drinks per week have the most severe cognitive decline compared with consumers of less than 1.0 drink per week. Heavy drinking (Eight or more standard alcoholic drinks per week) and drinking larger amounts of hard liquor are associated with a faster rate of cognitive decline in AD patients.

Despite the clinical importance of ARD, very few treatment options have been proposed and studied. If ARD is detected early enough, the effects may be reversed by abstinence. Chronicity and severity of alcohol use have been highlighted to be associated with worsening cognitive performance and determine the rate and the extent of cognitive recovery. The mainstay of ARD's treatment is abstinence. Recovery from alcohol dependence is associated with increases in cortical grey matter volume with 1 month's sobriety, increases in white matter volume, and decreases in ventricular size. Family and caregivers facilitate success and must be actively educated and supported.

Cholinesterase inhibitors (rivastigmine and donepezil) improved cognitive deficits in patients diagnosed with ARD [7][8]. Memantine, a low-affinity NMDA receptor

antagonist, has also shown promise in improving cognition in ARD. It must also be remembered that many patients with alcohol problems have a coexisting psychiatric disorder that will need to be managed. Where depression is suspected, selective serotonin reuptake inhibitors should be favoured over antidepressants with sedative and anticholinergic properties. Medical management of cognitively impaired individuals with alcohol use disorders should include treatment of medical conditions associated with sustained, heavy alcohol use (hypertension and hepatic cirrhosis are medical conditions often seen in individuals with alcohol use disorders that may have detrimental effects on cognition).

It is established that cognitive rehabilitation and neuropsychological training helps in slowing cognitive decline and accelerates the acquisition of new cognitive capabilities [10]. It is essential to consider the cognitive dimension of alcohol-dependent patients to adapt their treatment and to palliate their difficulties in activities of daily living.

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## Expert essay

# Down syndrome associated with Alzheimer's disease

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**D**own syndrome (DS), caused by a triplication of chromosome 21, is the most frequent cause of intellectual disability of genetic origin. The estimated life expectancy of people with DS has increased substantially, now exceeding 60 years of age [1]. As a consequence, individuals with DS are now experiencing a high incidence of age-associated health problems, most importantly young or early-onset Alzheimer's disease (AD), which has a cumulative incidence higher than 90% at age 65 years [2]. Consequently, AD is now the leading cause of death in this population [3]. The association between DS and AD (DSAD) is mainly explained by the presence of an extra copy of the amyloid precursor protein gene, located on chromosome 21 [4]. Assessment and care of people with DS living with dementia may be more complex than in the general population (see World Alzheimer Report of 2021, Chapter 23, pp 291–3) [5].

Currently, there are no approved disease-modifying drugs for the treatment of AD in DS. Furthermore, there is insufficient evidence to support the use of the drugs approved for the treatment of AD (only small clinical trials have been done in people with DS), however, a common clinical practice is to use cholinesterase inhibitors, but not memantine [4]. Some health concerns are more common in adults with DS, especially in elderly individuals, and should also be monitored regularly, as most of them are easily identifiable and treatable, and may impact the patient's quality of life [5]. Adults with DS are at risk of developing premature cataracts and keratoconus, as well as hearing problems [6]. Hypothyroidism, certain mental health disorders, and obstructive sleep apnoea are also common in adults with DS and may impact cognitive outcome and accelerate the progression of AD dementia [7]. Due to this higher prevalence of health problems, together with significant limitations in both intellectual functioning and in adaptive behaviour, people with DS tend to develop early frailty. The early identification and management of frailty is important, as many people with DS could have special care needs more often and at an earlier stage of life than people from the general population.



In some cases, treatments for behavioural and psychological symptoms of dementia are needed. Agitation, hyperactivity, and psychotic symptoms appear to be more prevalent in persons with both DS and dementia than in those with DS but do not have dementia, and are associated with increased carer burden [8]. As people with learning disabilities have a higher risk of side-effects when using psychotropic medications (and may find it difficult to report adverse effects), physicians should always seek to use drugs with the fewest side effects. All treatments should be started gradually, more than in the general population and, if possible, at lower doses. Individuals with DS have also an increased risk for late-onset myoclonic epilepsy (LOMEDS), which is linked to the development of symptomatic AD and increases with the severity of the condition (more than 50% of patients with DSAD will develop LOMEDS) [9].

In addition to the pharmacological treatment of dementia and associated medical or physical problems, much of the management of the symptoms associated with AD consists of providing appropriate support to the person living with dementia and carers at the different stages of the condition. Alzheimer's disease in people with DS may evolve rapidly, so it is imperative that care be adjusted to the changing needs.

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It is extremely important to help carers to understand the basic features of AD as well as to help them to learn general caregiving principles and strategies for a better management of the symptoms. It is crucial to create support networks to cope with the condition, and to plan ahead an environment that ensures the patient's safety and that can support increasing needs over the span of the condition[10]. Persons with DSAD often develop early impaired perception

of depth that, together with visual impairments, gait and balance disturbances, increase the risk for falls if the environment is not kept free of obstacles. Finally, it is also of importance to assess the person's psychosocial environment, especially for those remaining at home, since sometimes the main carers are elderly parents with their own health problems and special needs.

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## Expert essay

# Young onset dementias

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The diagnosis of dementia occurring at a younger age is difficult because of the lower prevalence of neurodegenerative disease in younger persons and the large variability in aetiologies not due to neurodegenerative disease [1]. In this essay, we will focus only on neurodegenerative diseases. The specific needs of this population are summarized in Table 1.

In the international literature, young onset dementia (YOD) refers to people with Alzheimer's disease (AD) or related disorders before the age of 65. The consideration in society of the particularity of YOD patients, their needs and those of their relatives is quite recent. The diagnosis of neurodegenerative diseases in young patients is often missed and remains difficult to establish due to a lower prevalence and more frequent atypical clinical features than in older people.

Early onset Alzheimer's disease (EOAD) often has atypical non-amnesic presentations with executive, language, or visuo-spatial dysfunction [2]. Other persons may only show behavioural changes leading to a diagnosis of psychiatric pathologies before a diagnosis of neurodegenerative diseases. In a recent study, 32% of EOAD patients had an atypical complaint that first manifested itself in the professional setting, leading to the initial diagnosis of a burnout syndrome. Among the EOAD persons with a professional activity (70%), a burnout-like syndrome was the first diagnosis in almost half of the cases [3].

The diagnosis of neurodegenerative diseases is also often not the first to be mentioned in such young persons, who are often referred to other specialists before neurologists. Misdiagnosis is not uncommon and can result in an average

Table 1. Specific care needs of persons with early onset dementias

|                                    | Critical issues   | Possible actions  |
|------------------------------------|---|---|
| <b>Medical specificities</b>       | Atypical presentations leading to challenging and delayed diagnosis, with an anxiety-provoking diagnostic wandering | Improve medical staff's knowledge of these situations to better interpret and detect the initial signs of the disease |
|                                    | Rapid disease progression leading to higher functional impairment at diagnosis                                      |   |
|                                    | More frequent associated symptoms (extrapyramidal syndrome, myoclonus, seizures)                                    |   |
|                                    | Possible hereditary diseases  | Specific medications (L-dopa, levetiracetam...)   |
| <b>Psychological specificities</b> | Low anosognosia and high anxiety  | Anti-anxiety drugs, psychological support, discussion groups...   |
|                                    |   | Raise awareness among occupational health physicians  |
|                                    | Initial work-related disorders  | Psychological assistance for spouses and children   |
|                                    |   | Information and support by specialised teams  |
|                                    | School-aged children  |   |
| <b>Medico-social specificities</b> | Implications for relatives of a hereditary disease  |   |
|                                    | Scarcity of day or complete care structures for these patients  | Anticipate as much as possible the administrative steps that can take time  |
|                                    |   | Provide the most accurate information on all possible financial aid and assist in the process                         |
|                                    | Sometimes expensive care while household resources are impacted by the disease                                      |   |

1.6-year delay before diagnosis compared to persons living with late onset dementia (LOD) [4]. The rapidity of clinical decline is also one of the main elements differentiating the YOD and LOD, especially in AD. Several studies indicate that YOD patients have a more aggressive disease course than LOD [5], highlighting the importance of early diagnosis and intervention. The rare hereditary forms of AD and FTD (frontotemporal dementia) most often concern young persons, which may constitute another particularity of YOD.

## Psychological disorders care

Young persons living with dementia (PLWD) are often still actively working, have active social lives and children at home. Their spouses work and cannot stay easily with the person during the day, who, in case of work stoppage, stay alone at home. All these points explain the importance of psychological distress of young PLWD. Furthermore, the topography of initial lesions in EOAD are predominant in cortical parietal lobes, leading to instrumental cognitive dysfunction (aphasia, apraxia, acalculia, visuo-spatial disturbances) without anosognosia. This reinforces the disarray and distress of the PLWD. When the diagnosis is finally announced, it is often experienced by the PLWD's relatives as a relief after this long period of diagnostic wandering, but it also constitutes an upheaval in their daily roles and responsibilities [6]. Due to the stigma of the dementia diagnosis, the social life of the PLWD and their family may gradually diminish [7]. The role of their family members prior to the condition changes from spouse or child to a carer role [9]. The children of persons with YOD may still be of school age or be young adults and the difficulties they face are often different from those affecting older people: gradually become a carer instead of receiving parental care, trying to protect and preserve their parent's dignity, coming to terms with their parents being unable to function fully in their parental role. PLWD and families need education on the condition and its consequences to allow them a better understanding and increase their confidence in the proposed treatment. Persons with YOD often have higher levels of awareness of the condition, which are a source of anxiety and depression. It is therefore important to inform them about psychological support, such as through caregiver or patient discussion groups, associations of patients, individual care, or respite care. The rare cases of hereditary diseases must lead to appropriate information of the patient's relatives, in particular her/his children, by specialized teams in order to discuss the possible implications that this may have for them.

## Rehabilitation and medico-social care

At the time of diagnosis, persons with YOD are often still working. The continuation of the professional activity, although sometimes desired by the PLWD, is often difficult,

leading to a work stoppage, or when it is possible, an adaptation of the workstation. It is important to refer the PLWD and their carers to a social worker to help them set up assistance at home and with administrative and legal procedures. Financial aid is available depending on the country.

Different forms of rehabilitation may be offered, among others speech and language therapy, physical therapy, occupational therapy, group therapy, day care service. Young PLWD often want to continue to be active, and support needs to be individualized, allow them to take the initiative, offering guidance rather than doing everything for them. When the PLWD can no longer stay at home, it may be necessary to approach specific structures, because the classic medicalised nursing homes are not adapted to these young persons.

## Drug therapy

The approved pharmacological treatments for YOD are similar to those for LOD. At present, except in rare cases related to a curable cause, drug treatment is symptomatic. In AD, pharmacological treatment includes cholinesterase inhibitors and/or memantine, which offer symptomatic benefit but do not modify the progression of the condition. In cases of parkinsonian syndrome (AD, LBD, CBD, PSP), clinicians may prescribe levodopa treatment, despite a response often modest in young PLWD. Depression or anxiety are frequent in all YOD and should be helped with antidepressants or anxiolytics. Selective serotonin reuptake inhibitors are privileged, as they do not tend to worsen cognition but their cardiac tolerance in combination with cholinergic therapy should be monitored. The prescription of anticholinergic antidepressants is contraindicated. Myoclonus is more common in EOAD and can be relieved by treatments such as levetiracetam. Finally, in the absence of disease-modifying interventions, PLWD and families are often interested to participate in therapeutic trials. However, because their cognitive and functional decline is more rapid, many of them no longer meet the inclusion criteria of most trials at the time of diagnosis.

## Conclusions

The main characteristics of the YOD are their often-rapid evolution, requiring the earliest possible diagnosis (although it is often challenging) in order to be able to introduce potential curative treatments early enough, and the fact that the PLWD are often of working age and may have young children, leading to different issues from those encountered in older people.

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## Expert essay

# Very late onset dementias ( $\geq 85$ )

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The significant increase in life expectancy during the past century means that a sizeable proportion of the world population can expect to reach tenth and eleventh decades during their life. The world-wide population of people aged 90 and older, estimated to be about 21 million at present, is expected to burgeon to more than 113 million people by 2060 [1]. This profound increase makes the oldest old the fastest growing segment of the population and, with the very high incidence of dementia in this age group, it is projected that half of all patients in the US with a diagnosis of Alzheimer's disease (AD) will be over age 85 by 2050 [2]. While numbers differ globally, essentially all countries will be dealing with this "tsunami" to varying degrees. Increasingly, we have come to understand that causes and risk factors for dementia in the very elderly differ from younger elderly. It is, therefore, prudent to consider the specific characteristics of dementia in this age group as it relates to aetiology, diagnostic challenges, and possible differences in risk and protective factors.

More than any other age group, dementia in the oldest old is typically related to multiple neuropathologic changes at autopsy [3]. Moreover, greater numbers of neuropathologic diagnoses are associated with greater dementia severity as well as higher risk [4] (Figure 1).

While AD remains the most prevalent neuropathologic change in the very old, other degenerative pathologies such as forms of vascular disease, hippocampal sclerosis of aging (HS) [5] and Transactive response DNA binding protein of 43 kDa (TDP-43) pathology become more frequent in the oldest old and are highly associated with dementia. In addition to large and small infarcts, studies note that atherosclerosis, arteriolosclerosis, and cerebral amyloid angiopathy are important vascular contributors to dementia in the oldest old [6]. Limbic predominant Age-related TDP-43 Encephalopathy (LATE) is a newly coined term to denote the significance of TDP-43 pathology in this age group [7]. Present in about a third of the

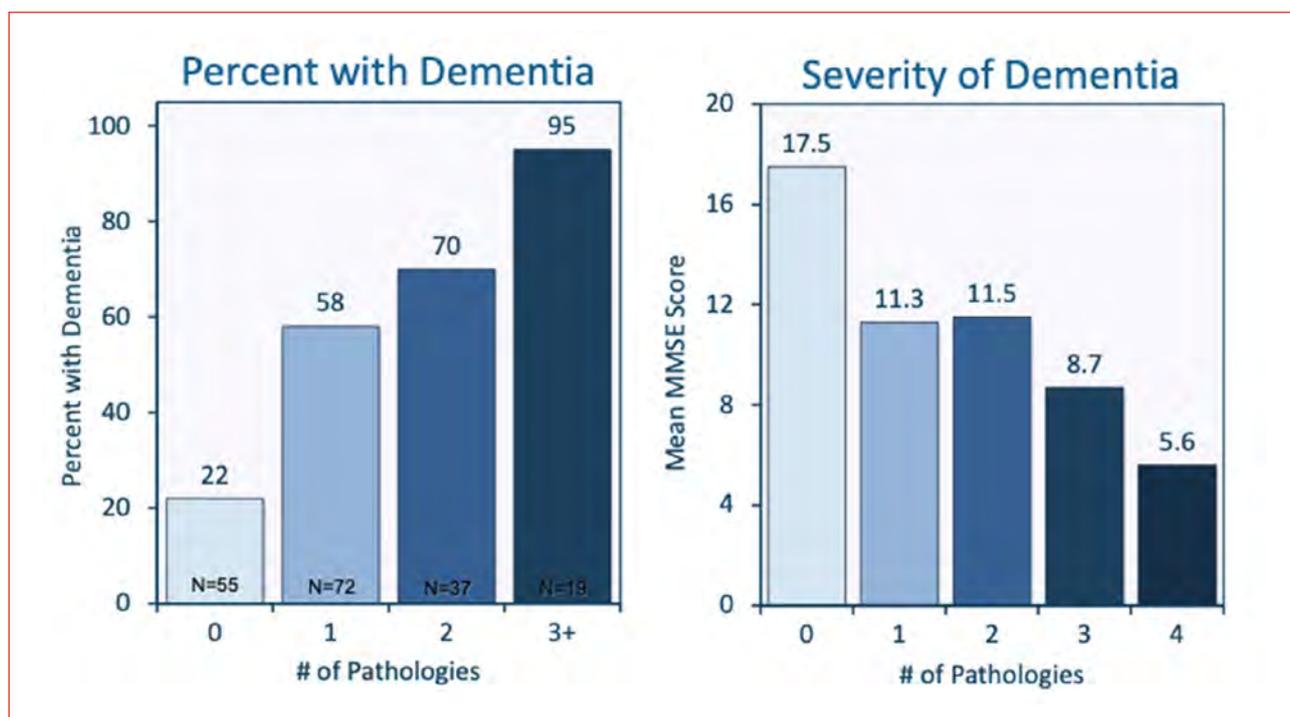


Figure 1. Prevalence and severity of dementia by number of pathologies in participants with dementia from The 90+ Study [4]

very old, research has shown that the attributable risk of dementia related to LATE is comparable to that of AD [7]. Clinical presentation of both HS and LATE is similar to AD with prominence of memory loss in all. The similar clinical presentation, coupled with frequent co-occurrence of pathologies and lack of pathology-specific biomarkers for non-AD neuropathologic changes, including HS and LATE, make accurate diagnosis of the underlying pathologies during life very challenging in this age group. Very old individuals have typically been excluded from treatment and prevention trials making it difficult to assess potential efficacy and side effects of therapies for this group. However, the frequent presence of multiple pathologic processes and co-morbidities in this age group raise considerable concern that therapies targeting a single process, such as AD, may have diminished efficacy in these individuals.

High frequency of sensory deficits and the accumulation of physical disabilities often referred to as frailty [8], is another important consideration in the oldest old. Age-related loss of hearing (presbycusis) and visual acuity (presbyopia) are almost universal among the oldest old and can complicate the interpretation of neuropsychological and other assessments, adding another layer of complexity to the diagnosis. However, increasingly we believe that hearing and visual deficits may be independent risk factors for dementia [9,10]. Therefore, use of hearing aids and correction of refractive errors should be encouraged in very old individuals as ways to maximize performance, and potentially stave off cognitive impairment. While cardiovascular diseases are prevalent in the oldest old and related to dementia, emerging evidence suggests that the development of hypertension after age 80 may have protective effects, possibly through maintenance of perfusion [11]. Therefore, current strict blood pressure targets might not be appropriate for the oldest old population.

Management of cognitive impairment and dementia in this age group has special challenges and requires unique considerations. While cholinesterase inhibitors are possibly

as effective in the oldest old as they are in younger age groups [12], one should pay additional attention to potential cardiac side effects given the high prevalence of heart block at this age. It is recommended that clinicians obtain baseline EKG before commencing patients on cholinesterase inhibitors. The anti-NMDA receptor drug memantine remains an effective treatment in the more advanced cases but again, clinicians should be careful in introducing the medication, beginning at 5 mg once daily and titrating up to 5 mg twice daily after one month, followed by 10 mg twice daily after an additional month. Depression is prevalent in the oldest old and often exacerbated by the sense of loneliness and social isolation, prevalent in this age group. Careful consideration of the impact of these factors and pharmacologic or cognitive behavioural treatment of mood disorders might lead to significant cognitive benefit. Serotonin specific reuptake inhibitor class retains its efficacy in this group. Agitation is another common problem that is best treated with behavioural modifications that remains the mainstay and safest option. Agitation that is resistant to behavioural modifications, can be treated with antidepressants or low doses of atypical antipsychotics although with risk of falls, stroke, and sudden death.

In summary, people aged 90 years and older are the fastest growing segment of the population worldwide and will account for up to half of all dementia cases by the middle of the century. Causes of dementia in these individuals are typically multiple and not easily diagnosed during life. Management of dementia in this age group, while similar to younger elderly, must be done with extra caution, generally using lower doses and gradual titration of all medications, while optimising physical and sensory functions. Given their huge, and growing, contribution to the public health burden of dementia in the world, all clinicians must become familiar with the special concerns for diagnosis and care of these individuals.

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## Conclusion

One common theme between all these conditions associated with dementia is that clinical phenomenology appears to be related to the location and severity of the pathological changes rather than the type of pathology. As discussed in the World Alzheimer Report 2021, aetiologic diagnosis requires biological tests, and the need for early and accurate diagnosis will increase as disease-specific modifying therapies emerge.

Until then, care plans must be person-centred and focus on the unique needs of the individual at a given time. The various symptoms associated with these conditions will change as the dementia progresses. Of particular importance is the need to support the person diagnosed with an atypical dementia and their carers with both practical and emotional support. This is better achieved with a team approach.

# **Part VII**

Societal perspectives  
on care for dementia

# Chapter 20

## Current global initiatives in dementia care

*Chloé Benoist, Wendy Weidner*

### Key points

- There are radical differences both between and within countries in education, acculturation, access to services, family responsibilities, and ability to mobilise resources. Understanding how these differences shape dementia care practice is crucial for developing appropriate dementia care policies.
- Providing adequate long-term care to people with dementia who need it is a growing challenge for both higher- and lower-income economies.
- The COVID-19 pandemic has underscored the importance of digital innovation for people with dementia and their carers.
- Peer support programmes can provide a structured environment in which people living with dementia can safely share their experiences with others who understand what they're going through.
- Supporting family and other informal carers is also widely viewed as an essential part of post-diagnostic support, through education, training, and support to reduce the burden of care and improve their mental health and wellbeing.
- A dearth of data, scientific evidence, and "in-country" research capacity continue to be major impediments for many countries as they grapple with the public health challenges of dementia.



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## General background

Dementia is a global issue, but not one with a one-size-fits-all solution. As seen in previous chapters, cultural, economic, social, medical, and individual differences each have an impact on how dementia is managed, and on what kind of post-diagnostic support is best adapted for each person living with dementia and their carers. As noted by Lenny Shallcross in his essay in this chapter, "It would be wonderful to point to a country and say: 'They are brilliant at post-diagnosis support; copy this.' But such exercises are doomed to fail, even were we to have such an exemplar."

This does not, however, mean that nothing can be done at the global level to address post-diagnosis support for dementia. The essays in this chapter seek to highlight efforts undertaken at an international scale to improve quality of life and care for people with dementia and their carers in a variety of ways.

In his essay, Alister Robertson explains how his organisation, Dementia Alliance International – which brings together people living with dementia from around the world – has developed its peer support group network to bring together those living with the condition, providing them with tangible benefits.

"The emotional benefit of realising that one is not alone cannot be overstated and this often inspires peers to become more independent," Robertson writes. "More experienced peers may also be empowered by being able to pass on their skills and experience, and in the process, they remind themselves of all they have learned about dealing with their condition."

"No matter who you are, what you do, we can all use more people in our lives who 'get it,'" he adds.

