



# Dementia:

## An urgent health priority

Briefing to the Incoming Minister 2020



# Introduction

*“I can think of no other condition that has such a profound effect on loss of function, loss of independence, and the need for care. I can think of no other condition that places such a heavy burden on society, families, communities, and economies. I can think of no other condition where innovation, including breakthrough discoveries, is so badly needed.”*

WHO Director-General’s address to G8 Dementia Summit, 2013

Dementia is major, rapidly escalating problem in Aotearoa. The reason is simple: our population is currently ageing at an unprecedented rate.

The 2017 [Dementia Economic Impact Report](#) estimated that around 70,000 New Zealanders have dementia now with that number expected to almost triple in coming years. That Report also indicates that if we continue as we are, then the economic cost of dementia to Aotearoa is likely to grow by 270% to around \$5 billion a year by 2050. However, the 2018 census data suggests that the ageing population (and the resultant dementia costs) may be increasing faster than is assumed by those projections.

Despite these projections, and despite the [WHO](#), [OECD](#), and [The Lancet](#) all highlighting that dementia presents a major global problem, successive New Zealand governments have failed to act. The 2013 *Framework for Dementia Care* has largely been ignored and woefully inadequate service provision has continued.

If the level of inequity and marginalisation associated with dementia occurred in any other sector of our society, there would be a public and political outcry.

Dementia is one of the most significant healthcare challenges for this nation next to Covid-19. It requires a planned, proactive, and cost-effective response. Much of the hard work has already been done. The dementia sector became so concerned it developed the [Dementia Action Plan](#) earlier this year. Implementing this Plan will significantly reduce the impact of these conditions on people living with dementia (both those with the condition and care partners), our communities, our health system, and our economy.

Aotearoa is not on its own. Other countries are facing an equivalent problem. [Japan](#) has been forced to act due to sheer numbers; [South Korea](#) has already implemented its action plan with specific targets. [Ireland](#), with the same population as Aotearoa, has a National Dementia Office which provides leadership and oversees the implementation, monitoring, and ongoing evaluation of their National Dementia Strategy.

Our briefing is designed to help you respond effectively to our country’s dementia challenge by:

- Outlining the size and scale of the dementia challenge New Zealand faces

- Describing the dementia sector's recommendations for responding to this challenge as set out in the *Dementia Action Plan*
- Showing how the sector's blueprint can be readily applied
- Identifying four initial priorities from the *Dementia Action Plan* which can be implemented readily in Budget 2021.

## Dementia – an urgent priority

**“...Particular focus has to be put on the needs of the most ostracized and the vulnerable of the vulnerable – like...those with dementia...”**

Independent Expert on the enjoyment of all human rights by older persons,  
Rosa Kornfeld-Matte, New Zealand, 2020

The term 'dementia' or 'mate wareware' describes a group of symptoms that affect how well our brains work. Dementia is a debilitating condition which is progressive and has no cure. It can affect anyone, and as people get older the chances of developing dementia increase. Around 90% of those with dementia are over 65. Alzheimers disease is the most common form, affecting around two-thirds of people with dementia.

Most people with dementia continue to live at home in their communities for most of their time with the condition, meaning adequate and appropriate community support services are vital. Right now, most of those support services are distressingly inadequate.

What is needed to improve the lives of people living with dementia and reduce the impact on the health system is well known. A best practice-based guide for District Health Boards (DHBs), the *New Zealand Framework for Dementia Care*, was developed in 2013. In 2015, a summit identified a national dementia plan as the most important first action for Government to take.

Internationally, in 2017 the World Health Assembly (New Zealand is a Member) adopted the *Global Action Plan on the Public Health Response to Dementia 2017-2025* and later that year a [Lancet Commission on dementia prevention, intervention, and care \(updated in 2020\)](#) published a comprehensive meta-analysis of the relevant research.

However, New Zealanders living with dementia are still being let down. The current inadequate services, of variable quality, are not capable of meeting the needs even now, and the system is under increasing pressure. For example:

- **Current service gaps make service improvement urgent** - Services exist but there are gaps across the whole dementia journey; the system is difficult to navigate, community-based living well programmes are hard to access; families are



overwhelmed yet respite care is limited and inflexible; and, palliative care services for people living with dementia are poorly developed.

