



Changing the game for New Zealand's dementia community - Recommendations for Budget 2019

Kaua e takahia te mana o te tangata - Do not trample over people;
Honouring our older people needs to be part of all aspects of society.

Introduction

Alzheimers New Zealand supports the Coalition Government's focus on the wellbeing of our people. We share your concern for vulnerable groups and the desire to make a real difference to the quality of people's lives.

Some of the most vulnerable and forgotten people in Aotearoa are those affected by dementia. Their numbers are growing rapidly with our ageing population. The impact of dementia on individuals, families/whānau, communities and our economy is significant, and the need for action is urgent.

Too many people are needlessly struggling – both people with a diagnosis of dementia and their care partners; they lose their health, jobs, incomes, relationships, friends, homes, mana, and independence amongst other facets of human dignity.

The consequences of continued inaction on these problems are well-researched. Yet successive New Zealand governments have ignored dementia as a health priority.

We see Budget 2019 as the Coalition Government's opportunity to make a positive difference by starting to change the game for New Zealand's ever-growing dementia community.

We implore you to recognise the critical problems being caused by the rapidly growing numbers of people in our society affected by dementia, and to act now to address them - before a tipping point is reached.

The true measure of any society can be found in how it treats its most vulnerable members - Gandhi

A true story

Susan (72) has been the primary caregiver for David (81) for over a decade. This is her story.

My GP and other health professionals insisted David accesses a fortnight of respite care every six weeks to ensure I don't suffer exhaustion."

Susan was told by the DHB to make her own respite care arrangements. But there were no beds in Dunedin. She approached all local rest homes and the hospital and there were no respite care beds. She has been told that the situation has deteriorated from 91 allocated respite days per year to 'when beds are available'.

These are usually beds that are available between the exit of one permanent resident and the entrance of another, but there is no predictability or consistent pattern of availability; just what suits the rest home at the time. I think I found 3 (5 weeks altogether) over 6 months.

I ended up having three cardiac experiences over two years. They were the result of panic attacks resulting from physical, emotional and mental exhaustion and stress as the caring role became more and more of a 24/7 occupation.

After each of these incidents, the only respite offered was the carer's allowance of \$9.35 per hour. However, it costs between \$25.00 and \$50.00 per hour to hire a carer, a total of between \$100.00 to \$200.00 for 4 hours, for which the refund is just \$37.40.

Most carers cannot afford this, and the rebate has not increased for 22 years.

My husband could attend day care but is not interested in the activities they do which tend to be "one size fits all" e.g. housework, quizzes and craft. He has an academic background.

Apart from free incontinence pads and the finding of a suitable carer by the local Alzheimer Assn we have received no other support over the 11 years. My husband has been in permanent care for 3 months.

This is a grotesque situation. It feels like the definition of elder abuse which is generally not thought of as being carried out by government institutions and generally accepted cultural norms.

This issue highlights the need for cultural change regarding how we treat our aging population; to see them as individuals who can continue living well in their communities with the right support.

I remind David every morning that he is a husband, father, and grandfather. He was an art historian, a singer, and is still sociable, but he is aware something terrible is happening to him and he is terrified.

Escalating Economic Implications

Nearly 70,000 people have dementia now and we expect that number to increase to 170,000 by 2050 as New Zealand's population continues to age. And that is just the tip of the iceberg. For every person diagnosed with dementia there are family and friends also affected by the diagnosis.

However, it is the marked growth in numbers, costs and impact that is the real problem. The population with dementia grew by 29% between 2011 and 2016. The total cost of dementia to New Zealand grew by over 75% during the same period.

Dementia is economically and socially expensive compared to other conditions. Annual costs of supporting people with dementia are about the same as the combined annual costs of supporting people with cancer, heart disease and stroke.

Most people with dementia live at home for most of their time with the condition. They and their care partners rely on community and home-based services which are underfunded, inadequate, and variable in quality. And the demands on the services keep growing.

However, no additional investment has been directed at specialist services for people with dementia for more than 10 years. Only residential care subsidies have increased.

Unless things are done differently, care of older people will account for 50% of District Health Board expenditure by 2025/26, up from 42% in 2015/16, and the cost of dementia to New Zealand will be around \$5 billion per year by 2050.

Unless something is done now dementia will grow to become an urgent and immediate issue which distracts future governments from progressing their other priorities. Inaction on dementia now means saddling future governments with an unnecessarily large multi-billion-dollar problem.

The Human Cost of Dementia

The wellbeing of our community is paramount, particularly the wellbeing of those most vulnerable. Mason Durie's Te Whare Tapa Wha model is very apt for dementia, as dementia challenges all dimensions of our humanity.