One notable point brought up by Robertson is the importance of harnessing technology to best serve people living with dementia – a concern shared by Tuan Anh Nguyen, who writes about the e-DiVA (empowering Dementia Carers with an iSupport Virtual Assistant) study. The project seeks to adapt the World Health Organization's (WHO) iSupport application, intended for informal family carers, to different cultural contexts in the Asia-Pacific region.

"Educating, upskilling, and supporting carers to reduce the burden of care and improve their mental health and wellbeing through low-cost and sustainable non-pharmacological approaches is much needed to avoid potentially

dangerous alternatives with limited efficacy, such as over-prescribing psychotropic medications, hospitalisation, and institutionalisation," Nguyen writes.

Another global challenge with the projected rise in the number of people diagnosed with dementia in coming decades is that of the fate of long-term care.

"The increasing need for long-term care and social changes make it unsustainable to depend on informal care, and require health and social sectors to integrate, reorganise, and coordinate their systems and services to provide long-term care, in collaboration with informal carers and communities," Anshu Banerjee and Hyobum Jang write. In 2021, their team at the WHO published a *Framework for countries to achieve an integrated continuum of long-term care* to address this growing issue.

Shallcross, meanwhile, advocates for a holistic strategic approach to post-diagnostic support – one that includes policy, research, and education but is also based on verifiable data to make sure such support is adapted to its specific environment:

"Many of the obstacles to providing good quality dementia care sit outside the 'dementia policy' box [...] But delivering change in complex health systems is challenging. Having worked at the UK Department of Health, I know it is a lot easier to develop pilot sites than to implement system-wide change!" he writes. "Delivering good quality post-diagnosis dementia care is often about making general improvements to the care system."

## Expert essay

# The value of peer-to-peer support as part of the post-diagnostic pathway for all people diagnosed with dementia

Alister Robertson

Chair of Dementia Alliance International (DAI), New Zealand

Dementia Alliance International (DAI) have been providing and facilitating free online peer-to-peer support groups[1] and social groups, as well as other virtual support groups for people with dementia through Facebook and Zoom (online video conferencing) for its members since 2014. These meetings are inclusive of anyone, at any age, with a diagnosis of any type or cause of dementia, and people with dementia can join for free.

Peer-to-peer support groups have a long history all over the world, including longstanding organisations such as Alcoholics Anonymous, which has been in operation successfully since 1935. A DAI peer-to-peer support group consists of a small group of people with a diagnosis of any type or cause of dementia, who meet regularly to discuss their experiences, problems, and strategies for coping with the condition, as well as strategies to live more positively with dementia. DAI hosts multiple types of support groups, most being weekly online peer-to-peer support groups, and occasional one-to-one buddying and mentoring.

The late Dr Richard Taylor, a co-founder of DAI who was a retired psychologist, had been hosting one support group via Google Meet, then Zoom, prior to DAI being launched. Another co-founder, Kate Swaffer, a retired registered nurse, had worked as a grief counsellor and facilitated and hosted in-person peer-to-peer support groups for people bereaved through suicide in Adelaide, Australia, from 1986 to 1995. Hence, although the DAI peer-to-peer support groups were not initially facilitated by paid professionals, two founders had significant professional experience with hosting them.

George Rook, a living with a diagnosis of dementia person in the UK, wrote the following on his blog[2] about peer-to-peer support groups:

*“Peer support occurs when people provide knowledge, experience, emotional, social, or practical help to each other... I like that. Note the “or” You don’t have to be a trained expert for peer support to work. Just need to have lived experience and a degree of emotional intelligence and self-awareness.”*

In 2017, Kate Swaffer wrote[3] the following, after attending a DAI peer-to-peer support group:

*“Just finished attending our weekly Richard Taylor support group... we’ve been laughing a lot (and almost crying a couple of times) for over 90 minutes. Discussions on grief and loss that we go through, ‘threesomes,’ and the Three Stooges, the recent FTD conference, and many other interesting things. Congrats to Jerry Wylie for setting up a local support group in his hometown, too; we were all truly inspired, and I get the feeling we will all help each other to do the same.”*

Virtual support groups are ideal for those who cannot drive to their local “in person” support group or who live in isolated areas with limited access to services. Since the COVID-19 pandemic, many other organisations have also started to provide them, basing themselves on the DAI peer-to-peer support group guidelines[4], developed by members with the support of professionals, to ensure best practice. What they have found is that although face-to-face support may be preferable for most people, as DAI discovered, the provision of virtual access to peer-to-peer support or other services has made it more accessible for those living in regional, rural, and remote areas.

Many of our members may also belong to a number of other groups run by different organisations or individuals, either online or in person, if they have them available in their local areas. DAI often also provides one-to-one, peer-to-peer mentoring and IT assistance to assist new members to feel confident and comfortable online.

The value of peer-to-peer support groups or one-to-one peer support as part of post-diagnostic services and support should not be underestimated. Research shows that hearing from and sharing with others with similar experiences can be very helpful[5]. A peer support program provides a structured environment in which people who share the same long-term illness or condition can safely share their experiences. The importance of meeting with peers facing the same things as you cannot be underestimated, whether

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it is a life experience, a terminal or chronic illness, or a pandemic. No matter who you are, what you do, we can all use more people in our lives who “get it.”

Peer-to-peer support has a wide range of both practical and emotional benefits, as listed below, although this list is not exhaustive. For example, many people with a chronic illness (especially those recently diagnosed) benefit from receiving practical tips about adjustments they can make to their day-to-day living to better manage their condition; the emotional benefit of realising that one is not alone cannot be overstated and this often inspires peers to become more independent. More experienced peers may also be empowered by being able to pass on their skills and experience, and in the process, they remind themselves of all they have learned about dealing with their condition.

Peer-to-peer support groups provide many benefits, for example they:

- Offer a safe place to discuss frustrations and joys of living with dementia
- Reduce isolation
- Reduce apathy and depression
- Strengthen motivation
- Show peers they are not alone
- Help group members develop new skills in relating to others

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- Modify and establish existing self-management activities
- Help and support members to overcome blocks and barriers or if not, to seek alternatives
- Allow people to “open up” and discuss their situation and feelings
- Discussions on practical skills and guidance – such as how to design and stick to a treatment plan, or manage living with the symptoms of dementia and memory and other cognitive changes
- Provide new coping strategies – share solutions and learn from one another’s experience
- Provide strategies for managing any stigma associated with dementia.

While family and friends, and even professionals working in the field of dementia, try hard to be supportive of us, they often don’t really know how we feel, or even why it can be so hard for us sometimes. Many of the disabilities caused by dementia are invisible or sporadic, so it is sometimes difficult for people without dementia to understand the day-to-day life and difficulties people with dementia face.

We at DAI hope that peer-to-peer support for those of us diagnosed with dementia will become the norm, will be hosted by all organisations providing advocacy, services, and support, and will be included in all post-diagnostic pathways or care plans from the point of diagnosis.

## Expert essay

# Adapting virtual assistant support for dementia carers in culturally and linguistically diverse communities

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As dementia prevalence grows exponentially, the condition has become a matter of global public health priority[1]. Most people with dementia are cared for by unpaid family carers[2]. The provision of unpaid care often causes pronounced stress, resulting in mental and physical health deterioration, and loss of productivity and income[1,3]. Women, who provide the bulk of family care, are disproportionately affected[4]. In lower- and middle-income countries (LMICs) where aged care facilities and other formal support services are underdeveloped, such impacts can be devastating[5]. Educating, upskilling, and supporting carers to reduce the burden of care and improve their mental health and well-being through low-cost and sustainable non-pharmacological approaches is much needed to avoid potentially dangerous alternatives with limited efficacy, such as overprescribing psychotropic medications, hospitalisation, and institutionalisation. Supporting family and other informal carers is widely viewed as an essential part of national dementia plans[6].

The World Health Organization (WHO) developed iSupport for Dementia, a generic version of an evidence-based online skills training and support program for informal dementia carers[7]. The Australian pilot study to adapt iSupport for use in the English-speaking community of Australia showed that the online iSupport program was acceptable to carers for self-learning[8]. Importantly, information on dementia care services was embedded in learning modules for carers to access as needed[8]. However, carers desired a more user-friendly version that enabled them to quickly identify solutions for immediate problems in real time. They also identified the need to adapt iSupport for culturally and linguistically diverse (CALD) communities in Australia given their different care needs[8]. iSupport has not been adapted for use in most Asia Pacific Regional (APR) countries. A dearth of scientific evidence and “in-country” research capacity are major impediments for many APR countries as they grapple with the public health challenges of dementia.

The e-DiVA (**e**mpowering **D**ementia Carers with an **i**Support **V**irtual **A**ssistant) study addresses these gaps in two ways, by: 1) developing and evaluating an iSupport Virtual Assistant (VA) to support dementia carers through a partnership of four APR countries – Australia, Indonesia, New Zealand, and Vietnam; and 2) building capacity of researchers and non-government organisation partners (that is, Alzheimer’s Disease International (ADI) member associations in these countries) to support this development and evaluation. Specifically, we are developing iSupport VA versions in seven languages: English, Bahasa, and Vietnamese for Australia; English and te reo Māori for New Zealand; Bahasa for Indonesia; and Vietnamese for Vietnam. We co-design with dementia carers and other stakeholders to adapt WHO iSupport to local languages, cultures, contexts, and social, health/wellbeing, and aged care systems in the e-DiVA countries. The adapted content is used to build the iSupport VA, comprising a website and an app for use on smartphones or handheld devices. The iSupport VA will enhance WHO iSupport by providing real-time support for carers with additional interaction options of voice command and video instruction to make it more user-friendly, quicker, and easier to learn.

Australia, Indonesia, New Zealand, and Vietnam have been selected as field sites. Australia and New Zealand are higher-income countries, while Indonesia and Vietnam are LMICs. All four countries are experiencing population ageing and offer some form of a “universal,” publicly funded health-care system. However, their national responses to dementia vary: Australia has an established National Dementia Plan (NDP)[9] and New Zealand is adapting its previous dementia care framework[10]. Dementia Australia, Dementia NZ, and Alzheimer’s NZ are well-resourced associations for people with dementia. Indonesia launched its NDP in 2015, but the implementation was poorly funded[11]. Alzheimer’s Indonesia (ALZI) is an active association relying mostly on

a strong volunteer basis. Vietnam has developed its national action plan integrating dementia into non-communicable diseases and mental health conditions, but no specific budget is allocated for dementia.

These settings are connected by migration. New Zealanders are the third and Vietnamese are the sixth largest immigrant communities in Australia. Indonesians are a growing migrant cohort, now 19th [13]. There are radical intra- and inter- country differences in education, acculturation, access to services, family responsibilities, transnational links, and ability to mobilise resources. Understanding how these differences shape dementia care practice in country and diaspora communities is crucial for developing appropriate dementia care policies that will also be a huge benefit to other APR countries facing similar dementia epidemics.

Over two million people are impacted by dementia in the four e-DiVA countries, a number that will triple by 2050. The vast majority live at home, cared for by family members, mainly women. Recognising the effects of long-term dementia care on carer's time, energy, income, health, and wellbeing, this study will provide a digital solution to support dementia carers to look after themselves and their care recipients. Using co-design ensures iSupport VA's user friendliness and trustworthiness; the study's diverse settings ensure the

cultural adaptability of iSupport VA across higher-, middle-, and lower-income settings. The COVID-19 pandemic has underscored the importance of digitally innovating for people with dementia and their carers. This study offers a solution to ensure quality care for people with dementia, no matter their location or income, or the crises facing them.

Our commitment to ongoing co-design and stakeholder engagement in every step of our research, along with our commitment to building capacity in our stakeholders and locally based researchers will support the successful translation and ownership of iSupport VA by the local ADI member associations. Thus, by the end of the project, we will have research-ready, stakeholder-engaged local champions to enable the final translation of iSupport VA nationally, as well as its ongoing development, increasing chances of having a longer-term impact beyond the life of the project. The project will build research capacity at an international level to produce evidence that enhances the WHO iSupport intervention and increases its transferability to other countries around the world. E-DiVA results will be disseminated through national project closeout workshops and an e-DiVA symposium at the ADI Conference 2024 and discussed with ADI member associations in each country to advocate with their governments for support to maintain the programs nationally.

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## Expert essay

# WHO framework to support countries to develop sustainable and equitable long-term care systems

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Dementia is a leading cause contributing to the need for long-term care globally. As dementia progresses, older people need more health, personal, and social care, either from formal care workers or informal carers. While some may maintain a level of functional ability with appropriate long-term care in home and community settings, others may need to eventually relocate to long-term-care facilities when they can no longer maintain independent lives and cannot be supported at home. In the US, about one-third of home care recipients and almost half of nursing home residents are diagnosed with Alzheimer's disease or other dementias[1]. In Canada, about 30% to 40% of people who have been diagnosed with dementia live in long-term-care facilities[2]. In lower- and middle-income countries (LMICs), informal carers, who are mostly family, women, and unpaid, provide the major proportion of dementia care, spending 70% of hours of care and two-thirds of care costs[3]. Providing adequate long-term care to people who need it, including people with dementia, is a growing challenge for both higher-income economies and LMICs to improve daily lives and wellbeing and help reduce the need for costly care.

While some countries are making efforts to expand long-term care and better respond to the needs of the ageing population, most governments do not provide sufficient long-term care. Some existing services are fragmented and uncoordinated. Traditionally, and still in many countries, family members and informal carers have been expected to provide informal care and have taken on the burden, while they cannot receive adequate training, recognition, and support. The increasing need for long-term care and social changes make it unsustainable to depend on informal care, and require health and social sectors to integrate,

reorganise, and coordinate their systems and services to provide long-term care, in collaboration with informal carers and communities.

## WHO long-term care framework

Providing older people who need it with access to long-term care is one of the four action areas under the United Nations Decade of Healthy Ageing 2021–2030, which is mandated to the World Health Organization (WHO) and all the collaborating UN agencies[4]. As a milestone guidance, WHO has published *Framework for countries to achieve an integrated continuum of long-term care*, which envisions long-term care systems that provide integrated health and social care services across the continua of individual needs, service settings, care roles, and care providers[5].

The principles and core elements of equitable and sustainable long-term care systems in the framework are summarised below:

- Long-term care services should be person-centred, rather than defined by the service, facility, or provider, and empower older persons and carers' goals, values, preferences, dignity, and autonomy.
- Long-term care systems need to be driven by and responsive to the full range of older people and their carers' aims, choices, and needs, upholding their rights.
- The integrated continuum of long-term care helps to identify and address an individual's specific needs, according to that person's intrinsic capacity and functional ability at the time.

- Long-term care integrates health and social care, and spans the entire continuum of care, from preventive to promotive, curative, rehabilitative, palliative, and end-of-life care.
- Care adjusts and evolves with a person's changing needs in a seamless manner.
- Long-term care services are accessible and affordable to all as needed without financial strain, as an essential component of universal health coverage in countries.
- Long-term care is offered across various long-term care settings in line with older people's preferences, without interruption and with proper transition, from health and residential long-term-care facilities when needed, to home and communities whenever possible, being supportive of ageing in place.
- A multi-disciplinary team with a range of competencies and specializations within the workforce coordinates and provides a holistic care, while incorporating, integrating, and supporting the role of informal carers.
- Long-term care systems provide appropriate and sufficient capacity building and support for all care providers, regardless of formal and informal, and paid and unpaid.
- Long-term care systems are integrated and coordinated at all levels, from policymaking to workforce training, service delivery, and information systems, across public and private sectors, and health and social care systems.

- Long-term care services, workforce, and facilities are governed by appropriate laws, policies, and regulations and are continually monitored for quality.

The framework provides a practical approach to make these many steps manageable. This approach considers what needs to be done in each of the six critical elements of a functioning long-term care system: governance; sustainable financing; information and monitoring and evaluation systems; workforce; service delivery; and innovations and research. The framework also includes checklists that itemise core elements and key actions for strengthening each element of long-term care systems. The checklists will help countries assess existing systems, identify gaps, implement actions, and monitor progress.

### Future long-term care guidance to support countries

In pursuit of the vision of access to long-term care for all older people who need it, WHO will continue developing and providing a series of technical products to help countries, policymakers, and long-term care providers to assess and implement long-term care systems and services. A service package of priority long-term care interventions is being developed to support countries to integrate a continuum of long-term care services into their health and social care systems and achieve universal health coverage. In the longer-term, WHO will share knowledge and provide guidance for countries to develop sustainable long-term care financing models, train and support care workers and informal carers, and integrate health and social care for a continuum of long-term care services in all homes, communities, and residential care settings.

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## Expert essay

# Understanding the challenges to global initiatives in dementia care

Lenny Shallcross

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When the G8 health ministers met at the London dementia summit in 2013, they declared: “Dementia is our collective social responsibility. We affirm our commitment to improving the lives of people affected by dementia, regardless of nationality, identity, background, culture socioeconomic status, language, or religion... Dementia requires long term health and social care support. Providing care for those with dementia can present challenges for families and carers. We need to provide better and more concrete measures for improving services and support for people with dementia and their carers, to improve their quality of life and wellbeing.”[1]

This ministerial statement emphasised the central importance to individuals of good quality care. It doesn't really matter what condition you have, or where in the world you live; there must be few on the planet who would not agree, in principle, that good quality care is a good thing. So why is good quality care so elusive for people living with dementia?

In contrast to many other illnesses, in the case of all forms of dementia, good quality care is not about medical interventions that slow or stop the spread of the condition. It is about social interventions to maintain quality of life and wellbeing as the condition progresses. When it comes to disease-modifying treatments, there is a knowledge gap, although we have made huge strides in understanding the underlying biology of the condition[2]. But when it comes to good quality care there is not that knowledge gap – although there is variation between countries, between communities within countries, and so on, fundamentally we know what good care looks like[3].

The Organisation for Economic Co-operation and Development (OECD) highlighted many of the policy gaps in a 2018 policy report Care Needed[4]. Some are dementia specific, such as the limited number of countries with post-diagnosis dementia pathways and the adherence within countries that have them to said pathway. In later stages of the condition, access to dementia-suitable care facilities is

weak. National dementia strategies have become one of the more generalised policy solutions, but the extent to which they have successfully driven change at a national level is highly variable.

In part, this has been because many of the obstacles to providing good quality dementia care sit outside the “dementia policy” box. The support provided to caregivers, something that is central to the wellbeing of many individuals living with dementia, is in many countries too little and too burdensome. Training for care workers is often insufficient. Of course, in many countries, most care is provided by the family, even in later stages of the illness progression, who can struggle to access to information and support to help them provide care.

But delivering change in complex health systems is challenging. Having worked at the UK Department of Health, I know it is a lot easier to develop pilot sites than to implement system-wide change! Delivering good quality post-diagnosis dementia care is often about making general improvements to the care system.

Delivering change within systems is driven by good quality data and, as the OECD has highlighted, many countries collect, at best, patchy data, much of which isn't comparable. There is very poor data on lived experience. Many countries have experimented with initiatives like “dementia friendly communities” or something similar[5]. These initiatives aim to give someone with the condition a better post-diagnosis experience (even without a formal diagnosis) by changing the community around them. But evaluating the impact of such initiatives is hard because of the absence of good quality data on lived experience.

Of course, accessing formal post-diagnosis care relies on a diagnosis. Most people living with dementia around the world don't have a formal diagnosis of dementia. There is significant variation in diagnosis rates between countries – and in how dementia is diagnosed and recorded. The nature

of the condition means someone with dementia can live for a number of years with clinical symptoms that will become more obvious as the condition progresses, while they may not be formally diagnosed in the early stages. But there is a good case for an early diagnosis at the point when an individual can access support and advice and plan for the future with their family. There will be significant change in the diagnosis pathway in the next few years with the development of blood and digital biomarkers and policymakers need to address the implications this has for accessing post-diagnosis support.

Post-diagnosis support exists as a part of a system, and diagnosis is a key stage. Measuring the success of a policy to ensure an accurate and timely diagnosis is underpinned by prevalence studies. Without accurate estimates of the

number of people living with dementia across diverse population groups within a country, it is impossible to have robust dementia diagnosis rates. Too many areas of the world lack high-quality prevalence data. Improving post-diagnosis care is challenging, but in itself is not sufficient; it is part of a policy continuum.

It would be wonderful to point to a country and say: "They are brilliant at post-diagnosis support; copy this." But such exercises are doomed to fail, even were we to have such an exemplar. But what all countries can do is collect better data. Because then, policymakers, civil society, and people with dementia themselves can better identify how to make progress within a country and hold decision-makers to account.

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## Conclusion

Looking at efforts implemented across the world, it is clear that a lot can be done by sharing knowledge and means on a global scale – as long as there is ample awareness of the need to adapt frameworks and resources to their local contexts, not just at a national level, but also taking into account the specificities of different communities within the same nation.

These adaptations take time and effort, as highlighted by the case of e-DiVA. But, as Shallcross argues, more reliable data from around the world would have a far-reaching impact on decision-making when it comes to dementia.

While the authors of this chapter caution against a singular approach to dementia, a few values apply across the board – most prominently, the necessity for person-centred approaches that humanise the person living with dementia and grant them dignity and respect.

PART I

PART II

PART III

PART IV

PART V

PART VI

PART VII

PART VIII

# Chapter 21

## Models of care and support around the world

*Chloé Benoist, Wendy Weidner*

### Key points

- Sharing knowledge across borders is key to finding out what works – and what doesn't – in post-diagnosis dementia support.
- Case studies from four vastly different countries – South Korea, Scotland, Brazil, and Canada – show varied approaches to addressing similar yet distinct challenges.
- Countries should lean on existing strengths in their healthcare systems to deploy their dementia care strategies.
- Robust models of PDS need to be purposefully constructed, tested, funded, monitored, and fine-tuned. They have big implications for health and care systems, often requiring redesign, training, and education and often based on the introduction of skilled and trained support roles.
- All PDS models need to be person-centred, developed with and by the key stakeholders, including people with dementia and carers.
- Stigma and lack of education on dementia among healthcare professionals continue to be barriers to accessing diagnosis and post-diagnosis support.
- All care models have room for improvement; national dementia plans provide a legislated framework that is key to ensuring that care and support models are improved and have a far-reaching impact.