- **Services are inequitable** - There are few 'by and for Māori' services, and access to and availability of services is inequitable across urban-rural and DHB boundaries, speciality area, and population groups.
- **Quality is variable** – Services are often task rather than person-centred, and can be limited to medical solutions; over-use psychotropic drugs continues; and, services often fail to consider the need for meaningful connection, activity, and stimulation.
- **Human rights are ignored or overlooked** - Stigma and discrimination create barriers to accessing services and support; decision-making authority is often denied to people living with dementia.
- **Population growth makes service development urgent** - The estimated 70,000 number with dementia right now is expected to rise to 102,000 by 2030 and to have almost tripled to 170,000 by 2050. These numbers exclude family/whānau/other care partners also impacted by the diagnosis.
- **Dementia is an important hidden player in the wider health system** – Dementia is associated with lower thresholds for acute hospital presentations, increased lengths of stay, failed discharges, and health system harms.

*“It takes a crisis to get help. Like when he had a fall and went to the hospital. Then the GP said you need more help.”*

Care partner

- **Dementia is a major cause of disability and dependency among older adults** - It has been estimated to account for 11.9% of the years lived with disability due to a noncommunicable disease and has a significant impact not only on individuals but also on family/whānau, communities and societies.
- **Dementia leads to increased costs** - The economic cost of dementia to Aotearoa increased by 75% between 2011 and 2016, with the total cost of dementia in 2016 estimated to be \$1.7b increasing to \$4.6b by 2050. People with dementia and their families/whānau face significant financial impact from the cost of health and social care, and from reduction or loss of income.
- **Workforce issues are worsening** - Significant numbers of additional staff will be needed as the numbers of people living with dementia increase. Recruitment and retention are already a problem and there is no workforce strategy.

- **Future community expectations will increase, perhaps suddenly** - When a disease-modifying treatment for dementia becomes available there will be huge demand for it. Any such treatment is likely to be expensive and the system is not geared to respond.
- **Demographic change heightens the issues** - While the population at risk of dementia is growing rapidly, the population needing access to services is likely to grow even more rapidly. Our highly mobile population, lower birth rates, and heightened job insecurity since the 1990s means more seniors living in relatively precarious circumstances. Increasing numbers are living alone in rented accommodation and are without family or friends.
- **Covid-19 is compounding the issues** – Covid-19 is highlighting the importance of care partners, and how much people do need meaningful contact just to [retain the will to live](#). Lockdown, social distancing and the concomitant cancellation of support services and withdrawal of respite care illustrate just how much care partners rely on these services to continue to care. Covid-19 is not going away quickly, and neither are the associated care issues.

## The Dementia Action Plan – a sustainable approach to dementia

Our nation clearly has a problem. Doing nothing is not an option. If Government fails to act, and act quickly, dementia will overwhelm the health system and prevent future governments from addressing other priorities. But Government also has a possible solution. In light of the very obvious and urgent need, the dementia sector prepared the *Dementia Action Plan*. The Plan was developed by Alzheimers NZ, Dementia NZ and the NZ Dementia Foundation, using our combined expertise, and the insights of several hundred New Zealanders. It is aligned with the *Healthy Ageing Strategy 2016*; *Better Later Life – He Oranga Kaumātua 2019-2034*; *Carers’ Strategy 2008* and the *Carers’ Strategy Action Plan 2019 to 2023*; *Aotearoa New Zealand Disability Strategy 2016*; *Government Inquiry into Mental Health and Addiction 2018*; and, the *Health and Disability Kaiāwhina Workforce Action Plan 2015-2020*.

It also based on the [NZ Framework for Dementia Care](#); the [Lancet Commission for prevention, intervention and care](#); the [Global Action Plan on the Public Health Response to Dementia](#); Alzheimers NZ qualitative research [This is our story](#); and, the [Dementia Declaration](#).

The Plan provides a blueprint for addressing the dementia challenge New Zealand faces. It explains what people affected by dementia need to live their best possible lives. It is eminently deliverable by any government. All it needs is a government commitment to fund and implement it.