There are the physical and emotional characteristics of the condition (taha tinana and taha hinengaro). Then there are the extra and needless physical and mental symptoms that go with the lack of care and support.

Dementia changes relationships (taha whānau) and causes stress, loneliness, lost careers and reduced income, putting a strain on a person's physical and mental health and social relationships. People caring for those with dementia often ignore their own health needs in favour of the person for whom they care. For example, around 40% of family/whānau dementia care partners have clinically significant depression or anxiety.

The lack of services and support for people living with dementia causes so much needless harm. It is shameful that their human rights are too often ignored and so many people:

- encounter stigma and discrimination;
- are being left out and ignored;
- experience the increased likelihood of stress-related abuse;
- are faced with health costs due to caring-related illness or disability.

Dementia has a disproportionate impact on women. Women are more likely to be living with dementia and are more likely to be providing care and support – both in a family situation and in a formal care situation.

Perhaps the greatest impact is the insult to the human spirit - taha wairua. Ending up restrained by antipsychotics, and/or being denied inclusion, legitimacy and love is a real indignity. It is particularly concerning when we know people with dementia who are well supported, receive appropriate care, and are loved can live well to the end of their lives. We just ask that this occurs for all.

Six steps to a solution

Yes, the problem is significant, but a blueprint already exists to address the challenge of dementia - the *NZ Framework for Dementia Care*.

Our chief recommendation is that the Coalition Government commits to implementing this *Framework* with a clear pathway to full implementation, consistently, across the country.

Six simple steps provide a pathway to immediate improvement¹:

1. **Invest in prevention and risk reduction**

Evidence suggests a lifecycle approach to risk reduction could lower the number of people diagnosed with dementia by 35%.

2. **Intervene early to improve detection, diagnosis and support**

Only about 50% of people with dementia get a diagnosis and even then immediate post-diagnosis services are inadequate.

Improvements can be made by:

- including hearing checks in the free annual health check for people 65 and over; and
- providing for 12 months' post-diagnosis support to equip people with dementia, their families and care partners with tools, connections, resources and plans to allow them to live as well as possible with dementia (\$4.95 million per year).

3. **Support people to live well**

Provide services that support people to live at home, healthier, for longer, wherever they live in New Zealand, by:

“One of the most critical times for assistance is the 12 months following a diagnosis of dementia. There is a need to learn about the disease and what services and assistance are available and how they will be navigated. This is a period when we are most vulnerable, mentally. Providing the right support will enable us to live well with dementia.”

Alister (person living with dementia in the Hawke's Bay)

¹ The steps have been costed where possible using a simple set of assumptions as a starter for discussion with officials. Steps that are 'pan-condition' have not been costed as Alzheimers NZ does not have information on which to do so. Costs for improvements to respite will be available later in October when a report we have co-commissioned with Carers NZ and IHC will be available.

- establishing navigation services across the country (\$9.6 million per year); and
 - providing high quality information brochures to support people with dementia and their care partners to better understand dementia, what to expect, and the care and support available (\$135,000 per year).
4. **Support family carers to continue to provide care**
Enable carers to have a break when they need it – by providing flexible, high quality respite (home, community and residential) services consistently, wherever they live in New Zealand.
5. **Build age and dementia friendly communities**
Raise awareness, tackle stigma and discrimination and build inclusive and accepting communities within New Zealand by:
- establishing a national public awareness and public health campaign on living longer, isolation and loneliness, and living with dementia (and potentially other chronic conditions), which is community and culture specific; and
 - actively supporting national age and dementia friendly initiatives including in the public health system.
6. **Establish indicators, monitor progress, and conduct research**
What gets measured gets done. There are currently no national indicators against which dementia progress can be measured and monitored. New Zealand needs better data collection, meaningful indicators and increased research.

These six simple changes² will improve many dimensions of community wellbeing across New Zealand, benefiting urban and rural communities and different ethnicities and demographics.

Making these changes will also deliver on New Zealand's international obligations under the WHO Global Action Plan on the Public Health Response to Dementia and the Convention on the Rights of Persons with Disabilities, and

² See Appendix 1 for more detailed information about these six steps

domestic obligations under the Healthy Ageing Strategy and the Carers Strategy.

They also make economic sense. Changes which keep people as well as possible and at home for longer could achieve cost benefit ratios of \$6.60 for every \$1 invested³.

Changing the game

It is astonishing that New Zealand has a well-supported government blueprint to address the dementia challenge that has been largely ignored for five years. The *NZ Framework for Dementia Care* needs to be implemented urgently, in full, and with the required funding.