## General background

While this report has so far made clear that there is no universal response to dementia, sharing knowledge across borders is key to finding out what works – and what doesn't – in different contexts. In this chapter, we are exploring established and emerging models of post-diagnosis around the world, with the aim of sharing experiences, advice, and inspiration, in order to facilitate knowledge exchange around the complex area of post-diagnosis dementia support. The development of robust models is essential to delivering care and support for people living with dementia and their carers. For governments, working with Alzheimer and dementia associations and all key stakeholders to develop these models makes sense not just in terms of health and long-term care, but economically.

Prominent experts in the field of dementia in South Korea, Scotland, Brazil, and Canada have been interviewed for this chapter as case studies of care and support models in their respective countries. These interviews, edited for length and clarity, seek to show examples of how dementia is addressed on four different continents – and how these policies have met successes, challenges, and opportunities.

In his interview with DY Suharya, director of the Korean National Institute of Dementia (KNID) Dr Im-Seok Koh highlights how South Korea's projected turn into a super-ageing society by 2025 has spurred the government to invest into a far-reaching medical and social network of local dementia centres to support the nearly one million people estimated to live with dementia in the country. Director of Policy and Practice at Alzheimer Scotland Jim Pearson tells Chris Lynch about Scotland's five pillars model, based on having designated case management professionals known as link workers helping people with dementia and their carers navigate the maze of bureaucracy and services after diagnosis. In Brazil, University Federal de São Paulo Professor Cleusa Ferri explains to Wendy Weidner how the country's far-reaching public health system can be a foundation for the future rollout of a national dementia plan. Finally, Dr Saskia Sivananthan, the chief research and knowledge translation officer for the Alzheimer Society of Canada, tells Claire Webster how civil society organisations play a crucial role in the conception and implementation of national dementia strategies.

## Expert essay

# Integrating medical and social care at a local level: post-diagnostic support in South Korea

DY Suharya

Asia Pacific Regional Office director, Alzheimer's Disease International, Indonesia

**Question: South Korea has what is perceived around the world as a leading post-diagnosis support model involving technology, innovation, diagnosis, care, and treatment, with dementia care clinics established in the entire nation. Dr Im-Seok Koh, director of the Korean National Institute of Dementia (KNID), supported by Jee-Won Suh, KNID's deputy director, are speaking with us about the post-diagnosis support model in South Korea. Can you give us a brief overview of what that looks like?**

Due to the ageing South Korean population, the number of people with dementia in the country is rapidly increasing. In 2021, the estimated number of people with dementia aged 65 or over was approximately 920,000, meaning that one in 10 elderly people has dementia. South Korea is estimated to become a super-aged society by 2025; therefore, dementia is a problem not just for individuals and families alone, but for the whole country.

To manage this issue, South Korea has integrated a medical and social model of care to meet the diverse and complex needs of people with dementia and their carers according to the clinical stages of dementia, from diagnosis until the end of life.

The most important feature of the model are local dementia centres (LDCs), which provide various services in the community such as dementia prevention, diagnosis, and post-diagnostic care. Typically, LDCs provide and coordinate services tailored to each person with dementia based on information resources linked to communities. While medical intervention is important for dementia, the social model is used in parallel to solve issues related to the negative perceptions of dementia. People with dementia want to live in the community to which they belong, but adequate services are not always available for them, and the economic burden is significant.

The model was launched in earnest as part of the National Dementia Initiative (NDI) in September 2017. It has brought about many changes in improving dementia awareness in

South Korea and building infrastructure such as LDCs and dementia-specialised institutions. The NDI has set up 256 LDCs across the country, has been expanding the number of long-term care service beneficiaries, and reducing medical and long-term care costs.

The specific issue that Korea's medical-social model must tackle is the establishment of a customised care plan for each clinical stage of dementia to prevent aggravation of the condition and to support community residents.

**Can you give us a bit more information about your current national dementia plan (NDP), the fourth for South Korea?**

The budget of the fourth NDP is part of the National Health Promotion Fund, financed by taxation. The central government contributes 50%–80% of the budget for LDCs depending on the region.

In order to provide continuous treatment and care to people with dementia, it is important to establish an organic, cooperative relationship among LDCs, long-term care, welfare institutions, and medical institutions. However, it is not easy for organisations with different characteristics to cooperate and share information with each other. In addition, inter-regional disparities in facilities, human resources, and LDC programs limit the ability to provide appropriate services to people with dementia and their caregivers. Therefore, the goal of the NDP is to ensure that LDCs provide seamless services in connection with various resources in the local communities and continue to improve the professionalism of the workforce and services.

The Korean National Institute of Dementia (KNID) has submitted the results of several projects, including by LDCs, to the Ministry of Health and Welfare (MoHW) as the basis for budget expenditure. It has emphasised the need to secure an appropriate amount of funding each year. Going forward, we plan to gather evidence to secure a national budget for the management and care of people with dementia.

**What have been the positive outcomes of your care and post-diagnostic support model? What are the challenges and barriers faced in implementing this model and/or providing for people living with dementia in South Korea?**

A positive outcome of the medical-social model is the increase in the number of people with dementia living in their own communities. This is tied to continuously increasing the registration rate of people with dementia at LDCs. Over half of all people with dementia nationwide are registered at LDCs, where they receive care goods, cognitive enhancement classes, support for dementia treatment costs, and case management. People with dementia who enrol in LDC group programs have been experiencing improved cognitive function and reduced depression. The carers also enrol in programmes such as education, counselling, and self-help groups to reduce their care burden.

Before the NDI, only a few areas in the country had regional centres, and these centres found it difficult to function properly due to limited human resources and facilities. With the establishment of LDCs nationwide, people with dementia and their carers can access information and appropriate support beyond learning to provide necessary care.

However, LDCs are still limited in what they provide. To prevent the aggravation of dementia and support people with dementia living in their communities, LDCs have been working toward creating hubs for a comprehensive range of functions, from customised care plans to care and treatment, all by linking various resources in the community for each clinical stage of dementia.

**What is the role of civil society to support people with dementia in South Korea?**

We believe that individuals, schools, organisations, hospitals, and clinics can play important roles in supporting people with dementia. Individuals can volunteer as dementia

partners to help people with dementia and their families in daily life. Organisations and companies can serve as the social safety net for people with dementia to live safely in the community by becoming dementia-friendly organisations.

Since 2019, we have been conducting a nationwide dementia villages project. These communities conduct specialised education and social activities on dementia and ensure its publicity in various regions, promoting a more accurate understanding of dementia.

**In 10 years' time, what would an ideal model look like for your government and for people living with dementia in South Korea?**

The government currently plans to develop and apply a model for dementia primary care physicians, managed by local hospitals and clinics, for the integrated treatment and care for people with dementia diagnosed through LDCs. The progression of dementia can be slowed significantly by allowing people with a diagnosis of dementia to receive continuous care at a local hospital without any interruptions in treatment.

The current medical-social model should strive toward becoming one that respects the decisions of people with dementia and their families and actively reflects their desires and wishes when providing medical and care services.

In this regard, the individualised needs of people with dementia and carers are significant because the severity of the condition may vary, as does the situation of the people with dementia and their carers during the long course of degenerative dementia. Providing better care and treatment to people with dementia and their carers in the community will allow people with dementia to live as respected members of society until their death.

## Expert essay

# The pillars of support: Scotland's model of care

Chris Lynch

Deputy CEO and policy, communications, and publications director for Alzheimer's Disease International, United Kingdom

**Question: I am joined by Jim Pearson, director of policy and practice at Alzheimer Scotland, to explore the post-diagnosis support model in Scotland. Scotland has what is perceived around the world as a leading post-diagnosis support model. Can you give us a brief overview of the current model and set the scene for us?**

It began back in 2007 with the Scottish government making dementia a national priority. At that time, just one in three people living with dementia were estimated to be getting a diagnosis. Working to improve the rate of diagnosis, we then asked the question: What do we do to support the people who get a diagnosis? From the national dialogues we held at that time, there were two very clear messages coming out from people living with dementia – improving post-diagnosis support and improving the experience in acute hospital settings.

Around that time, we carried out a piece of practice research to look at what good post-diagnostic support would look like. Out of that came the five pillars model of post-diagnostic support[1], and that is the model that underpins Scotland's commitment – a commitment that every person with a new diagnosis of dementia in Scotland is entitled to a minimum of one year of post-diagnostic support from a named person who will work alongside the person and those close to them. The five pillars model provides a framework for people living with dementia, their families, and carers with the tools, connections, resources, and plans to allow them to live as well as possible with dementia and prepare for the future.

**In relation to the post-diagnostic guarantee and how it came about – can you give us a bit more information about how is it performing; how do you see it going over the next few years?**

The first thing to say is that it has been a success. We came from a position where there was no effective or consistent approach to delivering post-diagnosis support in Scotland for people who had a diagnosis. Some people would receive some support from their community psychiatric nurse, with some models of post-diagnostic support being delivered in some parts of Scotland, but nothing nationally consistent.

Now, we have a national post-diagnostic guarantee that has helped tens of thousands of people. The reality, however, is that it has probably been underfunded and the consequence of that is that every year since it was introduced, there have never been more than 50% of those who have been diagnosed who were offered post-diagnostic support. So, while it is a success, there is a substantial gap in that commitment, and we have been campaigning consistently to improve that.

**I understand that you have co-developed a number of other post-diagnosis models. Tell us a little bit about that approach and about any of the new roles that have been introduced in terms of the dementia workforce.**

We have had a national vision for transformation for some time. It is fairly simple, but it looks at breaking down the barriers to a diagnosis. You need to demonstrate that there is an offer there for people if they come forward. We've argued for a long time that the mainstay of care and support and treatment for people living with dementia and their carers is other human interventions. So our models are based on that.

After the first national dementia strategy was published, we then started looking at what happens beyond post-diagnostic support and how to help and sustain people in the moderate, then severe stages of the condition. We developed our eight-pillar model[2] that is based on the concept of a named individual – a dementia practice coordinator – who, like the post-diagnostic link worker in the five-pillar model, works with that individual and is empowered to work across the boundaries of health and social care and housing and other community-based supports, to work with families and to utilise everything available in the system.

Many people describe that system as complex and bureaucratic – sometimes like being in a maze where you've been given a large ring full of keys and you have to find the right key to the right door. What we have argued is that a dementia practice coordinator is one key – they have the master key for all of those doors, and they can help people to access what is behind those doors. So we presented, coordinated, and integrated care as a model, which coincided in Scotland with the integration of health and social care, and when that

was being tested as part of the second national dementia strategy, we then started looking at advanced illness and we produced a model called the “Advanced dementia practice model” in 2015, which is being tested in the current national dementia strategy.

**A question about health and care training – we know these are integral to the success of any post-diagnosis model. How does Scotland approach training for health and care professionals?**

That was one of the key elements that was understood as a priority in the first national dementia strategy. We have people who work in health across Scotland, and social care professionals, who in their education and training were telling us that they got very little training around dementia. Take a nurse working in a general hospital, working in adult care – the reality is they will probably be working primarily with older people and within that primarily with people who have got either depression, delirium, or dementia. Yet, in their training, there was little about dementia.

So there were two things that needed to be done: Fix their training pre-registration and learn how to retrofit those people already qualified and in practice. A key element of the first strategy was the development of a model called “Promoting Excellence,” a knowledge and skills framework that sets out the knowledge, skills, and behaviours expected of anyone working with people with dementia, and which works at different skill levels.

For post-diagnostic support, we have identified that the post-diagnostic link workers working with people after a diagnosis should be working at the advanced level.

**Regarding cost barriers, how is post-diagnosis support funded in Scotland? Is it a national or local government remit? What about private and insurance sectors?**

Several years ago in Scotland, we had health and social care integration into what are called Integrated Joint Boards. It is these Integrated Joint Boards that are now responsible for the delivery of post-diagnostic support. They fund it. And this is where the barrier is. We've never seen that being funded to a level that could meet the demand of those people being diagnosed.

That became really evident during and in the buildup to the pandemic. We were arguing and saying to the Scottish government that ultimately this is your national dementia policy, and the key priority of the strategy is not being delivered at a local level and it needs investment. Last year, the Scottish government did actually commit to putting together a ringfenced fund in order to ensure that there was sufficient funding for post-diagnostic support.

We did some work with the Scottish government, the Convention of Scottish Local Authorities (COSLA), and others to look at what would be needed to ensure that we had sufficient post-diagnostic link workers. That is in the process now and that money has been allocated. This year, I would hope that that will translate into much greater numbers of people receiving the support to which they are entitled.

When we published the advanced dementia practice model, we described the complex and rapidly changing needs of advanced illness as primarily healthcare needs. Yet in Scotland and in other parts of the UK, people often find themselves in the social care system and they remain there – and, in Scotland, social care is not free. We've been arguing that people with advanced dementia are much more likely to find themselves in that system, much more likely to be in care homes, and we believe it should be considered healthcare and therefore free at the point of delivery in the same way it is for other complex, progressive, and terminal illnesses. And that is what we are currently campaigning for in terms of fair dementia care. That is progressing. The Scottish government has committed to implementing a new national care service, and it responds to some elements that we are not so happy with. We will continue to campaign until we get that equality.

**In 10 years' time, what would an ideal model look like for your government and for people living with dementia in Scotland?**

I think we have a model that has demonstrated that it works well, when a link worker is alongside an individual and a family and builds a close relationship and gives them that time to think about what they want out of post-diagnostic support. Our model is based on a minimum period of a year working with the family and the reason for that is to build trust. I would like to see a real commitment to measuring quality of outcomes around post-diagnostic support, rather than what we have at the moment, which is often counting how many people got it [the support], how many people started it, when did they finish it. We need to get better at capturing that quality – and some good work has been done around that in Scotland.

It has to be invested in and we need to make sure every person who is entitled to receive post-diagnostic support gets it. One thing we should add to that is that, in the future, we potentially may be able to reduce the numbers of people who get dementia by tackling some of those risk factors, by promoting greater brain health.

We are also getting nearer to being able to diagnose conditions like Alzheimer's before people become overtly symptomatic, and I think that will start to shape what post-diagnostic support looks like.

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## Expert essay

# Emerging post-diagnosis care models in Brazil: Primary care leads the way

Wendy Weidner

Head of research and publications, Alzheimer's Disease International, United Kingdom

**Question: I'm very pleased to be joined by Professor Cleusa Ferri, a psychiatrist, epidemiologist, and professor in the post-graduate programme of psychiatry at the Universidad Federal de São Paulo. Cleusa has been working in the field of dementia for over 20 years, a major contributor to the 1066 methodology across the Americas, and, most recently, a senior researcher for the Strengthening responses to dementia in developing countries (STRiDE) project in Brazil. Cleusa is also working closely with the government to develop dementia policy in Brazil.**

**Cleusa, as part of the STRiDE project you did a "situational analysis" that looked at dementia policy care in Brazil. What did you find?**

I think it's important to give people an idea about Brazil – we have more than 200 million people and more than 30 million people over 60. It's also huge geographically, so people are spread out with many different living conditions. If you travel around Brazil, you will see that there is diversity; we have mixed races and so many kinds of food, culture, language, and also services that people can access.

We have a national health system, which is free of charge and is for everyone. It is called SUS (Sistema Único de Saúde) and it's very much inspired by the NHS in the UK. The public services cover around 80% of the population, but don't spend as much money as the private sector on health. It's underfunded and not equal everywhere.

With STRiDE, we looked at what [services] exist already that people with dementia and their families can benefit from. The first thing that I would say is that they can benefit from what the SUS can offer, which I think is good, but of course, not ideal.

We don't have a clear pathway in the system for people with dementia so that people can know exactly where to go. But we do have primary care units, and we have a family health strategy outreach service where, among other things, health workers (agentes comunitários de saúde) go

to people's homes and assess their needs, advise them, and are the "door" to bring them to the primary care unit if they need it. The program in Brazil is key for recognition [of possible symptoms of dementia], but also in respect of long-term care.

We do have some kind of protection for older people, but not specifically for those with dementia – but there are so many things that people can benefit from indirectly. The Ministry of Health has a department responsible for old age health that has been working with dementia on different fronts. We have recently seen the establishment of some local dementia plans, including one in the city of São Paulo, which we are now trying to work on implementing.

**Do you find that there's a difference between rural areas and urban areas, in terms of people's access? You've got these primary care centres that actually go into people's homes, but are there areas that are harder to reach?**

I'm sure there are areas that are not covered as they should be. In some areas, people can only be accessed by boat, for example. In the national health system, we even have primary care units that are on boats – they can take the primary care unit to small, isolated villages. However, you are more likely to have access to secondary and tertiary care in urban areas.

**It's interesting that there's help for older people, but not necessarily a clear pathway for people with a diagnosis of dementia. Could you describe how an individual with dementia would get support?**

I think it has to do with where people live and the resources they can access, whether they are public or private. [In STRiDE, we developed] vignettes in which we tried to understand the trajectory [of a person's care pathway]. The pathways will be very different depending on whether you are poor and you live in a small town in the Amazon states; you live in a favela on the outskirts of São Paulo; you live in a farm in the country; or in a rich condominium in São Paulo or Rio de Janeiro. [This] starts well before the

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diagnosis because the knowledge that people have and how they recognise that someone is having difficulties and needs some help is very different.

We do have high rates of under-diagnosis in Brazil. [A person's symptoms] may not be recognised by families, friends, neighbours, or even health providers. They will take some time to get a diagnosis. But if they do, then they may find services are not well prepared or that health providers are not trained to recognise what is going on with the family and with the person. Accessing diagnosis can be difficult because people may not have access to resources or live in a rural area and need to go to a big city for an examination, and after all that, they don't always get the support that they need immediately, and in long-term care.

Families a people with dementia need a lot of support to understand, to accept, to plan – essentially multidisciplinary support. They may get dementia medication and then come every six months to get a new prescription, but what we need to ensure is that they get support according to their needs and their wishes.

**You're right - the [experience of] diagnosis often colours what happens in post-diagnostic support. Have you found homegrown solutions within Brazil that really work in the context of your country?**

Something that we got right is, as I mentioned before, our national public health system, because we do have a huge safety net provided by the work of our primary care units – having that close to where people live and having a family health strategy, with someone going to people's homes. If the health worker is well trained, even if they are not a specialist, they can recognise someone who may have dementia and they can refer or bring them to the primary care unit. It's an opportunity. They can advise people who have already been diagnosed and offer them access to other [resources] that the primary care units have. They can also give support or advice to the family.

I'm not saying that we got it right, because dementia is still not a priority; we lack knowledge and awareness, and we have stigma associated with the condition, but I think our primary care system is our main asset to guarantee access to what already exists.

**I'd love to hear more about the São Paulo dementia plan.**

We are in the very early stages in the city of São Paulo, so it's still [early] for me to say exactly what the focus will be. But I think there is a clear message that we need to integrate dementia into non-communicable diseases programmes. If you train people on dementia specifically, they can truly be specialists for services like a primary care unit, and they can be a reference for other primary care units.

**You have another plan that's gone through the senate and this one is looking more nationally. Are there similarities between those two plans [São Paulo and national]? Do you see that one is influencing the other?**

The National Health Plan and the São Paulo plan mention the importance of diagnosis and long-term care, but other things as well. We do want to talk about training, for example, not just for the health professionals who are already there, but also for people are in medical school and other health professionals training – to make sure that they have proper training regarding dementia, but also ageing in general, which is not valued as it should be during training. There needs to be intergenerational contact as well. You can talk about dementia to very young people in the schools, so they can have a better understanding from the very beginning.

We are undertaking a first national report on dementia with the Ministry of Health on epidemiological numbers and the impact of dementia in Brazil – and we are now going to work on a communication strategy; we will produce videos, booklets, fact sheets, and other kinds of material with appropriate language depending on which sector of the population we are addressing – whether it be a school, health professionals, graduate students, or the general population. We are going to create this over the next two years to expand information available to the population as a whole.

We did a lot of work with the situational analysis with STRiDE to try to understand what we have already in Brazil. But we are now doing another project with the Ministry of Health, something that I think is important, where we are going to interview about 150 people with dementia in the five main regions of Brazil. We are going into small towns, big towns, in the Amazon, in the northeast, in the north, in the south. This is going to help us understand what [people's] needs are, if they are met or not and give us an idea of what the obstacles in the system are and what people's real journey is: from people recognising that they have a problem to diagnosis, and then after diagnosis to the stage they are at the moment of the interview. We will also interview members of their families to find out what their needs are and how they are met in these very different scenarios.

The participants may not fully represent the two million people with dementia in Brazil today – but the idea is to get an understanding of the situation from different angles and in different scenarios.

I also want to think about other services that would be nice to have. For example, what we call “residenciais” in Brazil, which are long-term care (LTC) institutions. Even if they were available [in Brazil], it's likely that people would try to avoid putting their relatives in long-term institutions. The fact that we don't have many of them may to some extent be linked to this cultural issue. Most of those that do exist

are private and are not properly regulated – so the first step would be to ensure they can be registered and regulated, to see what proportion of people with dementia live in them, how many there are, and where. From there, we can think about a strategy. This is something we would need to think carefully about, as this type of care provision would be expensive in a country the size of Brazil; there would have to be a clear economic evaluation and strategy with respect to how this could be provided.

**Looking into the future, what would be the ideal post-diagnostic support model in Brazil in 10 years' time?**

I would want us to have better knowledge about dementia and less stigma – that would help with recognition and improve the rates of diagnosis. To have a system that's better

funded, expanding the care that is already provided to more people. Having a clear pathway so that, once diagnosed, people can be assured that they will have the best care from beginning to end, including end-of-life care.

**What you've described shows so well how important a national dementia plan is – it's about creating awareness, reducing stigma, and creating that pathway of care that supports the person living with dementia and their family all the way through to those palliative care stages and that framework and structure is so important. It's exciting to see how things are changing in Brazil and I know you and your team have been instrumental in galvanising that.**

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## Expert essay

# Canada: The challenges and opportunities of dementia care in a federal health system

Claire Webster

Founder, ambassador, and lecturer for McGill University Dementia Education Program, Canada

**Dr Saskia Sivananthan is the chief research and knowledge translation officer for the Alzheimer Society of Canada. She oversees the Alzheimer Society Canada Research Program and co-leads the inaugural non-pharmacological interventions working group of the Canadian Consensus Guidelines on Dementia. Dr Sivananthan has served as a senior strategy and policy advisor consulting for the World Health Organization (WHO) on its overall global dementia strategy and co-drafted the WHO's Global Action Plan on the Public Health Response to Dementia, which was unanimously adopted at the 70th World Health Assembly. For the World Alzheimer Report, Dr Sivananthan is discussing with us the situation in Canada. Could you please tell us about Canada's dementia care strategy? What sets it apart with respect to post-diagnostic support? What is Canada doing well, and where can it improve?**

Canada has a national dementia strategy that was published in 2019, and we welcomed it with a lot of excitement. When I say "we," I speak of the Alzheimer Society of Canada as a non-profit organisation that had really been advocating for a national strategy for 10 years. It was really a celebration for us that dementia was recognised within that strategy and that it was enacted into law, which meant that there was a commitment from the federal government to do more than just develop the strategy and put it on a shelf.