The *Dementia Action Plan* envisages an Aotearoa in which dementia is prevented as much as possible; and where people living with dementia, their whānau/families and care partners receive the support they need, while decreasing the impact of dementia on them, as well as on Aotearoa communities, the health system and the economy.

It has four action areas:

- 1. Reducing the incidence of dementia** - The diseases that cause dementia share many risk factors with other non-communicable diseases including heart disease, stroke, diabetes, and cancer. Research suggests that proactive evidence-based interventions focused on modifiable risk factors could reduce the population risk of developing dementia by between 10% and 20% and/or slow progression.
- 2. Supporting people living with dementia and their family/whānau care partners/supporters to live their best possible lives** - People with dementia and their family/whānau care partners/supporters can enjoy more full, active and meaningful lives when they have access to a timely, accurate diagnosis as well as to the right support and assistance. This will improve quality of life, reduce the impact on the health system and reduce the costs caused by higher levels of care and emergency care.
- 3. Building accepting and understanding communities** - Stigma and a lack of awareness, poor understanding and barriers to inclusion are extremely damaging, and make it harder for people to get the help and support they need. These issues also increase isolation.

*“I think there needs to be an awareness about people with dementia. I didn’t know anything about it before, and I don’t think most people know what it is.”*

Person with dementia

- 4. Strengthening leadership and capability across the sector** - The dementia sector is complex and fragmented. Making the changes needed to implement this Plan is a major programme of work, requiring leadership from government and a strong focus on capability across the sector.

We acknowledge and respect the fact that Covid-19 is the focus for Government right now. But after Covid-19, dementia must be a top priority for health as its impact is so large.

Urgent action on dementia is also needed because of Covid-19. The events of 2020 have illustrated just how precarious and how neglected those living with dementia really are. Even before the Covid-19 crisis, the UN Independent Expert on the enjoyment of all human rights by older persons, Rosa Kornfeld-Matte, referred to people living with dementia in New Zealand as among the [\*most vulnerable of the vulnerable\*](#). Covid-19 has just exacerbated this situation.

## ***The Dementia Action Plan* closely aligns with Health and Disability System Review**

We understand that you will be focused on implementing the recommendations of the *Health and Disability System Review Final Report*. The *Dementia Action Plan* is closely aligned with the approach taken in that Report. Changes set out in that Report critical to improving care and support for people living with dementia include:

- Placing the voice of the people using the system at its centre with a focus on services that are needs-based, improve equity, and address high need populations
- Placing Te Tiriti O Waitangi and Te Ao Māori at the centre of systems and services for Māori
- Services that are more connected, supported by care coordination and navigation
- A single, integrated system with national consistency, balanced with services that address local need - supported by stronger relationships, communication, and commissioning arrangements
- Community, home-based services, and primary care (Tier 1) carrying equal weight to secondary/tertiary services, both with a focus on wellbeing
- Stronger population health systems
- More focussed and active leadership and stewardship throughout the system, supported by a Charter driving behaviour change.

A focus on more transparent and long-term planning will also help prepare for foreseeable challenges such as increasing numbers with dementia. Addressing the impact of the long-term underfunding of the system and the central role that NGOs play in the health sector as recognised within the Report is also desirable.

In summary, the *Health and Disability System Review Final Report* recommendations are far reaching and fundamentally redesign the structural components of the system. The *Dementia Action Plan* is not about the structure of the system. Its focus is on the practical changes that are needed urgently across the dementia sector so people living with dementia can live their best possible lives. Therefore, progress on its four action areas is not dependent on or influenced by decisions on the Report's recommendations.

On that basis, the work to implement the *Dementia Action Plan* can begin now under the existing structures and progressively transfer to the new arrangements as they are established.

## First steps and recommendations for Budget 2021

The *Dementia Action Plan* is a five-year Plan requiring progressive implementation. Our recommendation is that the implementation starts immediately with four specific actions.