It is distressing to watch the hundreds of thousands of New Zealanders (people with dementia and families/whānau) struggle so much, and to see the spiralling impacts of that struggle. It is shameful when they are amongst the most vulnerable in our society.

It is not too late to change the game, to put in place the systems, support and services that Kiwis are going to need in coming years, and to reduce the cost burden on the country.

It is rare to have such easy options for improving people's lives. Failing to act now to start the change, when you know the impact dementia has on individuals and families/whānau, the health system and the economy, is unthinkable.

³ Dementia Economic Impact Report 2016, *Alzheimers NZ and Deloitte, March 2017*

Appendix 1: The six steps

1. Invest in prevention and risk reduction

Dementia risk can be reduced. Education for our tamariki sets them up well for later life and can reduce dementia risk by 8%. Dealing with depression, reducing smoking, and increasing physical activity can reduce dementia risk by up to another 12%. Addressing hearing loss can reduce dementia risk by another 9%. These things are not difficult but collectively could reduce dementia risk by almost 30%.

2. Intervene early to improve detection, diagnosis and support

Increasing the role of primary care services will help people live better, help keep them at home for longer, and help the health system to be more sustainable across the generations. Early intervention could make a significant difference as part of the super gold card holders' free health visit. These could easily be extended to include cognitive impairment and hearing tests.

Post-diagnostic support is successful in Scotland, and we can do it here. Their 5 Pillars Model of Post-Diagnostic Support provides people with dementia, their families and care partners with tools, connections, resources and plans to allow them to live as well as possible with dementia and make plans. We estimate provision of 12 months of this type of post-diagnostic support will require an extra \$4.95 million per annum.

3. Support people to live well

Community-based navigation services provide the first point of contact for the person with a dementia diagnosis, and their family/whānau. They give advice, encourage self-management, explain pathways, co-ordinate referrals, and help people find their way through the health and social support system.

Navigation services supplement rather than replace what already exists and would cost around an extra \$9.6 million per year. Some aspects of these roles are already provided; others will require a dedicated role, and others could be provided via technology.

People need to understand dementia and learn how to live with it. Good up-to-date information that is easily accessible, culturally appropriate, consistent and regularly reviewed is vital. Alzheimers NZ has worked with the Ministry of Health, DHBs and the dementia sector to develop quality national resources.

The information is available electronically, but clinicians tell us that hard copies are needed. We estimate the cost is around \$135,000.

4. Support family carers to continue to provide care

Care partners need to be able to care. But they can only care with sufficient support. Right now, 55% of home-care assessed family or friends, who care for a person living with dementia, report feeling overwhelmed by the person's support needs.

Too many care partners end up isolated, burnt out or develop anxiety/depression. Age/dementia friendly contexts, reduced discrimination, better primary care support will all help, but are not enough.

Quality respite care which is consistent across New Zealand, meets specific regional needs, and enables care partners to plan for respite in advance is essential.

Alongside Carers NZ and IHC, we have commissioned a piece of work to develop better options around respite care. This work is due later in October.

5. Build an age and dementia friendly community

Aotearoa must become age/dementia friendly. Cities and towns which exclude disabled people just encourage people with dementia to withdraw into the relative safety and comfort of their own homes. Isolation follows, generating further cognitive decline.

Age/dementia friendliness will make our country more inclusive, assist older people, those who care, those with disabilities, and those with young children, and will really help people with dementia to live better lives. This is well known overseas, is advocated for by the WHO, and acknowledged in the *Healthy Ageing Strategy*.

Twenty years after the successful *Like Minds* campaign began, people living with dementia still experience discrimination. Assumptions about people with dementia are appalling even by those who should know better.

Members of our Advisory Group tell us they get told to ‘pack up their lives’, are treated like ‘third persons’ and get considered as ‘no longer any good’ for their jobs/community roles. People lose confidence, jobs/roles and social status. The nation loses out as people withdraw and dramatically reduce their contribution to wider society. This is despite the 2012–2017 *Mental Health and Addiction Service Development Plan*’s references to dementia and commitment to including older people with high-prevalence conditions as one of four priority populations.

6. Establish indicators and monitor progress

The Ministry of Health does not gather much-needed statistical data to inform evidence-based policy. We, Brain Research New Zealand, the NZ Medical Association and others continue to cry out for quality, comparable information. Yet we have little despite being a signatory to WHO requirements to collect the data. The Ministry collects data on diabetes, cancer, arthritis, obesity, stroke. Some data is available from InterRai assessments but much more is needed to learn about dementia.

As well as data, we need meaningful indicators, so we can chart progress. Of course, charting progress requires research, and research on dementia as a public health issue is sorely needed.