The strategy aligns very well with the WHO dementia action plan and recognises the diversity of people living with dementia and their human rights in particular, which is often missing in a lot of strategies that we've seen internationally. Some of them are very much focused on care pathways, the clinical needs, and the sort of training that is required for healthcare professionals – all of which are core components, but we don't want to lose the person living with dementia and their care partner who are at the centre of all of that. Canada's strategy does that quite well; It focuses on prevention and risk reduction, and I would say more so than other strategies for a couple of reasons.

**The fact that Canada has a unique healthcare system, whereby the federal government has a minister of health for Canada, but then each of the 10 provinces [and three territories] has its own minister of health – is that a big challenge in terms of the federal government being able to implement plans?**

Canada has a very complex healthcare system. We have a federal government, which is the core funder for all healthcare including dementia care, and then each province has its own operationalising of health care. In other words, it's as if we have 10 different healthcare systems. I think this is where some of the weaknesses of the strategy come out, because of the difficulty in having a national approach to a lot of things.

The federal government can develop a strategy that could serve as a blueprint for provinces in terms of how they want to adopt and implement their own dementia strategies. However, operationalising that strategy is up to each province. Some provinces already have dementia strategies, which they are aligning with the federal strategy, others don't have any at all, and some are developing new ones.

For example, I live in Ontario, and you're based in Quebec. Just between those two provinces, which are side by side, there are differences in terms of healthcare, healthcare access, home, and community care, even access to drugs that are related to dementia care. The coverage varies based on the province you're in. So those are examples of where this becomes very complicated in terms of being able to enact strategies.

**What role does the Alzheimer Society of Canada play with respect to advancing Canada's dementia care strategy? I understand that it has taken the decision to engage people living with dementia and all aspects of research that it funds. Can you tell us how the types of projects that are being funded have led to innovations in post-diagnostic support?**

The Alzheimer Society has two core mission purposes – there's the one which is really focused on programmatic support for people living with dementia across the country and so we have offices and partners across the country that provide on-the-ground support, really filling the gaps in care that exist in our own healthcare system. One of the key programmes that we provide is called First Link. The intention behind that is to ensure that if a person is diagnosed with dementia, the onus is not all on them and their care partner to figure out how to navigate this really complicated system. The Alzheimer Society can reach out to them with their consent, and then help them navigate that system. We've had clients who, even after end of life, their care partners and families have continued to stay with us and receive support from us.

The second mission is research. You've probably heard it can take up to 17 years once research has found evidence for it to be put into practice. What we really want to do is to close that gap so we don't just fund the research, we also put that into practice in the programmes and the education that we provide. This is where people living with dementia have been so crucial. About four years ago, when I joined the Society, people living with dementia were engaged in different aspects of our work, but not end to end. We realised that this was actually a big gap, because the lived experience and perspective is crucial. It's changed the kinds of priorities that we fund in research, how we score the research and allocate funding toward it, as well as our advocacy goals and platform. We've taken apart our entire research programme and asked ourselves at each of these major milestones and phases: Where can we meaningfully engage people living with dementia and care partners so that we can shift and make the difference we know we need to make?

**What would you say are the major challenges that people living with dementia, as well as family carers, are facing in Canada?**

One of the crucial things that I've learned has [come] directly from people living with dementia, who have called [the Alzheimer Society hotline], is just how disconnected the health system is, even provincially. There is no clear pathway of care as there is with a lot of other diseases that are equivalent to dementia. You may be able to go in and get a diagnosis and after that you're entirely on your own to figure out what you need, whom to reach out to, and there's no real support system in place. Whereas if you look at some other major chronic conditions or diseases like cancer or diabetes, there is an entire support network in place where people actively reach out to you and guide you.

One of the most important things that has stayed in my head was when I heard a speech by Kate Swaffer from Dementia Advocacy International (DAI). When she got her diagnosis, she was basically told to go home, get her affairs in order, and wait. We would never do that for any other disease. We

would never treat anyone living with cancer that way, so why do we think that it's appropriate to do that for dementia? Post-diagnostic support, treatment options, even rehabilitation options are incredibly limited, and this is something that really needs to be built out far more.

**Can you talk about the impact that the COVID-19 pandemic has had on people living with dementia and their carers in Canada?**

It ripped through the system for Canadians, but particularly for people living with dementia. At the onset, we created the [Alzheimer Society of Canada's dementia] task force because we were hearing directly from doctors who were saying that this is impacting their patients living with dementia much more than we thought. As we started gathering more information, we realised that people living with dementia were disproportionately impacted. Most of the deaths happened to people living with dementia, particularly in long-term care and of course to older adults. We know that a lot of the systemic issues, the long-term issues that happen after an infection of COVID-19 include what appear to be long-term memory loss and other symptoms that are very similar to dementia.

And then stigma went through the roof for people living with dementia. Emergency room and intensive care unit systems were being put in place and, rightly so; people were looking at developing protocols for how you would prioritise people coming in with COVID-19 who need lifesaving care. People living with dementia were immediately excluded right from the onset. If you had a diagnosis, you could not access a ventilator, for example. That came directly from stigma and misunderstanding and a very low education about what it means to live with dementia. This was where the taskforce work was really cut out to be able to re-educate and change some of those protocols.

**Many challenges faced by people living with dementia and carers are global problems, regardless of whether you live in a high- or low-income country. What needs to change?**

There are three things that need to change from my personal perspective. The first is education around dementia, not just for the general public, but particularly for healthcare professionals who are meant to be the stewards of their patients' care. We know that this is one of the core issues in high-income and other countries, and in many ways a doctor is the advocate for the patient when they're armed with the information and support to be able to help them. That would mean that national dementia guidelines also need to be created, adapted, and supported nationally by the federal government and this is something we've been advocating for as we're working to develop those guidelines in a sustained way with Canadian Consensus Conferences on the Diagnosis and Treatment of Dementia (CCCDTD).

The second I would say is stigma, which is part of what really holds people back from getting a diagnosis or providing a diagnosis. We surveyed family doctors in Canada, and we heard first-hand that a lot of the reason why doctors hold back from providing a diagnosis is that they don't know what to give after that diagnosis to someone – there are no treatments; they feel that it's kind of a lost cause, so they might as well not bother. That is stigma within the healthcare profession and there's also our own stigma about reaching out and getting that support. How will you be perceived in the workplace, by your families and friends? I think about this being similar to HIV, AIDS, or cancer, which also had huge stigma when the diseases were first being diagnosed and were spreading through the population. It took a lot of focus work for us to shift our thinking, to looking at people as

survivors, looking at people as being able contribute a lot to society, even with a diagnosis. I think that's the second core thing that needs to change internationally, but of course, from a Canadian perspective, I think is crucial.

The third and last one is investment in research, because it is so low compared to any other disease, and it is that investment that will result in treatment options. I don't just mean pharmacological treatments: even nonpharmacological treatments require evidence. In Canada, we're fairly low in terms of our investment in research. If you look at the WHO Global Dementia Observatory, the global investment in research is incredibly low. We're not going to be able to make much movement or stride if we're not willing to put our money where our mouth is, in essence.

## Conclusion

The conversations in this chapter show that, while specific national circumstances may differ, many of the obstacles are the same. Stigma, a dearth of dementia-specific education for healthcare workers, difficulties in ensuring equitable support and coverage for all people with dementia across a territory... all affect how a care model is designed and implemented.

As a result of these similarities, we see some patterns emerge among the examples put forth in this chapter – including the crucial role of case management provided through appropriately trained professionals, local dementia centres, and/or mobile healthcare workers, all of whom provide outreach and support to help people with dementia and their carers navigate the often complex post-diagnosis journey. Many of these programmes would be impossible without the implementation of well-funded and thought-out national dementia plans.

While a lot of positive things are taking place, one thing is clear when looking at the state of dementia care and support in these four countries: there is always room for growth – a statement that should not be seen as discouraging, but, on the contrary, reflective of the continuous progress made in research and interventions related to dementia.

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# **Part VIII**

## The road ahead

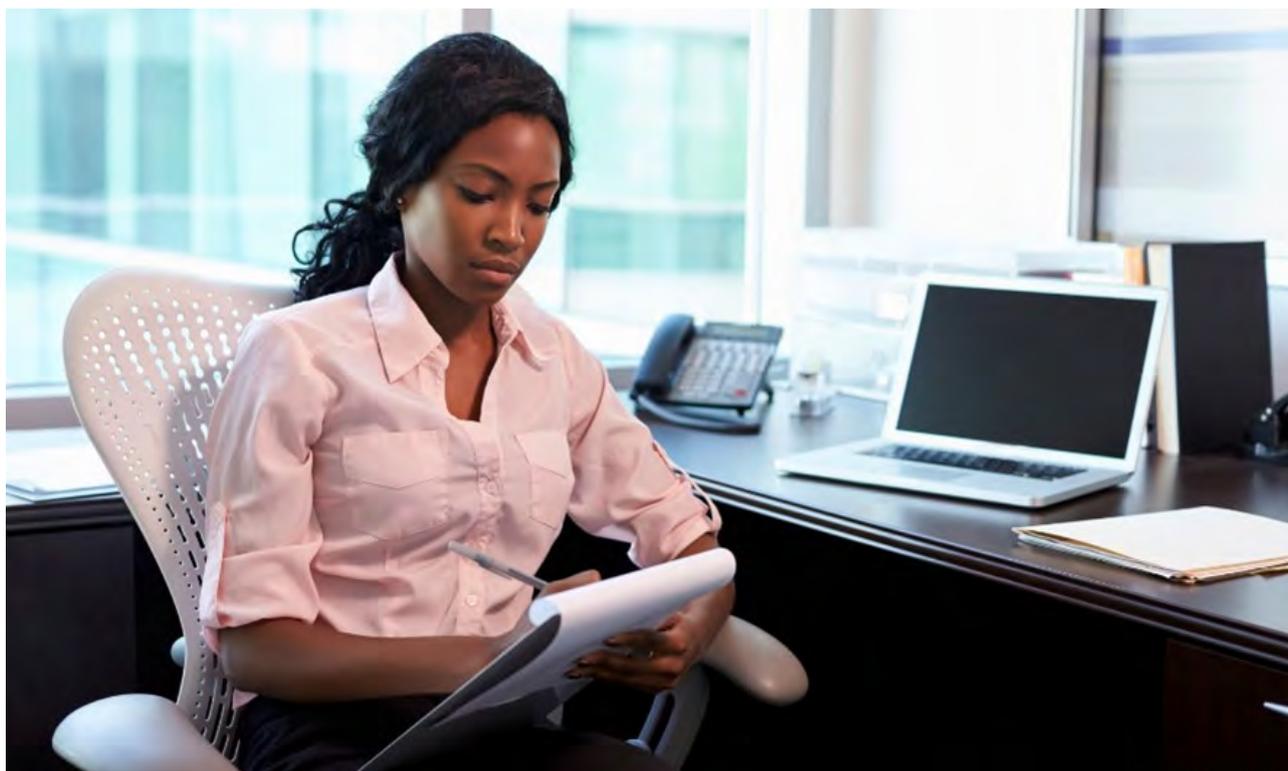
# Chapter 22

## Education about dementia for healthcare professionals

*Joseph Therriault, Claire Webster, Serge Gauthier*

### Key points

- Greater education about dementia is required at university and training centres in order to improve post-diagnostic dementia care.
- Dementia education and training for healthcare professionals cannot be structured as a single event, but rather as a continuing evidence-based process.
- Dementia care education and training should involve an interdisciplinary approach in order to respond to the multiple facets of the condition.
- Innovative dementia education programmes involve the use of immersive, experiential, simulated, virtual reality, and empathy training teaching approaches as well as direct involvement with persons living with dementia and their carers in order to gain real life perspectives.
- Dementia education for healthcare professionals must be tailored to the roles of the specific healthcare professionals (nurses, family physicians, specialists), serving the needs of the patient while also considering local cultural, linguistic, social, and economic factors.



## General background

As documented in last year's World Alzheimer Report, many physicians are not comfortable diagnosing dementia. Moreover, some healthcare professionals said they believed that there was little benefit in diagnosing dementia due to the belief that few therapeutic options are available. Therefore, there is an unmet need to integrate lifelong learning about dementia-related care into healthcare professional practice.

Dementia education for healthcare professionals must be tailored to the needs of the specific clinical practice. Often, medical programs place great emphasis on diagnosis and aetiology, but insufficient attention is given to post-diagnostic care. However, because persons living with dementia often *live with dementia* for several years, post-diagnostic care programs have the potential to substantially increase quality of life for patients and their carers. Furthermore, because neurodegenerative diseases are progressive and chronic disorders, dementia symptoms continue to worsen post-diagnosis as the condition evolves. Correspondingly, the needs of persons living with dementia, their carers and their families will also evolve over time. Education programs for healthcare professionals must therefore take this into account in order to provide appropriate care for all stages of the condition.

Dementia education for healthcare professionals must also be tailored to the roles of the specific healthcare professionals (nurses, family physicians, specialists), serving the needs of the patient while also considering local cultural, linguistic, social, and economic factors. Similarly, understanding the realities of a healthcare practice in a given environment is necessary.

It is also important to emphasize that dementia education will not serve as a cure-all for current limitations in dementia-related care. Several structural and economic factors are associated with poor prognosis for persons living with dementia. High levels of healthcare practitioner burnout, as well as record-high numbers of nurses and physicians leaving clinical practice must be kept in mind when designing education programs. If these factors are not considered, there is an important risk of creating programs that "tick the boxes" but are not associated with meaningful improved outcomes for persons living with dementia or their families.

Despite the challenges, improving education about dementia diagnosis and post-diagnostic care stands to make large contributions to global public health. Due to the projected increases in dementia prevalence over the next 30 years, creating improved support systems for persons living with dementia, their carers and their families stands to make substantial reductions in global morbidity.

## Expert essay

# What are the most effective strategies for dementia education for healthcare professionals?

Claire Surr<sup>1</sup>, Sarah Smith<sup>2</sup>

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Ensuring the health and social care workforce has appropriate dementia knowledge, attitudes, and skills lies at the heart of good services and has driven a global interest in delivery of dementia education and training. This however leaves a question as to what training is needed and how best to deliver it.

Internationally, there has been a growth of training standards or criteria to help guide the content of training. This has been driven by the growing recognition of the role dementia training plays within the sector and advocacy from many stakeholders (including people living with or caring for someone with dementia, care providers and academics), for clearer and mandated training requirements for the workforce. However, training standards still vary globally, relying most often on aspiration rather than government or regulatory requirements. Some training standards provide specific and comprehensive guidance for training content focussing on knowledge and skills (for example the English Dementia Training Standards Framework[1]); some are outcomes-based, meaning the knowledge and skills are linked to the outcome they should lead to for people affected by dementia (such as the Scottish Promoting Excellence Framework [2]); and some countries do not have specific standards for dementia training, but instead include more generic requirements for staff to be appropriately skilled and knowledgeable within wider care quality standards (for example the Australian Aged Care Quality Standards [3]). It remains challenging to evaluate the impact of training standards on dementia care quality since they are typically introduced alongside related policy initiatives. However, at a minimum, introducing training standards enables benchmarking and represents a commitment to the importance of dementia specific training to enhance the standard of care for people living with dementia.

However, introduction of standards and targets for numbers of staff attending training that meets these can lead to a 'tick-box' approach to training, where completion to meet a target is seen to be more important than its impact.

Our research set out to find what approaches to the design and delivery of dementia education and training were most effective at ensuring staff developed the right knowledge, attitudes, and skills to deliver good dementia care. It also looked at what needs to be in place for staff to be able to put their training into practice. To do this we:

- reviewed over 150 published research studies involving dementia training[4],
- conducted a survey of health, social care and training providers as well as staff who had attended their training programmes[5][6],
- looked in detail at the content, design, delivery and implementation of dementia training programmes, in 10 different health and social care provider organisations where the training seemed to be particularly effective[7][8][9].

From this we were able to establish the following key features of dementia training that is most likely to be effective:

## Content

- Is tailored to be relevant and realistic to the role, experience, and practice of the learners. Training should not be generic; including options for specialists and learners in leadership roles;
- Includes specific tools, methods/approaches to underpin care delivery, for example assessment tools for pain, behaviours, or nutrition and processes for acting on their outcomes;
- Encourages learners to engage with and reflect on what it might feel like to live with dementia (through video, simulation, or direct involvement of people with dementia and/or carers in training delivery).

## Duration

- Is ideally more than half-a-day duration per subject area, with longer and more in-depth programmes (1–2 days) which will more likely produce positive results;
- Where a programme is delivered over several sessions, individual sessions should last at least two hours.

## Delivery

- Uses small or large group face-to-face learning either alone or in addition to another learning approach (e.g., mentorship);
- Avoids lecture-style teaching methods where a trainer talks to/at learners for substantial periods of time;
- Includes interactive learning activities and opportunities for learner discussion and interaction, using case examples/video-based scenarios or drawing on examples from learners' own practice;
- Avoids self-directed learning alone, for example through booklets or e-learning. This might form smaller parts of training – for example activities in preparation for attending training or in-between training sessions;
- Is delivered by a knowledgeable, skilled, and experienced facilitator who is usually also an experienced clinician or practitioner and able to deliver the training flexibly.

## Context

- A supportive organisational context and learning culture, accompanied by strong, dedicated dementia training and practice leadership is crucial;
- A dedicated training space;
- A physical environment that is supportive of good dementia care education.

We also looked at the barriers to implementing training into practice and the facilitators that supported this, using the Capability, Opportunity and Motivation and Behaviour (COM-B) model for understanding behaviour change<sup>[10]</sup>.

We found most staff felt that they had the capability (knowledge, skills, etc.) to implement training in practice. The strongest facilitator associated with feelings of capability was having attended interactive, face-to-face learning that was relevant to their role and needs.

Opportunity (social influences, environmental context, and resources) related barriers and facilitators were raised most commonly. The most frequent barriers to being able to put training into practice experienced related to a lack of resources

including time, financial issues, competing demands, staffing issues and turnover, and the physical environment (e.g., its dementia friendliness). A key facilitator was internal support including supportive leadership and management, a positive organisational culture that valued training and practice development and peer support for training implementation. Regular mentorship, supervision and feedback were also valued and supported training implementation.

Motivational factors (roles, beliefs, goals, intentions, etc.), while mostly seen as facilitators to training implementation, were less influential than other factors. A skilled facilitator who could motivate and create a memorable learning experience was a strong motivational facilitator. Also important were incentives for attending training such as completing it within working or paid hours and providing certificates. A personal desire to learn and improve practice was a facilitator to putting training into practice, however disinterest in learning or in providing care for people with dementia and low morale were a barrier.

We also found that dementia training standards introduces a wide range of topics and content areas that can be unfeasible for organisations to practically implement across their workforce. It can also lead to organisations choosing to provide training that superficially covers many topics rather than providing impactful, more in-depth training. Therefore, flexibility is needed in how frameworks and standards are applied. Completing a training needs analysis for different workforce roles, which is where the specific knowledge and skills within a framework or standards are mapped to a particular staff role, can help to prioritise training topics. For example, a member of staff working in a service that undertakes dementia diagnosis will need knowledge and skills on dementia types, symptoms, assessment, and diagnosis, but knowledge and skills on end-of-life care may be less relevant. The opposite would apply to a member of staff working in a long-term care setting.

Our research therefore shows that there are many factors to consider in developing and delivering effective dementia education and training. Having the right content tailored to the staff attending and using interactive and engaging methods is important. However, considering training content or delivery methods alone are unlikely to lead to the delivery of high-quality dementia care. The organisational context and support for training implementation are vital. Staff need to see that there is managerial support and leadership for training and that it is valued. Health and social care provider organisations need to have the requisite resources to support training attendance and subsequent implementation. If these are lacking, then no training programme, no matter how innovative, or impactful on individual knowledge, is likely to lead to any sustained impact on care delivery. Training is not a sole intervention but needs to be embedded within a wider context supportive of high-quality dementia care.

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## Expert essay

# Innovative dementia education programs for undergraduate healthcare students

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The increasing prevalence of dementia demands a future healthcare workforce with the necessary knowledge, positive attitudes, and skills to deliver effective assessment and support to those living with the condition. To date, dementia education for undergraduate healthcare students has not met this aspiration [1]. Relying on didactic teaching and an emphasis on acute episodes of care serves to re-enforce an overly negative picture of life with dementia. Current teaching also fails to ignite motivation in healthcare students to specialise in dementia care. This in turn feeds into a negative cycle, whereby dementia services fail to attract newly qualified, highly motivated healthcare professionals, who bring with them the potential to energise and innovate care practices. This failure to enhance practice acts as a further disincentive to the future healthcare workforce to work in dementia care facilities. There is a need therefore for undergraduate teaching to adapt to produce a future multi-professional workforce, of both dementia generalists and specialists.

There have however been some areas of innovation, which have harnessed the lived experience of people living dementia to challenge the overriding therapeutic nihilism of current undergraduate teaching. These newer models of undergraduate dementia education include long-term experiential programmes, activity-centred learning, interprofessional education and simulation.

*Long-term experiential* programmes, which provide longitudinal contact between students and people with dementia, have grown in popularity. The original 'Buddy Program' was developed by Darby Morhardt and colleagues at Northwestern University as an elective component of medical education. However, the model has since been expanded to a much wider range of healthcare students as a mandatory component of training. The active ingredient underpinning these programmes is 'relational learning', namely deeply embedded learning in the context of an authentic relationship built over time between student learners and people with dementia and their carers [2].

A second area of innovation is *activity-based learning* projects that involve individual or groups of undergraduate students undertaking a defined activity, for example art or storytelling, with people living with dementia. These projects are conceptually underpinned by 'service learning', whereby students engage in community-based activities which allow students to connect theory into practice [3]. Projects such as Opening Minds Through Art (OMA) involves students engaging with people living with dementia on an art activity on a one-to-one basis over a 12-week period within residential care facilities [3].