1. Our first recommendation is to strengthen the leadership in the sector by establishing a national cross-sector stewardship and leadership group to engage with the Ministry of Health and DHBs on the *Dementia Action Plan* and its implementation. There is currently no mechanism for this type of active national engagement for dementia services, which are fragmented and uncoordinated.

Our three remaining recommendations relate to Action Area Two in the *Dementia Action Plan – Supporting people living with dementia and their family/whānau care partners/supporters to live their best possible lives*. We recommend that funding is provided in Budget 2021 to provide:

2. At least 12 months' post-diagnosis support to equip people to live their best possible lives, including but not limited to:
  - Information on what to expect, the services available, and their rights
  - Education programmes on living well with dementia
  - Tools and support to plan and prepare for the future
  - Support services to strengthen resilience and wellbeing
  - Cognitive Stimulation Therapy and other proven interventions to maximise function
  - A long-term plan including referrals to ongoing services and support
3. Dementia navigation services to coordinate and support access to much-needed services, including emergency support, so people have as smooth as possible a journey through the course of their dementia and get the services they need and that are right for them.
4. Support for family/whānau supporters/care partners, including information, education and support, and flexible, [available and accessible respite services](#).

Funding is an issue. The ageing population and chronic illness are going to be major challenges for the foreseeable future. Right now, the NGO sector struggles to fill the ever-growing gaps in dementia services. Around 70% of people with dementia live in the community for most of their time with the diagnosis.



***“I’m just taking myself off...Because you know otherwise the pressure just gets too much and you start to blow up....”***

Care partner

Community organisations such as local Alzheimers and Dementia organisations are the primary organisations supporting people living with dementia in the community. Yet these organisations are chronically underfunded. A 2019 study undertaken for the Social Service Providers Association by [MartinJenkins](#) indicated that government is funding service providers for less than two-thirds of the actual cost of delivering the essential services they are contracted to provide, and that the total underfunding is estimated to be at least \$630 million annually.

The *Health and Disability System Review* noted long-term underfunding of the system as a whole and the problem of unmet need in the community. Our own estimate is that local Alzheimers organisations are currently funded for only about 20% of current need and must fundraise for the balance which in turn relies on gambling funding through local trusts, Pub Charity and Lotteries, and as well as other funding sources hit heavily by Covid-19.

While funding is an issue, it needs to be put in context. The funds required to make a difference in this area are relatively modest when compared with recent investments in other sectors. It has not been possible to fully cost the *Dementia Action Plan*, both because the information we would need to do so is held by the Ministry of Health and DHBs, and because the cost would depend on the approach taken by DHBs to implement some of the changes. However, our preliminary estimate is that the immediate improvements to frontline services could be achieved with around \$20m/year in additional funding – less than 1% of the estimated total cost of dementia to the New Zealand economy of \$1.7b/year.

## Conclusion

Dementia is widely acknowledged as one of this century’s most difficult health challenges. It is one that Aotearoa is not prepared for. Action to address this issue cannot wait for the implementation of the *Health and Disability System Review Final Report’s* recommendations. Action is desperately needed now.

***“You’re given the impression well, go home and put your affairs in order and wait.”***

Person with dementia

The dementia sector has laid the groundwork for action. We have prepared a *Dementia Action Plan* to drive the changes needed for New Zealand to address the dementia challenge in a way that is sustainable and that builds on the services already in place.

But we cannot implement the Plan; that requires your help which is needed urgently.

We look forward to working with you as you work through the Government's response to the urgent and growing need for better services to support people living with dementia and the changes we recommend in the *Dementia Action Plan*.

We also stand ready to work in partnership with the national leadership group, the Ministry of Health and DHBs to give life to this first *Dementia Action Plan*.

## Appendix 1: Who is Alzheimers NZ?

Alzheimers NZ is the lead organisation at a national level representing people living with dementia. Our role includes raising awareness of dementia, providing information and resources, advocating for high quality services, providing practical tools to support a dementia friendly New Zealand, and promoting research.

Alzheimers NZ was established in 1986. We support local Alzheimers NZ organisations throughout New Zealand, each of which is a member of Alzheimers NZ.