A third model of innovation is *interprofessional education (IPE)* whereby groups of two or more undergraduate healthcare students undertake dementia education together. Whilst not an essential component of IPE, many of these programmes do include students directly interacting with people living with dementia or their carers [4]. The additional benefits of such programmes include the enhancement of positive attitudes and skills in interprofessional working, along with improved dementia knowledge.

The final model, *simulation* programmes involve undergraduate healthcare students experiencing an immersive multisensory simulation of what people with dementia may experience. Such approaches can include the use of devices intended to mimic cognitive impairment, for example, the Alzheimer's Australia Virtual Dementia Experience (VDEÖ), whereby students undertake a virtual reality experience, with multi-sensory simulation of light, colour, and visual content to experience the effect dementia can have on an individual [5]. Alternatively, these programmes may involve the use of professional 'actors' role-playing somebody with dementia, within a 'simulated' clinical encounter, for example, de-escalation, assessing capacity and engaging with a distressed patient or carer [6]. Such programmes allow for students to practice and develop skills and awareness in a safe environment.

A recent scoping review [7] which sought to assess the effectiveness of innovative approaches to dementia education for undergraduate healthcare students found that all of these

models demonstrated positive effects on either knowledge, attitude, confidence or all three: either quantitatively or qualitatively. This is perhaps not surprising, as it is known that didactic 'classroom'-based teaching and traditional placements, the bedrock of much of undergraduate teaching, do not provide as profound level of learning [8] as an experiential education format may.

It is also of note that most of these models include lived experience, or simulation of lived experience. Meaningful first-hand exposure to the challenges which people living with dementia and their carers may experience on a daily basis cannot be replicated in the classroom, and in this respect, people living with dementia are the 'teachers' of our future healthcare workforce [9].

It is also recognised that whilst these models are described separately, there is a significant potential to combine aspects of each, for example, by embedding activity within

a longitudinal duration, or by students undertaking simulation activities within an IPE context. Such developments maintain the active ingredient of each model yet have the potential to enhance learning outcomes further. It could be suggested that IPE as an underpinning component should be present within all undergraduate dementia education, given that optimal care delivery to people living with dementia is best through a multidisciplinary approach [10].

There is a pressing global requirement that the future workforce be equipped to fully support people living with dementia. Undergraduate healthcare education is therefore an important resolution to this need, and these innovative models, with meaningful involvement of people living with dementia as a cornerstone of their success, illustrate how this aspiration can be met.

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## Expert essay

# Behavioural interventions to enhance empathy in dementia care

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Empathy is a complex behavioural response to another person's circumstance that impacts health outcomes. Empathic care increases patient and carer satisfaction, improves diagnostic accuracy and treatment adherence, mitigates carer and clinician burnout, and is person-centred [1][2]. Empathy consists of affective and cognitive components: affective empathy is the capacity to feel similar emotions to another, while cognitive empathy is the capacity to understand what another is feeling. Cognitive and affective empathy can be further decomposed into component processes that can be targeted with behavioural interventions aimed to enhance empathy. An example component process of affective empathy is empathic concern, defined as the experience of compassion in response to another's pain or suffering. Component processes contributing to cognitive empathy include perspective taking (i.e., putting oneself in another's shoes to understand how they feel) and affective theory of mind (i.e., the ability to detect others' feelings and understand that their perspective differs from our own).

Fostering empathic care is critical for persons living with dementia (PLWD). The 2018 Alzheimer's Association Dementia Care Practice outlines the importance of person-centred care for persons living with dementia. This identity-affirming care is fostered through interpersonal relationships [3]: "To have an identity is to know who one is, in cognition and in feeling. It means having a sense of continuity with the past; and hence a 'narrative', a story to present to others" [4]. Cognitive decline among persons living with dementia may create an identity penumbra, making it necessary to find strategies to have others "hold their story" [4]. Such strategies can be implemented at the level of health professionals, trainees or through intergenerational community engagement initiatives. An exciting example of the latter is the Cleveland Regional StoryBank, a multidisciplinary initiative at the nexus of health science, humanities, social science, and ethics [5]. This project began with gathering stories from persons living with dementia at an assisted living facility; the residents then read their stories to children at the Intergenerational School in Cleveland. The initiative has since grown into a "big humanities and social science" project borrowing the framework of neurobiological "big

data" projects. StoryBank takes a meta-approach to narrative medicine and seeks to compile, store, and analyse individual stories in order to cultivate empathy and enhance our understanding of illness experiences, coherence, quality of life and purpose in persons living with dementia.

Narrative medicine is a multidisciplinary field that fosters narrative competencies to derive meaning and empathetic understanding of patients' stories of illness [6]. It emphasizes the unique content, metaphor, language, temporality, and experiences that patients use to describe their illness or symptoms to healthcare professionals. Literary principles such as close reading can be applied by clinicians to reflect upon and understand patients' narratives. Close reading emphasizes the singular and is achieved through attentive interpretation of short passages of text in order to give "truth to individual experience" [7]. Clinicians actively listen to patients' impressions, hopes, and ideas about their illness or symptoms, and apply their imagination, memories, and interpretations to identify meaning in the patient's narrative and the deep connection between patients and themselves. Among persons living with dementia, the narrative is multidimensional since it is told from multiple perspectives, namely from the point of view of persons living with dementia and their carers or informants. This allows clinicians to acknowledge the unique experiences of patients and carers, empathize with them, establish a stronger therapeutic alliance, provide more effective care and "restore to medicine some of its passion, its meaning, and its joy" [6].

**“ This allows clinicians to acknowledge the unique experiences of patients and carers, empathize with them, establish a stronger therapeutic alliance, provide more effective care and “restore to medicine some of its passion, its meaning, and its joy”**

Interventions that incorporate narrative medicine-based approaches have demonstrated increased empathy in clinicians and trainees[8]. In one study, medical students interviewed older adults about their life stories, transcribed and reviewed the written narrative with the patient, and incorporated the patient's narrative into their medical chart [9]. While this study did not have a control group, they found that the trainees demonstrated significantly higher empathy scores after the intervention, as measured by an adapted version of the Consultation and Relationship Empathy Measure. Further, another study examined the efficacy of a life history intervention for healthcare professionals who worked with persons living with dementia and showed enhanced scores on the Jefferson Scale of Physician Empathy and perspective taking, compared to a control group[2]. In addition to narrative medicine-based approaches, virtual reality (VR) interventions that simulate the experience of dementia have also demonstrated modest efficacy in enhancing empathy as measured by the Interpersonal Reactivity Index (IRI) in clinicians and trainees, with the largest increases found among those with the lowest empathy scores pre-intervention [2][9]. Multiple behavioural interventions have focused on empathic communication training (e.g., positively framed statements, direct eye contact, avoiding elderspeak, active listening, group storytelling, avoiding assumptions, and, listening to the preferences, desires and needs of persons living with dementia)[2] and have been shown to reduce agitation and depression in persons living with dementia.

Carers that display empathy derive more meaning from providing care and experience less mental illness and burnout. Further, persons living with dementia who receive empathic care report more trust and satisfaction in their relationship with their carer. Prior studies have investigated the effect of perspective-taking interventions on carers for persons living with dementia's empathy and well-being. In one randomised controlled trial, intervention participants had eight weeks of weekly telephone sessions where they reflected on their caregiving role and how dementia has affected the life of their care recipient [10]. The goal of the intervention was to increase intergenerational carers' self-awareness and empathetic understanding of their care recipient. Compared to a control group, the intervention group reported increased

life satisfaction, with perspective taking mediating this effect. Another perspective taking intervention consisted of a four-month psychoeducational program[11]. The program used e-learning modules on the medical model of dementia, functional consequences experienced in daily life, and strategies for coping with the psychosocial consequences of dementia. Affective and cognitive empathy were measured with the IRI. They found that the control group's empathy remained stable while the intervention group demonstrated significantly higher empathic concern, less personal distress, and higher perspective taking after the intervention.

## Conclusions and future directions

For carers, healthcare professionals, and trainees, both affective and cognitive empathy are vital for providing person-centred care for persons living with dementia. Research in this area is still in its infancy and is limited by small sample sizes, lack of control groups, and different methods for measuring empathy. Future research should focus on developing scientifically rigorous randomised controlled trials for enhancing empathy in clinicians and caregivers as well as assessing the effects of these methods on the well-being of persons living with dementia. This could be achieved by adopting the research framework of applied cognitive neuroscience such as the Science of Behaviour Change. Despite the importance of empathy to health outcomes, many trainees demonstrate decreased empathy throughout their medical education. Thus, clinical training programs should incorporate empathy training, such as narrative medicine, into their curricula. Important unanswered questions remain. For example, the impact of virtual diagnostic assessment of persons living with dementia on empathic care is poorly understood. So too is our understanding of the cultural, demographic, and linguistic influences on empathic communication. Finally, developing innovative transdisciplinary intervention programs that promote creative exchange (e.g., artist in residence programs embedded within memory centres) between persons living with dementia, their care team and communities will further enhance person-centred care.

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## Expert essay

# ADI's accreditation programme and how it could benefit healthcare professionals, universities, and associations in diverse populations

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The needs of people living with dementia and their carers change over time as their condition evolves, and care systems need to respond appropriately to ensure that they provide the best services and support at every step. As detailed in the World Alzheimer Report 2016[1], this involves maintaining regular contact, monitoring people with dementia's wellbeing, reviewing care plans, and providing support as needs arise, all while ensuring that care is continuous and person-centred.

Professional care providers require training to carry out their duties effectively – and training programmes must make sure that they not only know how to fulfil the medical and psychotherapeutic expectations of their work, but also take into account the cultural, linguistic and identity specificities of the people to whom they provide services. The need for culturally sensitive and adapted formation programmes has become more evident during the pandemic with the rise of online training, in which world-class training providers, many of them based in high-income countries, are asked to give courses to care professionals in other countries. Even within a singular organisation, such as a university or a training centre, students come from diverse global and local backgrounds, varied socio-economic circumstances, professional or personal backgrounds – and so will the people they serve.

Without adapting their dementia care training programmes to these varied circumstances, training providers and their trainees are bound to face challenges that impede the effectiveness of these educational courses. It is vital that training providers adapt their programmes to the contexts in which care providers operate. So how do we cope with these variations and provide quality dementia care education adapted to the specific needs of people with dementia, wherever they are?

This question led to the creation of Alzheimer's Disease International's (ADI) accreditation programme[2] in December 2020, with the aim of supporting the provision of better care for people with dementia across the world, reducing

variation in the quality of care, and ensuring a more focussed approach to meeting people's needs by certifying that participating organisations meet high standards when providing informed, in-depth, and adapted dementia care training.

ADI's programme takes a structured approach to sharing the necessary knowledge and skills with its participants and establishes standards that they would need to adhere to in order to earn ADI accreditation following the successful completion of an evaluation. Accreditation means that the organisation's training and learning activities have reached the required ADI standard, ensuring integrity and quality at all levels. Alzheimer and dementia associations, universities and colleges, health and care institutions, community care training providers and government training programmes are among the organisations that can participate in ADI's accreditation programme.

What makes ADI accreditation unique is that our accreditees are not only academically educated through comprehensive theory modules and programmes but are also practically involved with people living with dementia, civil society, communities, and local organisations while prioritising person-centred care. With more than 100 member associations across the globe, ADI's well-established dedication to diversity is an essential asset to our accreditation programme.

The accreditation review process includes the involvement of an ADI Global Review Panel (GRP), composed of representatives from Alzheimer's and dementia associations, people living with dementia, and dementia care organisations. The four to six members of the GRP, appointed by ADI's CEO, include at least two people from the region where the review is being held. The local reviewers will be familiar with the local healthcare and dementia care environment, as well as any local, national, or regional specificities.



The Kiang Wu Nursing College (KWNC) of Macau was the first organisation to receive ADI accreditation, starting in September 2021. The pilot project launched with several captivating discussions around external and internal governance, trainers and programme committees, students, graduates, and other stakeholders. Though the first accreditation proceeded virtually due to pandemic, the synergy between the ADI Accreditation team, KWNC team and GRP brought a lively dynamic throughout the journey.

Following a three-day virtual visit of KWNC’s facilities and a final review by the GRP over the course of October and November, we were pleased to present KWNC with ADI accreditation during a virtual ceremony on 25 January 2022.

“Dementia has become a global priority health issue in response to the increasing dementia population... In effect, Kiang Wu Nursing College of Macau is now able to offer training to nurses for people living with dementia and carers, which is recognised by ADI standards,” Professor Van Iat

Kio, president of KWNC, said during the ceremony. “We believe that this first accreditation symbolises the beginning of a new path towards standards in dementia care, both in Macau SAR (special administrative region) and across the world.”

In early 2022, we began the process with the Hamad International Training Centre in Qatar and Silverado San Diego in the United States. Other organisations in the Middle East, Europe, Asia Pacific, Latin America, and Africa have also expressed interest.

ADI supports the goals set out by the WHO Global Action Plan on Dementia[3], particularly Action areas 4 and 5 dedicated to treatment, care and support of people living with dementia and support for carers. Through this programme, we aim to ensure high-quality care training is more widely available around the world and benefits people living with dementia, who deserve the best support possible wherever they are.

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## Conclusion

The introduction of this chapter outlined some of the limitations in current dementia-related care and highlighted how improving dementia-related education tailored to the specific needs of local professionals can help improve outcomes in persons living with dementia.

The essays in this chapter raise important questions about what dementia education programmes can look like, how novel approaches to dementia education can transcend traditional lecture approaches, and the importance of fostering empathy among healthcare workers towards carers and persons living with dementia starting in medical school. The essay by Fonk-Utomo meanwhile addresses the problem of how to standardise education programs while understanding the specific needs of populations.

Taken together, these essays provide a framework to improve education for healthcare professionals about dementia care. Understanding the needs of the aging global population, as well as the needs of individuals, will increase the quality of life for persons living with dementia and their families.

PART I

PART II

PART III

PART IV

PART V

PART VI

PART VII

PART VIII

# Chapter 23

## Strategies towards dementia risk reduction

*Pedro Rosa-Neto, José A. Morais*

### Key points

- Despite formidable progress in the understanding of aging and dementia, effective dementia prevention remains an unmet need.
- Dementia is a slowly progressive, indolent neurodegenerative illness that evolves over decades. This long incubation period supports the concept of disease prevention as a viable public health approach.
- The availability of biomarker-based diagnoses offers the potential for detecting the disease progression prior to symptom development in at-risk individuals, testing of effective therapies, and possibly, prevention of symptom onset.
- Updated estimates indicate that up to 40% of dementias are associated to modifiable lifestyle, vascular and environmental risk factors, providing for a clear prevention potential. New risk factors including stress, sleeping disturbances, and dietary factors, also indicate further potential for prevention.
- Population-based approaches show that dementia risk can be reduced by targeting the societal conditions that determine the environments in which they grow up, work, live, and grow old.
- There is good evidence that risk factors in midlife (hypertension, obesity, hearing loss, traumatic brain injury, and alcohol misuse) and later life (smoking, depression, physical inactivity, social isolation, diabetes, and air pollution) contribute to increased dementia risk.
- The lack of knowledge about dementia risk factors, how these risk factors impact on personal susceptibility, and fear of developing the condition are main barriers for the public engaging in behavioural and lifestyle change for risk reduction.
- Atrial fibrillation (AF) is a major preventable cause of stroke, heart failure, and dementia. Its considerable impact on both life expectancy and quality of life means prevention, detection, and prompt management of this arrhythmia is essential.



## General background

When facing a potentially devastating diagnosis, it is human nature to want to prevent something grim from happening, if given that opportunity. We want to protect ourselves, our friends, and family from anything that could disrupt life as we know it. We especially want to avoid pain and steer clear of a journey that is paved in stress, anxiety, and grief – and dementia certainly has the potential to do all of this.

Today, specific measures can already have a tangible impact on dementia prevention. Cumulative research reveals that controlling cerebrovascular risk factors such as obesity, high blood pressure, high cholesterol, or cardiovascular disease reduces dementia in at-risk populations. Indeed, B12 vitamin deficiency or abusive alcohol intake are considered reversible causes of dementia [1].

Although regular physical exercise, restful sleep, balanced nutrition, and mental stimulation are recommended to maintain cognitive health, the effective dosage (intensity, frequency) of these non-pharmacological interventions remains elusive as a practical prescription to prevent dementia [2][3].

Disease modification with medication targeting protein aggregation (i.e., anti-amyloid and anti-tau) and antioxidants constitute an attractive strategy in current development. These interventions leverage the availability of Alzheimer's disease biomarkers and nurture hope for dementia prevention [4].

As dementia has many causes, combining synergic approaches may be the best strategy to prevent or delay it. While researchers work to find these preventive recipes, combining multiple approaches may represent the most effective strategy for maintaining cognitive health and preventing dementia.

When that mindset moves into a clinical setting, the question then becomes: What if disease intervention could be made more effective before symptoms set in?

William Jagust and Helen Wills explore this very premise in the thought-provoking first essay of this chapter. The availability of biomarker-based diagnoses has changed the landscape of Alzheimer's disease research by offering an observable and quantitative way to trace its trajectory even without the presence of symptoms. Furthermore,

the impact of healthy lifestyle changes is also touched upon as a non-pharmaceutical strategy when a person performs below standard on cognitive tests.

This transitions nicely to the next informative essay by Miia Kivipelto, Francesca Mangialasche and Nicola Payton, which details preventative measures from a lifestyle modification perspective. The global numbers of people who will face a dementia diagnosis will balloon to approximately 154 million by 2050. There is no denying that we are in crisis mode and all clinical avenues must be explored to help halt this upward trend. Such measures include the pioneering FINGER trial (Finnish Geriatric Intervention Trial to Prevent Cognitive Impairment and Disability), an ongoing long-term randomised controlled trial encompassing a multidomain intervention approach.

Next, Sebastian Walsh, Lindsay Wallace, and Carol Brayne advocate strongly for a population-based approach to mitigate the escalating incidences of dementia and its risk factors. By delving into four fundamental pillars – namely scale stratification, life course, sustainability, and mitigating

inequalities – they look at how specific factors and conditions surrounding individuals should be addressed as a viable and impactful clinical method of study as well as a building block to changing public health policies.

Dr Isabelle Choi takes an in-depth look at how modifiable risk factors for middle-aged and older adults such as hypertension, obesity, smoking, and physical activity contribute to an increased dementia risk. She further postulates that targeting these types of behaviours would be a sustainable preventative measure towards developing the condition. By educating the public more thoroughly about dementia and creating personal risk profiles, the medical community would need to support changes such behaviours.

In the final essay of this chapter, Jacqueline Joza provides a fascinating look at the impact of atrial fibrillation on overall health and on dementia risk in particular. Often undiagnosed until an incident occurs, the detection and prevention of atrium fibrillation is crucial. Joza makes a case for targeted intervention efforts coupled with public education and knowledge as major contributors to risk factor control.

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## Expert essay

# Is there a pre-symptomatic stage of Alzheimer's disease leading possibly to prevention?

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Alzheimer's disease is widely recognised as a slowly progressive, indolent neurodegenerative illness that evolves over decades. While aggressive forms of the disorder exist, often in younger individuals and those with autosomal dominant gene mutations, even these disorders take years to develop. Alzheimer's disease is not unique, as many medical illnesses have long incubation periods, supporting the concept of disease prevention as a public health approach. Interventions for virtually all illnesses are likely to be most effective before symptoms develop.

Although Alzheimer's disease evolves over a long period of time, it is only relatively recently that we have been able to measure this evolutionary process through the application of biomarkers that track Alzheimer's disease pathology. The crucial pathologies of  $\beta$ -amyloid plaques and tau neurofibrillary tangles can be assessed with cerebrospinal fluid (CSF), positron emission tomography (PET), and most recently plasma. PET measures detect, quantify, and map the amount and location of these pathological protein aggregates, and CSF and plasma measurements provide quantitative levels that may be associated with clinical diagnoses of Alzheimer's disease and PET evidence of  $\beta$ -amyloid or pathological tau.

The availability of biomarkers has also led to a new framework to define Alzheimer's disease solely in terms of the biomarkers that reflect its pathology, without regard to clinical symptoms [1]. This definition considers any individual with biomarker evidence of  $\beta$ -amyloid and tau pathology that exceeds pathological thresholds to have Alzheimer's disease, regardless of whether they are symptomatic, while those with evidence of brain  $\beta$ -amyloid alone are characterised as having Alzheimer's pathological change. These biomarker categories define an Alzheimer state regardless of cognitive function and even in the face of normal cognition. This approach is recommended for research; clinical application of biomarker characterisation currently recommends categorising those with biomarker evidence of Alzheimer's disease as "asymptomatic at risk" of progression [2], also a group that could benefit from therapeutic trials. Thus, the availability of biomarker-based diagnoses offers potential for detecting people at risk of progression prior to symptom development, testing of effective therapies, and, potentially, prevention of symptom onset.

To consider pre-symptomatic treatment, we must ask the crucial questions as to whether abnormal biomarkers (1) are present in a substantial proportion of cognitively normal older people (2) predict the development of Alzheimer's disease and (3) can drive effective therapy. With regard to the first question, the study of individuals with autosomal dominant mutations that cause Alzheimer's disease has definitively shown both  $\beta$ -amyloid and tau deposition in these mutation carriers decades prior to disease onset [3]. More relevant, in community samples the prevalence of biologically defined Alzheimer's disease is higher than clinically defined Alzheimer's disease, and can range between approximately 10% and 30% depending on age [4]. Regarding prediction, assessment of longitudinal cognitive performance in normal older people, which often focuses on memory ability, has definitively established associations between  $\beta$ -amyloid and tau measured at baseline and subsequent decline [56]. There is limited, but growing evidence that the age of symptom onset may be somewhat predictable based on biomarker results [7]. Together the data indicate the potential for using biomarkers to establish a pre-symptomatic phase that confers a high risk of cognitive decline and progression to Alzheimer's disease.

The final question is the most complex, involving issues of therapeutic efficacy, the precision of detection and prediction, and biomedical ethics. However, it is worth noting at the outset that clinical trials of asymptomatic individuals with risks for Alzheimer's disease by virtue of biomarkers or genetic factors are well underway [89]. These approaches raise questions of whether therapies aimed at lowering pathological proteins will effectively improve symptoms; while brain amyloid can be lowered, the clinical benefit of this approach is debatable. These approaches also raise ethical challenges since the risk/benefit calculation is difficult in subjecting healthy older people with no symptoms to a drug that may have adverse effects. Entry into such a clinical trial also requires revelation of biomarker status in a situation where the full risk to a person is not clear. These issues have already been confronted in existing clinical trials, but they will continue to be important as different models of such trials advance.

Pharmaceutical approaches to the prevention of Alzheimer's disease are not the only available approach. Although still limited, lifestyle interventions, particularly those employing broad interventions involving manipulation of nutrition, exercise, cardiovascular risk factors, and cognitive training have shown signs of promise [10]. Such multidomain lifestyle interventions are being pursued worldwide. Because they do not specifically target a single putative mechanism and have limited risk of adverse events, such approaches do not necessarily require detailed biomarker characterisation or even standard diagnostic criteria for disease. They may be directed at individuals performing at sub-normative levels on cognitive tests without the necessity of arriving at a specific causal mechanism.

In sum, the availability of biomarkers makes the detection of Alzheimer's disease pathology possible in living people, and existing data is beginning to provide insight into how these biomarkers can be used for identifying those at risk of decline. Combining biomarkers of  $\beta$ -amyloid and tau with other information such as genetics, family history, demographics, and other imaging modalities such as magnetic resonance imaging may provide even more accurate predictions of cognitive decline. The recent availability of plasma measures of  $\beta$ -amyloid and tau offer a way to scale this approach so that those at risk of Alzheimer's disease because of biomarker abnormalities can be screened in a cost-effective way. Screening large samples of individuals with computer-based/internet measures of cognition may also identify those at risk who could be further assessed for biomarkers, therapeutic trials and eventually treatment. These approaches have not yet produced benefits to those at risk, but if an effective therapy for Alzheimer's disease

is developed, we can be optimistic that it might be applied at a large scale to those who are at risk but have not developed the disease.

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## Expert essay

# Strategies for risk reduction and prevention of late-life Alzheimer's disease and dementia based on multidomain approaches

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Recent estimates predict that the worldwide number of people affected by dementia will increase from 57.4 million in 2019 (95% uncertainty interval 50.4–65.1), to 152.8 million cases in 2050 (130.8–175.9), with substantial geographical heterogeneity in the projected increase, which will be larger in lower- and middle- income countries (LMICs) [1].

**Prevention has been highlighted as the key element in managing the global dementia epidemic.** Updated estimates indicate that up to 40% of dementias are related to modifiable lifestyle, vascular and environmental risk factors, providing a clear prevention potential [2]. Moreover, several novel risk factors are emerging, including stress, sleeping disturbances, and dietary factors, indicating further potential for prevention.

The multifactorial aetiology of late-life Alzheimer's disease (AD) and dementia highlights the importance of multidomain prevention approaches, based on the simultaneous management of several risk factors and disease mechanisms, to optimise the preventive effect. The World Health Organization (WHO, 2019) Guidelines for Risk Reduction of cognitive decline and dementia support the multidomain paradigm, and provide evidence-base guidance to develop and implement preventive strategies globally [3]. The guidelines also point at knowledge gaps which must be addressed, including identification of main modifiable risk factors in populations from lower- and middle- income countries, role of midlife-life versus late-life exposure and implications for public health preventive actions, harmonisation of research methodology, and need of long-term randomised controlled trials (RCTs) [4].

The FINGER clinical trial (Finnish Geriatric Intervention Trial to Prevent Cognitive Impairment and Disability) [5] was the first large, long-term randomised controlled trial demonstrating that it is possible to prevent cognitive and functional decline among elderly persons at risk of dementia, through a multidomain lifestyle-based intervention. The intervention phase lasted two years and the extended 11-year

follow-up is ongoing. Beyond the effects on cognition, there were several other beneficial results such as a 30% lower risk of functional decline, better health-related quality of life, lower risk of chronic diseases (20% decrease in cardiovascular events, 60% lower risk of multimorbidity), and health economic benefits. Overall, this data highlights the value of the multidomain approach, not only for cognition but also for prevention of other noncommunicable diseases (NCDs) and healthy aging in general, with individual and societal benefits [6].

Notably, recent analyses from the FINGER trial emphasised the importance of enabling adherence to the multidomain approach, as clear cognitive benefits were reported only for participants who followed at least 50% of the FINGER intervention [7]. Supporting long-term adherence is thus essential in future trials and implementation.

Successful scalability and sustainability of the FINGER model in different populations is paramount for effective risk reduction and prevention globally and relies on adaptation and testing of the multidomain model, while ensuring alignment with the core scientific methodology. Towards this aim, the World-Wide FINGERS (WW-FINGERS) global network of multidomain trials for dementia risk reduction and prevention was launched in 2017, to support different countries in testing, adapting, and optimising the multidomain lifestyle intervention model in various populations and settings [8]. The network is now comprised of research teams from over 45 countries and across 6 continents (Figure 1). As lower- and middle- income countries will experience the greatest burden from growing dementia prevalence and are often underrepresented in randomised controlled trials on dementia prevention trials, there is a particular drive to include and support research groups from such areas. Studies within the WW-FINGERS network aim to increase knowledge on prevention potential and feasibility in different populations, including those in Asian urban and rural settings [9][10]. WW-FINGERS intends to enable the sharing of knowledge between existing lifestyle interventions, create new multidomain trials

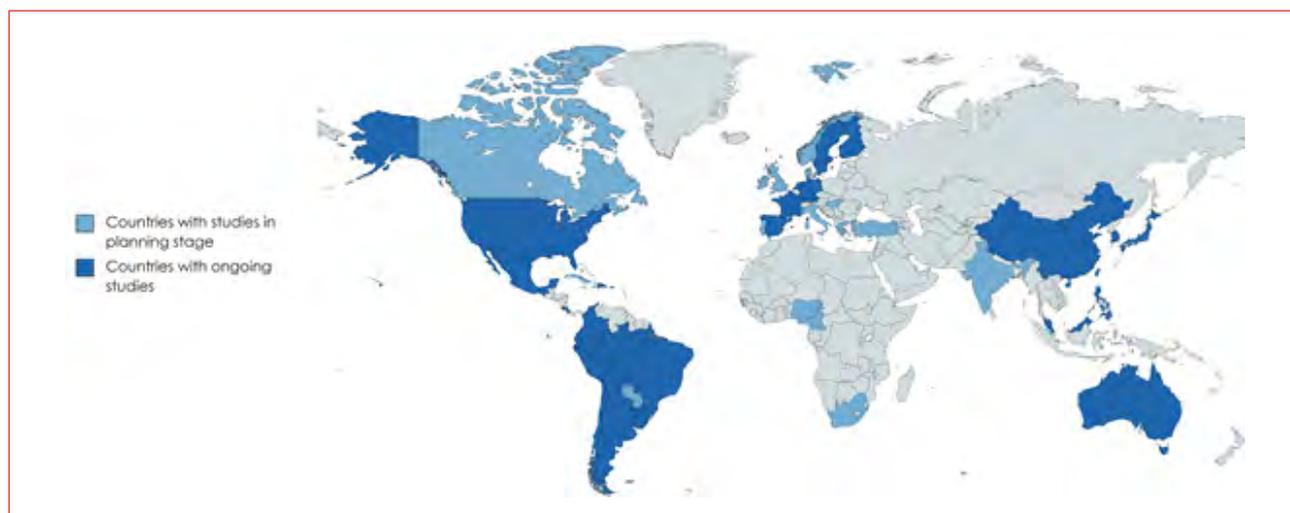


Figure 1. Countries participating in the World-Wide-FINGERS network (May 2022).

following a common methodology, and facilitate joint analyses, in a bid to combat cognitive impairment and dementia. Towards the optimisation and tailoring of multidomain-based prevention, there is an increased focus on biomarkers (blood-based), and the stored biorepository data in FINGER as well as other prevention trials are facilitating the proliferation of knowledge on mediating pathways and mechanisms. These efforts go further in identifying which individuals respond best to such interventions. The overall aim is to develop multidomain interventions within the framework of Precision Prevention. In short, a comprehensive overview of a person's underlying and specific pattern of risks needs to be propelled to the foreground when undertaking clinical research aimed to slow the cognitive deterioration.

The COVID-19 pandemic significantly disrupted preventive interventions and delayed planned or ongoing multidomain randomised controlled trials, given that these models require face-to-face interaction. In response to such challenges, there has been a rapid surge in the testing and implementation of digital tools as well as more flexible study designs, including transitions to virtual activities/interventions and digital monitoring of adherence [11]. This may facilitate personalised, effective, and feasible interventions and implementation in the context of pandemic-related mobility restrictions, and also in geographically remote areas. As current findings suggest that social components of multidomain interventions are important, there are ongoing efforts to create hybrid models that combine face-to-face and digital components to promote social engagement.

There is mounting evidence that the COVID-19 pandemic has also had a negative impact on several risk factors relevant for brain health, including reduced physical activity, as well as increased sleep disturbances, feelings of loneliness, anxiety, depression, and subjective memory problems [1213]. Considering these findings, the focus on dementia

prevention and risk reduction is even more important now, through innovative approaches which might include skills training for coping and resilience and stress reduction.

Building upon the cumulative experience from the current multidomain models, the FINGER model is currently being expanded and upgraded to “FINGER 2.0” models, targeting the development even more individualised and optimised lifestyle interventions, while also combining pharmacological and nutrition-based interventions. Studies such as MET-FINGER, which combines the original FINGER study and the diabetes medication metformin, will spearhead research into the effects of combining lifestyle and pharmacological interventions to reduce dementia risk. This is an important step towards a precision prevention approach, where the right interventions are targeted to the right people at the right time. MET-FINGERS represents a model for the next generation of randomised controlled trials, where other potential disease modifying drugs for dementia can be tested.

While refining the evidence concerning risk reduction and prevention of late-life Alzheimer's disease and dementia, it is important to concurrently support the rapid translation of results into clinical practice and application. Initiatives such as EURO-FINGERS are working towards these goals, currently identifying the best ways to communicate about dementia risk reduction and how to better motivate people to adhere to lifestyle changes. As people living with dementia and participant involvement are so important to both research programmes and policy development, initiatives such as this will provide the understanding needed to apply prevention research to real-world settings with the greatest impact.

The WHO has recently launched its *Global status response on the public health response to dementia* [14]. It indicates that to achieve the goals of the global action plan 2017–2025, joint

global efforts, coordinated research, and implementation of available knowledge are needed. We are moving from observation to action in dementia prevention and risk reduction.

Scaling up interventions to address modifiable risk factors will be key in tackling the expected growth in the number of individuals affected by dementia.

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PART I

PART II

PART III

PART IV

PART V

PART VI

PART VII

PART VIII

## Expert essay

# Population-based approaches to prevention

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## Dementia is preventable at a population-level

As one of the more prevalent medical issues facing us today, dementia is being studied and researched from a multitude of perspectives. When faced with a syndrome that affects millions around the world, there is a strong incentive to determine predictive analytics to diagnose, treat, and with a measure of hope, prevent its occurrence.

One such methodology is the population-based approach and one such proponent of it is the Cognitive Function and Ageing Study (CFAS). They conduct studies of people 65 years and over with a stated mission to examine dementia, determine what services are needed, what factors increase the risk of developing dementia, what other diseases may cause or contribute to dementia, and finally, how quickly it progresses.

Between 1991 and 2011 the Cognitive Function and Ageing Studies examined changes in dementia occurrence across a 20-year span in the UK [1]. Demographic characteristics such as age groups, gender, location, and residential status were used. In both the 1991 (CFAS I) and 2011 (CFAS II) studies, population-representative samples of over 7,500 people aged 65 and over were recruited, using virtually identical methodology and diagnostic procedures for this two-decade comparison. Prevalence rates of dementia were calculated for men and women in 5-year age-bands (for example in CFAS I, women aged 70–74 had a 2.9% chance of having dementia; in CFAS II it was 2.5%).

By applying these standardised age and sex-specific estimates of prevalence to the population, CFAS I estimated that approximately 664,000 individuals aged 65 years and older in the UK would be expected to have dementia in 1991. CFAS II used the same CFAS I criterion, only adjusted to 2011 population rates. Considering only how the UK population would age in the two intervening decades and that the five-year bands remained consistent (Figure 1), they projected that 884,000 people would be expected to have dementia in that year. In fact, only 670,000 were diagnosed. When converted to real numbers, this reduced amount

represents 214,000 individuals and their families (24% less) who were not subjected to the consequences of a dementia diagnosis.

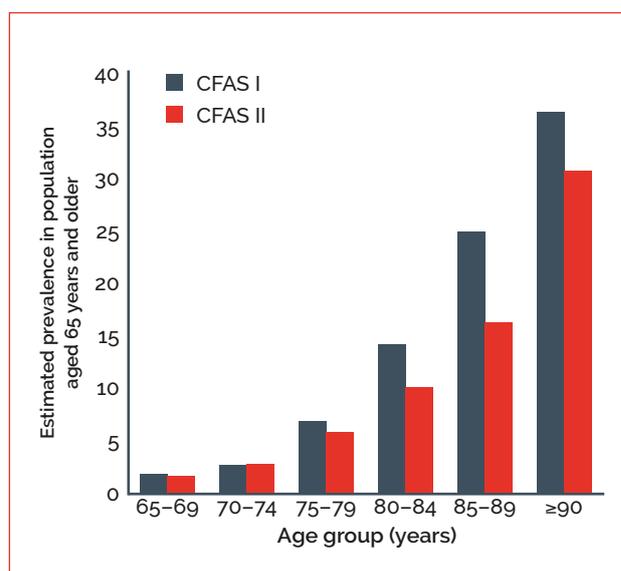


Figure 1. CFAS I and CFAS II age-specific dementia prevalence

The findings of these landmark studies, reproduced in several other cohorts (from high income countries) [2], demonstrates that dementia risk can, and has been, reduced and prevented through population attributable strategies. This essay will make the case for why overall healthcare matters surrounding dementia and its preventive measures should be repositioned to be population-based.

## Understanding population-based approaches as a health determinant model

The construct of a population-based approach as a strategy towards preventive medicine proposes an important shift. While other research methodologies focus solely on the people at risk, population models look to both the individual and the collective dynamics that influence the health of populations. These health determinants – be it social, political,

environmental, cultural, economic or lifestyle choices – are best represented by the enduring 1991 [3] ‘Rainbow Model’ by Dahlgren and Whitehead (Figure 2) and can be benchmarks for defensive strategies. These conditions shape the environments in which we grow up, work, live, and grow old.

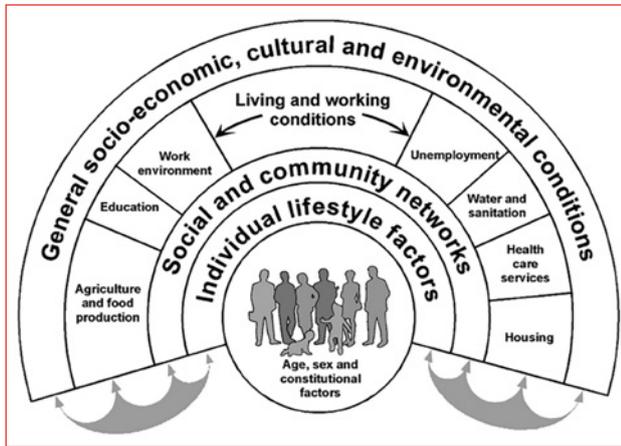


Figure 2. The ‘Rainbow Model’ of the Main Determinants of Health[3]

## Four key pillars of a population-based approach

Every research method stands on certain defining principles. In order to generalise findings to a larger population four benchmarks intrinsic to the population-based approach are detailed below. They are scale stratification, life course, sustainability, and mitigating inequalities.

### 1. Scale stratification

Population-based policies that aim to improve quality and access to such things as education, green spaces, active transport infrastructure, and healthy foods can affect thousands of people in a significant way. It stands to reason then that policymakers have a vested interest in promoting these initiatives. When looking through the lenses of the aforementioned 2011 UK CFAS II study, the 214,000 individuals who eluded a dementia diagnosis may never have feasibly been reached through an individually targeted approach.

In specific terms, in settings where data is available it is possible to stratify populations in order to identify those with a higher risk of developing dementia, and subsequently direct individualised prevention approaches to those with the greatest capacity to benefit. However, there is always a greater proportion of people who are categorised within the ‘normal’ or ‘slightly elevated’ risk levels than there those in the ‘high risk’ group. In essence this means that most cases of disease occur from the segment of the population who are not targeted by these interventions [4].

**Assertion:** Population-based approaches are a therapeutic imperative in order to correlate with the *scale* of dementia and its risk factors.

### 2. Life course

We don’t live in a vacuum. We encounter any number of decisive periods throughout our lives that are shaped by our surrounding familial, social, educational, economic, psychological, and physical factors. These weave the complexity of who we are. Thus, is it not incumbent on us to examine modifiable risk factors at various points in our lives to generalise how these can be used to help reduce, manage, and treat occurrences of dementia?

The susceptibility to the development of the pathologies that cause dementia, and the counterbalancing development of cognitive reserve that may delay the onset of clinically diagnosed dementia, generally occurs over decades. This is exactly why life course is a crucial component of the population-based model. The reduction in age-specific prevalence demonstrated by CFAS represented an entire generation of people who grew up and grew old in healthier conditions. When made available, population-based strategies to dementia prevention can benefit many with access across their life course. One such example is the promotion of outdoor activity and social interaction. A well-designed, conveniently located park can be enjoyed by a family of working adults and children as much as an older couple taking a walk with friends. Park benches can both provide a place to interact with other parents as well as the opportunity for a quick rest en route if needed. Conversely, an intervention that targets late middle-aged individuals at high risk for dementia, and encourages them to undertake individual behavioural changes, cannot reverse the prior decades of risk factor development, and is unlikely to extend beyond the individuals targeted.

**Assertion:** Population-based approaches can exert influence at the start of people’s life courses. This can help improve their overall health and reduce the incidence of dementia and its associated risk factors. The value of that for the generation who will inevitably grow old tomorrow and beyond is considerable.

### 3. Sustainability

When propelling the advantages of a population-based strategy, one can easily make a case by looking at two very common initiatives people take on. Indeed, deciding to change a long-standing habit in your life may seem challenging but maintaining that change is much more difficult. So, when measuring modifiable lifestyle changes like eating healthier or quitting smoking to avoid a host of adverse health effects, a sustained methodology that considers how the amount of cheat days may deter efforts or that it can

take up to 30 attempts to quit smoking long-term [5] is an absolute necessity. Targeting individuals with lifestyle advice, only to send them back to live in the conditions that made them unhealthy in the first place, is problematic for achieving lasting health gains. In contrast, population-based policies like building infrastructures, introducing taxation policies, improving access to high-quality education, and tackling the commercial determinants of health, have the potential to change living conditions for entire generations. These are enduring public health interventions that could provide ongoing treatment and prevention protocols for dementia.

**Assertion:** Only population-based approaches and strategy sustainability can truly evaluate the long-term effects and successes of an implemented change over a long period of time when looking at the incremental reduction of dementia occurrences and its risk factors.

#### 4. Mitigating inequalities

The starkest inequalities exist between geopolitical regions. The majority of new dementia cases occur in lower- and middle-income countries (LMICs). Prevention strategies that target high-risk individuals require data availability to perform that population stratification. Often this data does not exist in these settings (where we need prevention policies the most). This necessarily disadvantages the disadvantaged. In contrast, population-based approaches aim to reduce risk for everyone, and therefore does not require this data.

Even within countries, resources (be they financial, social, cognitive) are not evenly distributed across different levels of society. Interventions that focus on the centre of the rainbow model, in other words that puts the onus on individuals to consciously make healthier lifestyle choices, still require them to avail themselves of these resources. As a result, individual approaches only tend to widen the gap of health inequalities.

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**Assertion:** We need population-based approaches to reduce socioeconomic inequalities in the incidence of dementia and its risk factors.

## What are the challenges, and how do we overcome them?

Population-based approaches are not easily studied using conventional clinical trials. However, it is possible to conduct robust analysis of the effectiveness and return on investment from policies like taxation on unhealthy foods, investment in education, and investment in infrastructure to promote physical activity. Sometimes this requires turning the traditional model of science to policy on its head [6] using well-conducted observational studies to influence policy, and then quasi-experimental designs to evaluate the policy after implementation (rather than the randomised clinical trial coming before policy implementation).

To do this requires political buy-in. Public health policy cannot be apolitical. It is, by definition, highly political. Public health policies like taxation and built environment redesign can be controversial and are often labelled 'nanny state.' However, the COVID-19 pandemic has shifted public perceptions of public health policy significantly, and public health has moved up the agenda at an accelerated pace. As we emerge from the pandemic, and social and political landscapes are re-shaped, we must advocate with a strong, unified voice for the adoption of healthy, population-based, public health policy at a scale and intensity that matches the global pandemic that is dementia.

If we are serious about reducing the incidence of dementia, improving the profiles of risk, and protection of brain health on a significant scale, across generations, and in an equitable way, we must urgently engage more researchers and policymakers in advocating for, co-producing, implementing, and evaluating population-based approaches to dementia prevention.

## Expert essay

# Communicating personal risk profiles of Alzheimer's disease

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## The potential for Alzheimer's disease risk reduction

There is strong evidence that risk factors in midlife (hypertension, smoking, diabetes obesity, hearing loss, traumatic brain injury, alcohol misuse and air pollution) and others specific to seniors (depression, physical inactivity, and social isolation) contribute to increased dementia occurrence [1]. It is estimated that up to a third of Alzheimer's disease cases worldwide can be attributed to potentially modifiable individual risk factors including those mentioned above [2]. Reducing the prevalence of each risk factor by 10% per decade would potentially reduce the worldwide prevalence of Alzheimer's disease by 8.8 million cases [2]. Many of these factors are also associated with progression from mild cognitive impairment to Alzheimer's disease [3], suggesting these are good targets for dementia reduction and prevention.

Although the research evidence supports the potential for prevention of Alzheimer's disease on a population level, this is discordant with the most people's knowledge regarding these deterrents. While activities that challenge the brain, healthy diet, physical exercise, and social engagement have long been acknowledged as proactive prevention measures, it stands to reason that both mental and cardiovascular health disorders often fail to be recognised as essential in the assessment of overall risk factors [4]. The lack of knowledge about dementia-related factors and how they impact personal susceptibility, as well as the fear of developing the disease are main barriers for the public engaging in beneficial behavioural and lifestyle changes [5].