The local Alzheimers organisations provide support, education, information, and related services directly to members of their communities who are affected by dementia. These services include but are not limited to:

- Information and education to assist with understanding and living with a dementia diagnosis.
- Support for family, friends and whānau coping with the demands of caring.
- Support groups and day programmes for people affected by dementia.

Alzheimers NZ is an active member of New Zealand Carers' Alliance, and Catherine Hall, our Chief Executive is Co-Chair of that organisation. She is also Chair of the Neurological Alliance.

## Appendix 2: The Dementia Declaration



### Dementia Declaration: Our Lives Matter

**“We ALL want to be seen, valued, appreciated and loved for who we are.”**

As New Zealanders living with dementia, we are citizens whose lives matter. We have the same rights, privileges and obligations as everyone else. Our Declaration sets out what we need to live well.

**We live our best possible lives when:**



We have control over our lives; we have support to make decisions that are important to us.



We live in knowledgeable communities that include, accept and understand us.



We have consistent quality support, care and information which is timely and appropriate to us; it is provided with kindness by compassionate people who have the right skills and knowledge, our interests as a focus, and with whom we are comfortable.



We continue to be actively engaged in roles and activities which are meaningful and important to us.



We have the things we need to live well such as housing, privacy, an adequate standard of living, and ways of getting where we need to go.



A circle of support protects our wellbeing, allowing us to maintain strong mutual relationships with our families, whānau, friends, colleagues, and those who are important to us.



We are loved; our presence matters.

**“I am still me.”**

*This Declaration was developed by people living with dementia on Alzheimers New Zealand's Advisory Group.*





## He Whakapuaki mō te Mate Wareware: He Mea Nui Tō Mātou Noho i Te Ao

**“E hiahia ana mātou KATOA kia kitea mai e te tangata kē, kia whakanuia, kia kīa he tangata whai painga, kia arohaina mai mō tō mātou āhua tūturu.”**

Hei tāngata nō Aotearoa e noho tahi ana me te mate wareware, he kirirarau mātou, ā, he mea nui tō mātou noho i te ao nei. He rite tonu ō mātou tika, ō mātou whiwhinga, haepapa hoki ki ō ngā tāngata katoa. Tā tō mātou Whakapuaki he whakataki i ngā mea e hiahia ana mātou kia noho pai i te ao nei.

### Ka eke mātou ki tō mātou tino teitei ina:



Noho tonu te mana mō mātou ki a mātou anō; kua kaha hoki ngā reo tautoko i ā mātou whakatau mō ngā mea hira ki a mātou.



Noho mātou i ngā hapori mōhio e awhi nei, e whakaae nei, e mārāma pū nei ki a mātou.



Tōkeke tonu te tautoko i a mātou, te tiaki me te whiwhi mōhiotanga i te wā tonu e tika ana, e hāngai ana hoki ki a mātou; e horaina mai ana i roto i te atawhai e te hunga ngākau pūaroa, he tāngata whai pūkenga tōtika, mātauranga tōtika e arotahi ana ki ō mātou hiahia, he pai tō mātou noho tahi me rātou.



Whakauru tonu mātou ki ngā tūranga me ngā mahi whai tikanga, hira hoki ki a mātou.



Tukua ki a mātou tonu ngā mea e hiahia ana mātou ki te noho pai, te tūmataitinga, kia whai moni e pai ai te noho, me ngā āhuatanga kawē i a mātou ki ngā wāhi e hiahia ana mātou ki te haere.



Karapōtingia mātou e tēnei kāhui tautoko, he kāhui e ngāwari tonu ai te noho pipiri ki ō mātou whānau, ki ngā hoa, ki ō mātou hoa mahi, me te hunga e noho nei hei mea nui ki a mātou.



Aroha nuitia mātou; he mea nui tō mātou noho i te ao.

**“Ko au tonu ahau.”**

*He mea tuhituhi tēnei Whakapuaki e te hunga e noho tahi ana me te mate wareware i roto i te Rōpū Tohutohu o Alzheimers New Zealand.*



A dementia friendly New Zealand  
Aotearoa, he aro nui ki te hunga mate wareware

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This document is produced in a dementia friendly style. It uses fonts and spacings that makes it as easy as possible for people with dementia.