## Communicating modifiable risk for Alzheimer's disease

Communicating information on personal modifiable risk factors and levels has the potential to provide individuals with accurate knowledge on their individual potential of developing Alzheimer's disease, motivate change of health behaviour and lifestyles to reduce its occurrence, as well as manage uncertainty and worry around developing the disease. Much of dementia communication research has

focused on people's susceptibility of contracting Alzheimer's disease based on family history, genetic information, and biomarker tests. Notwithstanding the complexities of the decision to undergo these tests and the interpretation of results, they do not normally lend themselves to widespread population testing and exposure modification.

However, epidemiological approaches allow for widespread but targeted prevention through individually tailored risk communication and interventions. A number of dementia predictive risk algorithms comprising of easily measurable and modifiable factors have been implemented and validated for middle-age and older adults in the general population [6]. For example, the Cardiovascular Risk Factors, Aging and Dementia (CAIDE) risk score includes age, sex, education, cholesterol level, body mass index, and systolic blood pressure of middle aged individuals, while the Australian National University Alzheimer's Disease Risk Index (ANU-ADRI) assesses probability of later life Alzheimer's disease based on age, sex, education level, diabetes, traumatic brain injury, depressive symptoms, smoking, social networks, cognitively stimulating activities, alcohol consumption, physical activity and fish intake.

The advantage of these risk algorithms is that the variables can be easily obtained, individuals can assess their odds alone or within a primary care setting, with relatively good predictive accuracy, and at a low cost. More importantly, communicating these results is key. This includes reporting on one's overall likelihood of developing dementia, personal modifiable risk factors, and how to lower it using personalised recommendations. The combination of this information may empower individuals to act proactively. These risk models allow for selective prevention for those who have yet been diagnosed but are at high-risk parameters. This enables them to focus their efforts on targeted modifiable risk factors. Compared to universal prevention approaches, where general risk and protective factors (physical activity, healthy eating habits, or social engagement) are disseminated to the general public, communicating personal profiles to susceptible individuals may be more effective in reducing prevalence of Alzheimer's disease.

## How should we communicate Alzheimer's disease personal risk profiles?

A key question is how to effectively communicate these profiles and engage at-risk individuals. They need to make informed decisions. Thus, providing them with accurate information and the tools to reduce their risk is essential. One of the main challenges is the difficulty in interpreting numbers and probabilities. This can be particularly challenging for older adults or those with cognitive difficulties. Studies have demonstrated that middle-age and older adults tend to view risks as a signal of danger or emotional threat rather than a neutral statistical concept. This necessarily makes it difficult to understanding the implicit uncertainty and possibly confuse objective risk (frequency of an event) and subjective risk (subjective confidence about a future event) [7].

Personalised risk dialogue regarding cardiovascular disease, diabetes, and cancer has been around for decades, and many lessons can be extracted from this wealth of information for dementia [8]. Based on the available literature and focus groups, our team has developed an Alzheimer's disease personal risk profile using the ANU-ADRI. The personal profile presents users with standard information about dementia, an explanation about their personal profile, and information about the ANU-ADRI model to show credibility. Users

are presented with a visual representation of their risk level in the form of a thermometer graded from 0 to 100, along with an explanation about their score (Figure 1). They are reminded that this is an estimate based on their personal information rather than a definitive guarantee. Obviously, there are some they cannot change, such as age or gender, but the results also point to efforts they could make to reduce their risk. A summary of the dementia risk factors featuring their individual scores, as well as a recap delineating why each is essential for proper brain functioning come together to create a customised recommendation page to manage each one.

## What is the impact of communicating Alzheimer's disease personal risk profiles?

Our pilot trial found that communicating these personal profiles improved older adults' understanding of their risk, protective factors they could modify, as well as the accuracy of perceived susceptibility of developing Alzheimer's disease [9]. Communicating personal profiles did not have any negative psychological impact on trial participants, though many of them were low-risk and highly motivated to manage their brain health. However, on its own, communicating personal profiles did not impact motivation levels regarding health behaviours and lifestyle changes for dementia reduction. Participants reported that a lack of motivation, health

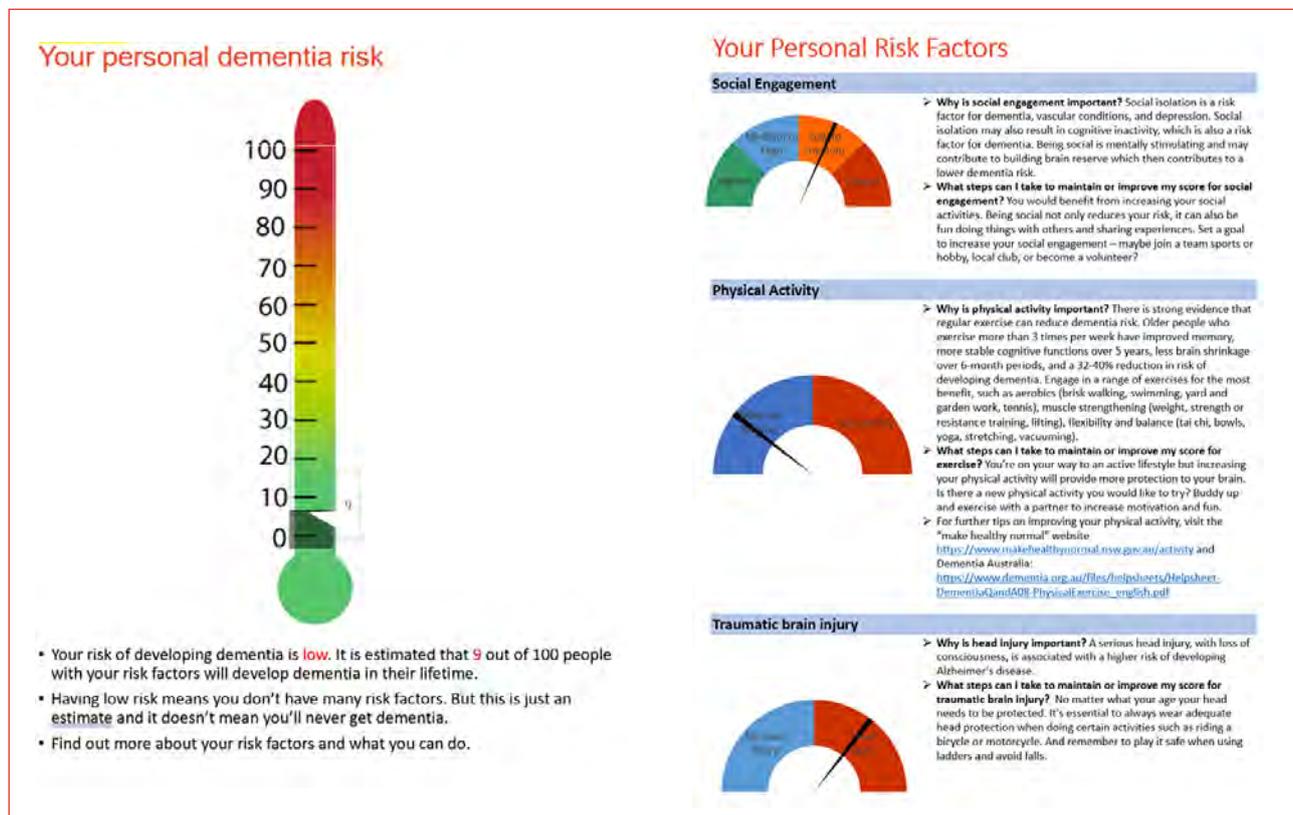


Figure 1. Example of the risk level and selected risk factor feedback provided in the personal risk profile.

problems, and difficulty with organisation became the main barriers for behavioural change after receiving their profile. This suggests that at-risk adults need additional support in order to take concrete steps towards meaningful behavioural change in the hopes of reducing susceptibility. We suggest that Alzheimer's disease profiles could be used as a collaborative tool between at-risk individuals and clinicians, in which they can draw on evidence-based, tailored information to mitigate the probability of developing dementia. Indeed, it could bring about a collaborative decision-making process in determining which health or lifestyle factors to target, and more importantly, how best to maintain long-term behaviour change.

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Further research is needed in this area. Dementia is a chronic condition and communicating where an individual lands on the risk spectrum may be an all-important first tool used for moderate or high-risk adults in primary care as well as the general public. Indeed, exciting large-scale real-world research is currently underway to monitor the impact of such a protocol with an eye to promote both dementia knowledge and adjustments in modifiable behaviour. This will necessarily inform clinicians on how to decrease dementia risk and put them in a position to translate this scientific data into relatable tools for individuals (10).

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## Expert essay

# Prevention and management of atrial fibrillation

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**A**trial fibrillation (AF) is a major preventable cause of stroke, heart failure, and dementia. It is characterised as an abnormal and irregular heart rhythm that is incredibly common, affecting at least 2.5% of the population to upwards of 10–12% of those aged 80 and older [1]. The prevalence of atrial fibrillation has increased threefold over the last 50 years [2]. Although frequently symptomatic, atrial fibrillation may often remain undiagnosed due to its silent nature in one-third of people [3]. Given the high prevalence of atrial fibrillation in the general population and its considerable impact on both life expectancy and quality of life, prevention, detection, and prompt management of this arrhythmia is essential.

## Diagnosis

Atrial fibrillation is traditionally diagnosed through documentation of the abnormal rhythm on a 12-lead electrocardiogram (ECG). Where an irregular pulse may raise suspicion for atrial fibrillation, an ECG is necessary to make the diagnosis. Atrial fibrillation may be paroxysmal, persistent, or permanent in nature where it may come and go on its own or be present all the time. Common symptoms include breathlessness particularly with exertion, light-headedness, and rapid and irregular palpitations. Clearly, these symptomatic individuals would require immediate medical attention. Where atrial fibrillation is silent and people are unaware of its existence, the presenting symptom may be that of an ischemic stroke or heart failure. Knowledge of the condition coupled with emerging technology in the form of portable or wearable cardiac monitoring watches or devices has allowed early diagnosis of “subclinical atrial fibrillation” that is asymptomatic and not clinically apparent. Timely diagnosis is important so that treatment can be instituted for primary or secondary stroke prevention in addition to medical therapy to prevent atrial fibrillation progression and heart remodelling.

## Risk factors and primary prevention

Ageing, hypertension, heart failure (reduced or preserved ejection fraction), coronary artery disease, valvular heart disease, and diabetes mellitus have been identified as

independent risk factors for atrial fibrillation development [4]. Several of these in addition to obstructive sleep apnea, obesity and excessive alcohol consumption have become clear targets for intervention. For example, in at-risk obese people without atrial fibrillation, bariatric surgery with nearly 20% weight loss has been shown to reduce the long-term risk of incident atrial fibrillation [5]. There is evidence supporting tighter blood pressure control with target systolic pressures <130mmHg in reducing incident and recurrent atrial fibrillation in hypertensive individuals [6]. Chronic high blood pressure causes structural changes within the left ventricle leading to impaired relaxation and pressure build-up into the left atrium (LA). This in turn leads to left atrium enlargement and the development of an atrial myopathy, the substrate for atrial fibrillation. Continuous positive airway pressure therapy (CPAP) has been shown to reduce the risk of recurrent atrial fibrillation in people with obstructive sleep apnea with imaging evidence for reversal of atrial fibrillation-related LA structural changes. Alcohol reduction is an effective strategy for atrial fibrillation prevention, where low alcohol consumption defined as one drink/day was not associated with increased atrial fibrillation incidence, but each additional daily drink translated into an 8% increased atrial fibrillation risk in a linear dose-response relation. Finally, advancing age is the most important non-modifiable risk factor for atrial fibrillation that sharply inclines after the age of 65 [7]. Healthy ageing, through control of these known atrial fibrillation risk factors should be considered a primary goal in atrial fibrillation prevention to slow the myocardial and vascular degenerative processes and promote fit longevity [8].

## Atrial fibrillation management: arrhythmia control and stroke prevention

Beyond risk factor control, the course of treatment for the abnormal rhythm itself is a medical therapy approach of drugs that aims to either slow down arrhythmia or maintain normal rhythm. A rhythm control strategy may be preferred for those of younger age, presence of symptoms and/or presence of heart failure. Catheter ablation for atrial fibrillation has emerged as a highly effective interventional option and can be considered as a first-line treatment for symptomatic

individuals. Ablation has been shown to improve a person's quality of life through the reduction or elimination of atrial fibrillation recurrence, but thus far has not demonstrated a clear reduction in stroke, for which randomised controlled trials are ongoing (OCEAN study).

Atrial fibrillation is associated with a five-fold increased risk of ischemic stroke and is the primary cause of about 1 in 7 strokes. Stasis of blood flow within the left atrium due to the existing atrial myopathy and fibrosis is at the centre of thrombus (blood clot) formation. As a result, the atrial fibrillation rhythm itself does not need to be present at the time of stroke. Oral anticoagulation, or "blood thinners," are the cornerstone for the prevention of intracardiac thrombus development and therefore of stroke prevention. Direct oral anticoagulants are preferred over vitamin K antagonists (Warfarin) because of each person's stroke risk, having assessed several risk factors including age, sex, and the presence of heart failure, hypertension, diabetes as well as prior stroke/transient ischemic attack.

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## Dementia and atrial fibrillation

Clinical strokes from blood clots (thrombi) formed within the left atrium are a major cause of dementia. Not surprisingly new-onset dementia was described in one-third of all stroke patients within five years [9]. Atrial fibrillation also confers an increased risk of cognitive decline and dementia development that is *independent* of stroke. This association may be a result of silent cerebral ischemia through micro-embolic events occurring in the cerebral circulation, a reduction in cerebral perfusion resulting in lack of adequate blood supply to the brain, vascular inflammation, and genetic factors. Atrial fibrillation is also related to cognitive impairment in younger people where stroke-free individuals with atrial fibrillation demonstrated difficulties in learning, memory, attention, and executive function as compared to non-atrial fibrillation healthy individuals [10]. Studies of early initiation of oral anticoagulation in younger atrial fibrillation subjects to prevent dementia are ongoing.

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## Conclusion

While the vast majority of this report has focussed on facing the aftermath of a dementia diagnosis in the best ways possible, the logical next question becomes: how can we try to mitigate the predicted increase in dementia cases globally in coming decades?

The authors in this chapter have highlighted how biomarkers may predict the risk of developing dementia and allow individuals to implement lifestyle changes early on that may lower their risk. But risk reduction isn't only an individual endeavour – there must be population-based approaches to address many of the systemic factors that are beyond any one person's control. It is incumbent on researchers and clinicians to further explore these avenues, whether from an individual or population-based approach. Meanwhile, educating the public as well as decision makers is primordial.

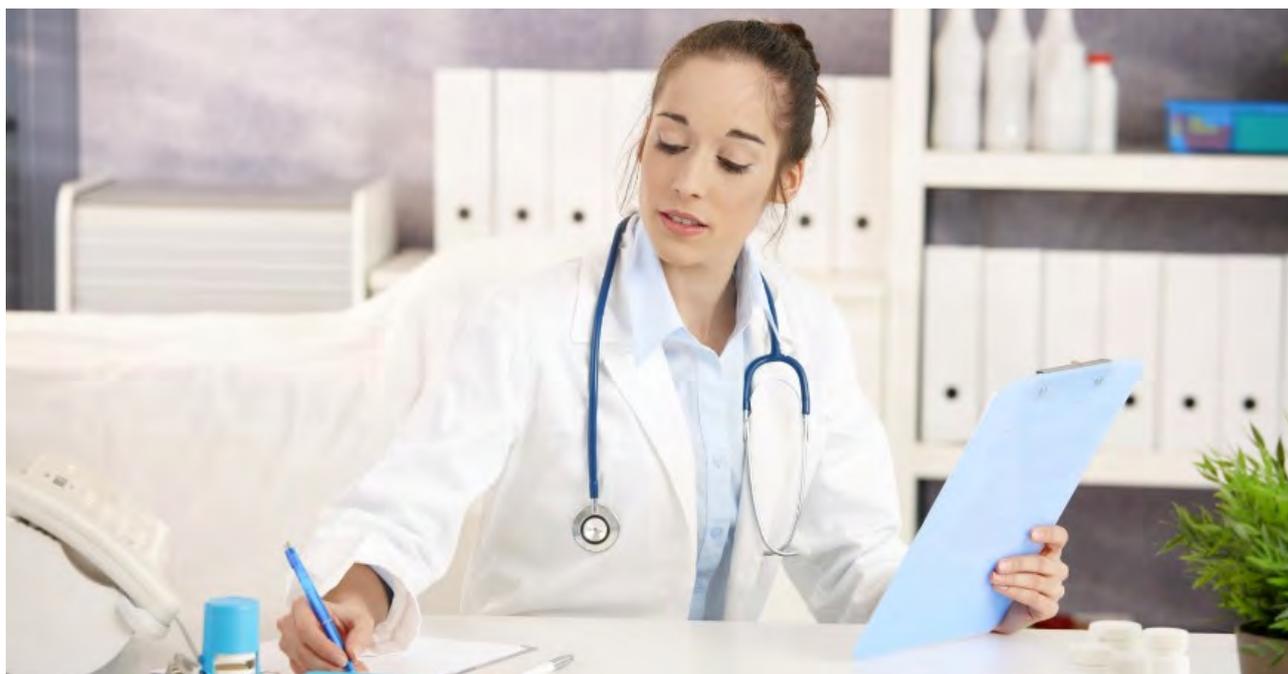
# Chapter 24

## Principles of care: knowledge, support and compassion

*Claire Webster, Serge Gauthier, José A. Morais,  
Pedro Rosa-Neto*

### Key points

- On a global level, there is a need to improve education and professional development for clinicians and other health and long-term care professionals in post-diagnostic management and support from both pharmacological and non-pharmacological standpoints.
- Clear and ongoing communication by clinicians and health and long-term care professionals is key for persons living with dementia as a best practice to navigate their illness.
- Education is critically important to help care partners learn about the condition and how to manage situations that will challenge them emotionally and physically.
- People living with dementia and carers reported receiving inadequate communication about diagnosis, management and prognosis, lack of management plans, lack of referral to support services and poor follow-up arrangements. They received neither hope nor practical strategies.
- Learning techniques that incorporate simulation, interactive, blended, and online learning can provide a much more engaging, enriching, and personalised dementia learning experience.
- Lifelong learning skills are an important way in which health and long-term care professionals can better meet evolving societal health needs by developing new competencies, reinforcing and refreshing previous knowledge and skills, and reflecting on attitudes that may also inhibit quality of care in dementia.



## General background

A fundamental building block for best practice care and support for people living with dementia and their families is the education, training and ongoing practice development for clinicians and health and long-term care professionals. Equally important is providing the right information and education at the right time for people living with dementia and their families in order to help them navigate care pathways and make informed decisions about future care.

Care pathways for dementia are rarely straightforward or easy to negotiate. Having access to the right educative approaches and information is as crucial for health and long-term care professionals as it is for families affected by dementia. Understanding the evolution of symptoms, pharmacological and non-pharmacological approaches, managing responsive behaviours, safety, impact on activities of daily living, driving, employment, finances, mandates, access to resources and healthcare professionals, end-of-life care... are just a few of the issues that must be addressed upon receiving a diagnosis. As dementia is a progressive, ever-evolving condition that can last throughout many years, persons living with dementia, their carers, and their care team must constantly be adjusting and updating their knowledge and skills to be able to provide the best quality of care possible, as well as manage their own needs and expectations.

The four excellent essays in this chapter describe the important role that education plays in significantly enhancing the quality of life of persons living with dementia and their carers, as well as how imperative it is to properly educate clinicians and healthcare professionals – a gap

that currently exists on a global level. Anthony Levinson highlights in his enriching essay the importance of ensuring adequate dementia care training for all healthcare professionals.

The essay by Brodaty et al., highlights their international programme, *Forward with Dementia*, co-designed by people living with dementia and carers, which highlights the need for adequate communication about diagnosis, general information about the condition, symptom management and prognosis, as well as referral to support services.

There are various ways to teach dementia education at the university level, such as McGill University's Faculty of Medicine and Health Sciences' comprehensive Dementia Education Program launched in 2017. The essay by Tamara Carver and Gerald Fried introduce us to the world of simulation and education technology and how it has allowed teaching to evolve from passive materials, which were often incomprehensible to the learner, to more personalised and engaging learning that incorporates simulation, interactive, blended and online learning, providing a more enriching and enduring learning experience.

Finally, the essay by Aaron Greenstein and Brent Forster describes the importance of better investment in the training of healthcare professionals and how developing a team-based interdisciplinary approach in primary care can greatly improve the diagnosis and management of dementia, ensuring that individuals and their carers receive the support they need from the moment of diagnosis through to end of life.

## Expert essay

# Campaigning for change: improving diagnostic conversations and post-diagnostic support

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## Introduction

In order to better understand how people feel after receiving a diagnosis of dementia, we surveyed and interviewed people living with dementia and carers across five countries (Australia, United Kingdom, Netherlands, Poland and Canada) as part of the COGNISANCE PROJECT[1]. Fifty-seven percent of people living with dementia (N=91) and 62% of carers (N=300 carers) indicated they deemed support received after a diagnosis as helpful[2]. In contrast, they reported dissatisfaction with information provided and the lack of care plans, treatment, and rehabilitation services. In interviews, people with dementia and carers expressed shock and said they felt lost, confused and like they had stepped into a void. In most countries, there was an absence of advice about living positively with dementia, coping or re-enablement strategies. Issues in diagnostic practice reported by people living with dementia and carers included inadequate communication about diagnosis, management and prognosis, lack of management plans, lack of referral to support services and poor follow-up arrangements. They received neither hope nor practical strategies.

## How can diagnostic communication be improved?

In our surveys and interviews with people living with dementia, carers, and health professionals, all agreed that clear and ongoing communication is key. Health and social care practitioners need to engage the person living with dementia and their carer in discussions. It is disrespectful for doctors to talk *about* the person living with dementia to the carer rather than *to* the person. Time, compassion, hope, and follow-up are critical elements. The shock of receiving the diagnosis may numb the recipient from processing or retaining the information being provided after being told the diagnosis. Time and repetition are often needed to process the information. It is advisable for a family member or friend to accompany

the patient. After leaving the consultation they will think of other questions; a follow-up appointment within a few weeks was regarded by people with dementia and carers as critical.

## Gaps, evidence, and available post-diagnostic care

COGNISANCE research participants told us that compared to other neurological conditions such as stroke or traumatic brain injury, people living with dementia are much less likely to be offered rehabilitation. This is consistent with other research that has highlighted that people diagnosed with dementia are advised to get their affairs in order but offered little else, yet much can be provided[2][3].

People living with dementia and their carers told us they were interested in evidence-based ways to live well and manage their symptoms. Cognitive stimulation therapy has been shown to have benefits equivalent to the use of cholinesterase inhibitors[3], cognitive rehabilitation[4], exercise[5], occupational therapy[6], speech therapy[7] and carer support[8], can all be beneficial.

Despite diagnosis being a shock, even if expected, people told us that certainty of diagnosis was helpful. However, lack of referral to services such as counselling or therapy with a psychologist impaired coming to terms with the diagnosis. People also emphasised a desire for practical advice about legal and financial management, driving, work, and entitlements to social benefits as well as managing stigma and other people's reactions to the diagnosis. These matters require discussion by the diagnosing clinician, dementia-literate allied health worker or nurse.

There was low awareness of online supports available for people with dementia or care partners such as the World Health Organization's iSUPPORT programme and through Alzheimer Associations. People who had accessed their

support emphasised the valuable information available through Alzheimer and Dementia Associations, which provide, and Dementia Alliance International, which provides online support groups *for* people living with dementia, *by* people living with dementia.

## Forward with Dementia

To address these gaps and respond to the needs in post-diagnostic support, the Forward with Dementia Program was co-designed with people living with dementia, family carers and health care practitioners. Forward with Dementia has been supported in Australia, Canada, the Netherlands, Poland, and the UK, providing online resources in four languages with practical information about how people can move forward and live positively with dementia in the first 12 months after diagnosis. In the UK and the Netherlands, the website is accompanied by a toolkit where users can build their own library of resources.

## Forward with Dementia campaigns

### UK

In the UK, we developed campaign strategies with potential users and relevant agencies such as the Alzheimer's Society, Dementia UK, and NHS England. The campaign specifically targeted four key geographical areas within England chosen for high rates of older population, dementia diagnoses, and representing a mix of coastal, inner city, rural and a range of socio-economic and diverse populations. Strategies included use of social media, webinars, education sessions, media buying such as advertisements on buses and at bus stops, and in 'door-drop' regional magazines. Copy was produced for a variety of channels such as professional and third sector newsletters, bulletins, and magazines targeting the three key audience groups.

### Netherlands

In the Netherlands, the campaign was supported by Maastricht University and Alzheimer Centrum Limburg and had twice weekly social media posts on Facebook, LinkedIn, and Twitter. We launched a webinar series, provided guest lectures at local Alzheimer cafés and regional care organisations; distributed collateral to target health and social care professionals and participated in information stands at national memory clinic and other conferences. We particularly targeted dementia case managers in use of the toolkit.

### Poland

In Poland, we responded to low community knowledge about dementia and stigma by undertaking general dementia awareness raising in the city of Wrocław. Our public campaign, which launched on World Alzheimer's Day, included lighting the City Stadium and the Wrocław Provincial Office in the colour purple for dementia awareness. A city bus with

the campaign logo travelled different routes around the city and attended community centres. An art exhibition by artists living with dementia was held in different locations around the city. Four mobile memory screening events for the public were held in different areas of the city and involved memory testing and a short consultation with a psychologist or psychiatrist. The campaign was featured on television, radio, newsprint, and social media. Educational animations were projected on local area public transport, a film screening was held, and the campaign closed with a concert in Wrocław. Additionally, a webinar series targeted all key audiences, high school and university students. Physical and digital promotional materials were distributed including flyers, brochures, posters, pencils, bags, pins, and reflective bands.

### Australia

In Australia, limited by COVID-19 pandemic restrictions, our campaign was virtual. We designed different messages for people living with dementia and carers, and health and social care professionals. Key activities included collaboration with professional colleges of physicians, psychiatrists, and neurologists to produce and promote resources for doctors; webinar series for diagnosticians; an active social media presence; weekly blog posts; a monthly campaign newsletter; writing for professional magazines and newsletters; and appearing on podcasts for professional and carer groups. We engaged with and trained Dementia Australia client services and telephone helpline staff and worked with Dementia Australia on updating their post-diagnostic webinar content. We engaged with government policy makers to share findings relevant to post-diagnostic support policy.

### Canada

In Canada we conducted campaigns in three provinces: Ontario, Quebec, and New Brunswick. Activities included webinar series in French and English; an active social media presence; distribution of collateral printed and online information; partnering with local dementia organisations in each province to reach people living with dementia and carers.

## Conclusion

The Forward with Dementia campaigns have successfully engaged people living with dementia, carers, and health professionals around the need to improve the diagnostic experience and post-diagnostic supports. Through tailoring campaigns to local conditions, we have shown there is motivation to improve post-diagnostic care!

To improve outcomes and quality of life for people living with dementia and carers a multi-pronged approach is required:

- Empower people living with dementia and care partners by letting them know what is possible and how to access services and more information;

- Win the hearts and minds of health and social care practitioners so that they feel motivated to improve post-diagnostic support and help improve outcomes for their patients or clients;
- Use multiple social and traditional media, creative thinking and enticing events to increase public awareness and reduce stigma;

- Partner with professional organisations (especially diagnosticians), Alzheimer Associations and government departments so that good post-diagnostic care becomes business as usual; and
- Ensure these initiatives are continually updated and maintained.

\*COGNISANCE GROUP: Doucet S, McAiney C, Rait G, Robinson L, Rymaszewska J, Vedel I, Verhey FRJ

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Expert essay

# Dementia Education Program: learning design and experience matter

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Caring for a person living with dementia can be challenging, whether one is an informal family/friend carer or a professional. Education is critically important to help carers learn about the condition and how to manage situations that will challenge them emotionally and physically. How this education is created and delivered matters! Fortunately, education technology has allowed us to evolve from passive teaching materials that were often incomprehensible to the learner, to more personalized and engaging learning.

We present three principles on which to base these educational programs: accessibility, experiential, and usability.

**Accessibility:** Learning must be accessible; in this context, this implies that it is provided at a time and place convenient for the learner, in language that can be clearly understood, incorporating a combination of delivery methods that include video, audio, and written material.

**Experiential:** It implies an educational program that evokes personal experiences to which they feel emotionally connected and that will resonate with the learner. This experiential learning provides the learner with the most effective and durable knowledge and skills that they can apply to caring for people living with dementia. We use multimedia content, simulations, and other interactive technology, wherever possible, to engage the learner.

**Usability:** Learning should be designed to recognize that learners in these programs may be older adults who may not be comfortable with technology or may have limitations in bandwidth and connectivity (access to the internet). It must be effective and facilitate learning, be well received by users, and be both enjoyable and stimulating.

Professional educators use these principles to design dementia education programs using an instructional design framework to deliver blended learning experiences. This

'blended' delivery consists of online material that can be accessed when convenient for the learner, in addition to a live experience that can be a group videoconference or in-person session. The addition of in-person simulations using professional simulated patient-actors creates an immersive experience. Debriefing after the simulation allows the learners to reflect on the scenario in the context of their own lived experiences and to share those with the experiences of other participants. It is important to hold the simulations in a setting that reflects where acts of daily living occur; we use a simulated apartment for this purpose. For the online material, there are important benefits for the care partner in accessing this education 'when they need it' and when they can devote the time. As we know, caring for a person living with dementia is a full-time responsibility with many unknowns from day to day. Having education at your fingertips that can be continually accessed for reference and reinforcement is optimal for efficient learning.

A framework that is commonly used is the ADDIE model. ADDIE is an acronym for the five stages of a development process: Analysis, Design, Development, Implementation, and Evaluation. In this approach, each stage is done sequentially allowing time for reflection and revision. One of the attractions of this model is the opportunity to develop educational material in a structured and efficient way with feedback leading to continuous improvement.

**Analysis:** This phase is crucial to the development of material that is relevant to the learner. It provides clarity about the goal of the education, the context, and the observed or measurable changes one would like to see. That then helps the designer create a design plan accounting for who the learner is, what needs to be learned and the optimal technology to deliver the content. *The outcome of this phase is an understanding of the learning needs and a plan for education.*

**Design:** This is the stage where the outcome of Analysis helps inform the design, considering delivery methods, structure, duration, assessment, and feedback. Here the opportunities to use delivery methods, such as in-person simulations, online learning, virtual reality, or hybrid forms of these technologies may be proposed. Information from the analysis will be crucial to this stage as it provides information about literacy level, time and scheduling, location and access for users, requirements for technology/hardware, and budget. Based on these determinations, the next step is to create a storyboard with the finalized content. This can be used for demonstration and feedback from stakeholders and modified, as necessary. *The outcome of the Design phase is a clear overview of the course design and storyboards or prototypes.*

**Development:** Based on the Analysis and feedback from the Design phase, the course is created using the storyboards as the template. This is where we add the creative components. A style is selected, graphics, videos, animations are developed, specific simulations are created. This is an iterative process, and the outcome should be a refined and attractive product

that the learner feels comfortable using, especially with the use of technology. For the online components, navigation is reviewed, links are tested to ensure they work as designed, and all technical components are verified. For simulations, logistical issues, timing, human resources, supplies, and backup plans need to be considered. The course is tested by stakeholders, including patients living with dementia and their care partners, contributing valuable information in this iterative process. It also provides data, such as how long the course takes to complete, whether the learners left the course before completion, if they found it to be engaging, etc. *The output of this phase is the actual course content.*

**Implementation:** After the course has been developed, and feedback from the pilot testing has been incorporated, the course can then be administered to the learners. This Implementation phase considers logistics; for example, if the course is to be given online, it can then be uploaded to a learning management system (LMS) and parameters can be set. These include who can access the course, time limits, assessment that the goals of the program have been achieved, tracking of learner progress, etc. *At this phase, the course is live and ready for the users.*

**Evaluation:** While the goal of a framework for instructional design is to direct the process for creating an effective learning program, these courses are not set in stone. They are living and evolving programs that can and should be revised and improved during this Evaluation phase. The basis for improving the quality and effectiveness of educational programs is feedback. Every aspect of the course should be subject to evaluation, including the content areas, the outcome of learning, the delivery, the convenience, logistical problems, whether it was engaging to the learner, etc. This is the time to learn whether the goals set in the Analysis phase were met. The outcome of the evaluation informs the Analysis phase of the next iteration. It can identify any gaps in content, help suggest other delivery methods and help determine if and when the course needs to be redesigned. *The outcome of this phase provides information about how well the goals originally defined in the analysis were met and what changes need to be made for future courses.*

## Conclusion

Learning needs for carers of people living with dementia are complex and these carers represent a diverse population of individuals. They may have differing levels of education, age and life challenges in which learning must take place. This instructional design framework, incorporating the principles of accessibility, experiential education, and usability, forms a foundation for effective carers education. Input from representatives of actual learners, coupled with a deep understanding of the possibilities provided by current technology, is the best way to ensure that the needs of carers are met. The result of this collaborative education design process is impactful and enduring learning. Learning design and experience matter.

## Expert essay

# Should dementia education be a lifelong process among health professionals?

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Imagine you are a nurse working in a hospital environment, and an increasing number of admissions to hospital involve people living with dementia. You've been asked to conduct a comprehensive assessment and other staff are looking for advice for the management of responsive behaviours, but you are not confident in your knowledge or skills in this domain.

Now consider that you're a family physician, and a patient recently diagnosed with moderately advanced dementia and their family come to you for advice about advanced care planning and palliative care approaches, but you feel ill-prepared to have the conversation.

And what if you were an occupational therapist, and you've been redeployed to a geriatric rehabilitation unit that has several patients with cognitive impairments. You're advised to do cognitive testing on many of the patients, but it's been years since you have done those assessments.

These are just a few examples of very realistic scenarios that highlight the importance of health professionals having the skills to provide high-quality care to people living with dementia. The reality is that most national and international dementia strategies identify the importance of building capacity through increased training of health professionals; but also, the importance for all health care providers to continue to develop a wide range of knowledge and skills to improve dementia quality of care.

This essay aims to highlight why dementia education should be an important part of continuing professional development for health care providers. First, we will provide a brief overview of lifelong learning, before outlining some of the specific goals with respect to dementia education for post-diagnosis support.

## Lifelong learning

Lifelong learning is somewhat of an ambiguous term but is typically characterized by activities and information-seeking skills to continue one's professional education and

development. It is often seen as a core competency related to continuing professional development, and increasingly linked with related concepts like practice-based learning and improvement [1]. As part of the graduate program of the McMaster University problem-based learning medical school, there was often emphasis on the importance of self-directed learning to stay up to date with new evidence and guidelines. While lifelong learning is frequently conceptualized as more of an *individual* attribute of continuing education; it is important to consider other ways that lifelong learning can be linked with broader initiatives such as learning healthcare systems, small group learning, interprofessional education, communities of practice, or coaching models that extend beyond just the image of an isolated, self-directed learner.

The global pandemic with a novel infectious disease has underlined the importance of health professionals being able to rapidly adapt and learn new knowledge (about a particular illness) and skills (e.g., how to effectively use virtual care modalities). In an analogous way, lifelong learning skills are also an important way in which health professionals can better meet evolving societal health needs. Such is the case with respect to dementia education, as the rising prevalence of dementia is a global emergency [2][3].

In addition to the importance of lifelong learning due to new scientific knowledge and evidence, or changing societal health needs, the shift to lifelong learning also represents a more sophisticated understanding of how people learn more generally. While previously an 'information acquisition' metaphor of learning might have conceptualized learning as merely 'adding information to memory', there is now a more prominent notion of learning as 'knowledge construction' [4]. In this view, health professionals are not just passive recipients of information, but rather, active sense-makers who are hopefully processing new learning with a view to apply it to their patients. Learning is more of a continuous process, not an episodic event[5][6].

## Dementia education goals

Many countries around the world have identified the importance of training more health professionals with a view to capacity building in dementia care [7]. In addition, while we are focussing on post-diagnosis support in this report, providing a diagnosis is certainly one of the areas of professional development for physicians that requires attention. In that domain, there is underdiagnosis, misdiagnosis, and a failure to communicate a diagnosis compassionately [8].

Our Canadian province's Health Quality Ontario group recently published an evidence-informed quality standard on care for people living with dementia in the community, which nicely articulated many of the specific areas of dementia care that should be part of the education and training for health care providers [9]. See Table 1 for their list of content areas. Many of these areas could have a substantial impact on the quality of life of patients living with dementia and their families, including:

- Improved use of person-centred care and communication
- Appropriate use of pharmacologic and especially non-pharmacologic interventions, as well as increased awareness of de-prescribing
- Better use of outreach strategies and community resources

- Counselling related to advanced care planning and enhanced skills in palliative care.

Most of these education and training needs have also been identified as part of the Canadian national strategy and others [3][7].

## You can't change what you can't measure

While it is reasonably straightforward to identify the importance of lifelong learning and domains for improved health professionals' education and training in dementia care, it may be more challenging to accurately measure it. Ontario's provincial quality standard has identified process and structural indicators, such as the percentage of health care providers who care for people living with dementia who have received education and training in dementia care [9]. However, quantifying this is likely to tell us little about the extent of the training or impact on outcomes such as knowledge, skills, attitudes, or patient-related outcomes.

Health professional educational research often suffers from a lack of reporting quality and methodologic rigour [10]. Many interventions are not described in detail, and systematic reviews with respect to various aspects of dementia education for health professionals tend to suffer from heterogeneous studies with relatively low- to moderate-quality evidence [11][12]. Many only report satisfaction or reaction; fewer report knowledge outcomes; and even fewer outcomes

**Table 1. High quality of education and training: quality statement definition**

**Education and training need to be tailored to the providers' scope of practice. This information should include, at a minimum, content related to:**

- |   |  |
|---|--|
| ● Comprehensive assessment of people living with dementia and an assessment of carers' needs  | ● Appropriate use of nonpharmacological and pharmacological treatments                                   |
| ● Dementia signs, symptoms, and progression of the condition  | ● Self-care and safety for health care providers   |
| ● Specific subtypes of dementia   | ● How to communicate with people living with dementia and their caregivers                               |
| ● Approaches to diagnostic uncertainty in persons with complex conditions   | ● How to coordinate multidisciplinary care   |
| ● Person-centred care   | ● Impact of dementia on people living with dementia, caregivers, families, and social networks           |
| ● Development of care plans that meet the goals, preferences, values, and cultural expectations of care of people living with dementia and their caregivers | ● Outreach strategies to connect people living with dementia and their caregivers to available resources |
| ● Early identification of behavioural and psychological symptoms of dementia and techniques for de-escalation and management                                | ● Ethical and medical-legal considerations   |
| ● Early identification of behavioural risks and safety issues and techniques for de-escalation  | ● Requirement for informed consent   |
|   | ● Detection of and strategies to manage abuse  |
|   | ● Advance care planning and palliative care  |

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such as behaviour change or patient-related outcomes, or follow-up effects. Given the range of priority topics and goals related to health professional education, it will be important to improve some of the research in this area, to improve the strength of recommendations and potential generalization of approaches across various health care settings, contexts, and disciplines.

## Conclusion

Having a sufficient and skilled workforce to provide evidence-informed care is central to many nations' dementia strategies; and it is essential that these care providers have the necessary knowledge and skills to provide quality care. Lifelong learning is critical to developing new competencies, as well as reinforcing and refreshing previous knowledge and skills; and reflecting on attitudes that may also inhibit quality care.

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## Expert essay

# The future of dementia care

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It is projected that by 2050, there will be 12.7 million Americans over 65 living with Alzheimer's disease, nearly double the 6.5 million living with it today[1]. People living with dementia have healthcare utilization that costs three times more than age-matched individuals without dementia. Dementia care is primarily delivered by about 11 million family carers who will deliver the equivalent of US \$271 billion in unpaid care this year. At present, dementia is not typically diagnosed until later stages of the condition because of misattribution of symptoms to normal aging, denial, and primary care physicians not having adequate training in dementia work-up and diagnosis[2]. People living with dementia have poor clinical outcomes and high healthcare utilization because of untreated behavioural symptoms and carer strain[3]. As the United States population ages and neurocognitive disorders increase in prevalence, it is essential to develop a system of care for people living with dementia to meet their needs, and the needs of a strained healthcare system. This system should treat patients from diagnosis until end of life and should include screening, diagnosis, care, and in the future, treatment. Access to specialty physician-level dementia care is difficult for most people as there is a dearth of specialists and care is often siloed. Additionally, most people living with dementia do not need specialty medical care; rather, they need care that meets their needs based on their diagnosis, cognition, behavioural symptoms, and functional abilities. Utilizing existing resources and restructuring clinical care into team-based interdisciplinary models will allow for the management of most dementia patients at the primary care level. This is of particular importance because there is strong evidence that people living with dementia have worse outcomes from the rest of their co-occurring health conditions – and this should not be the case. Utilizing the best of technology, clinical evidence, and pragmatic clinical trials, we can aspire to meet the needs of our rapidly growing population of people living with dementia.

Developing a system of dementia care will require training teams of professionals to direct care from the primary care setting. This includes training advanced practice clinicians in basic cognitive exams and dementia assessment, training social workers and case managers in caregiver support

and community-based dementia resources, and empowering primary care physicians to disclose dementia diagnosis to their patients, while managing these teams. Extending the reach of dementia specialists, such as neurologists, geriatric psychiatrists, and geriatricians, so they can influence the care of many patients without direct contact is essential to maintaining primary care as the locus of dementia care. Models for designing and implementing collaborative dementia care have been studied in detail and have shown to improve patient and caregiver quality of life, and to decrease healthcare spending. Some examples of care models include the University of Indiana Aging Brain Care model, the UCLA Alzheimer's and Dementia Care model, and the UCSF Memory and Aging Center Care Ecosystem model[4]. In addition to optimising and organizing the existing workforce for a surge of people with dementia, dementia care needs to become a focus or specialty track in training programs for advanced practice clinicians, social workers, and physicians. Creating a framework for care and populating it with a workforce that is trained in the standard of care will enable us to meet the needs of the aging population.

The eventual arrival of biomarker tests for dementia and disease-modifying treatments will transform how we treat dementia but will certainly not eliminate the need for holistic dementia care. While some will have the good fortune of Alzheimer's treatment during early stages, many people will be diagnosed when the condition can no longer be treated. Furthermore, treatments for other dementias (vascular dementia, synucleinopathies) are even further from being developed. Frameworks for dementia care will be necessary for the foreseeable future and we must invest in studying the development and implementation of humane models of care. Utilizing pragmatic clinical trials will allow healthcare systems to quickly roll out large-scale interventions and adapt them to meet the needs of the patient population and care resources. We have an opportunity to meet the needs of our aging population and their family carers through humane care, but we need to invest in our work force, care models, caregivers, and patients, while we wait for transcendent technologies to diagnose and treat dementias.

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## Conclusion

This chapter of the report emphasises the importance of providing dementia information and ongoing education and training on many levels. First and foremost, we have learned that people with dementia and their carers *want* more information. They want to learn about their condition and what to expect. Essential to this is a workforce that is well-resourced and trained – and that has access to ongoing practice development and life learning to ensure they build their competencies and update their practice. To facilitate this, tailored training programmes that use collaborative education design processes can deliver impactful and enduring learning.

Finally, we have learned that these practices are best implemented by multi-disciplinary teams within primary care. Lifelong learning, training, and educative approaches to dementia care for both professionals and people living with dementia and their carers will help make care more person-centred, easier to access and to provide, and help make the dementia journey easier to navigate.

## Report conclusion

It is our hope that this substantial and comprehensive report has contributed to overcoming some of the apprehensions surrounding post-diagnosis dementia support and helped identify some of the barriers to overcome – but also some opportunities that provide direction and hope. Much more still needs to be done globally in terms of improving access to information, education, and resources to ensure equitable access to care, wherever people with dementia may live. Stigma and a lack of understanding remain tremendous obstacles for people living with dementia and their carers to receive adequate care and support.

While there is still no cure for dementia, it is care that can bridge the gap and provide hope. Post-diagnosis support can be viewed as complicated and intimidating, but we must do away with the belief that those affected by dementia are somehow less deserving of respect, dignity, and care than others. Knowledge is power, and this report hopes to be a resource giving people with dementia, their carers, health and long-term care professionals, and broader communities the tools to better navigate this journey in humane, empowering ways.





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