



Improving dementia services in New Zealand: Recommendations for Budget 2020

Alzheimers NZ is urging the Government to use Budget 2020 to begin to address the Dementia Challenge facing our country. ¹

A key tool for doing this is the draft NZ Dementia Plan that is being prepared by leading representatives in the dementia sector, including Alzheimers NZ. ²

The Dementia Plan is consistent with *Better Later Life – He Oranga Kaumātua 2019-2034*; the *Carers' Strategy 2008* and the *Carers' Strategy Action Plan*; the *New Zealand Disability Strategy 2016*; the *Government Inquiry into Mental Health and Addiction 2018*; and, the *WHO Global Action Plan on the Public Health Response to Dementia 2017 - 2025*. It is underpinned by the *Dementia Declaration* which sets out what people living with dementia require to live well (see Appendix).

The Plan focuses on a three-year horizon (2020 - 2023) and concentrates on the delivery of **four** main objectives that, if achieved, would dramatically reduce the major impact that dementia will have on New Zealand, both fiscally and in terms of the human cost. These objectives are:

1. Reduce the incidence of dementia

Research suggests that proactive evidence-based interventions focused on modifiable risk factors could reduce the risk of developing dementia and/or slow progression by between 10% and 20%.

2. Support people living with dementia and their family / whānau care partners to live well

Current services are woefully inadequate. Enhancing them would greatly improve the quality of life for people living with dementia and significantly reduce the adverse impact of dementia on health system resources.

¹ Alzheimers NZ produces dementia friendly documents which is why we use size 14 font.

² Including dementia NGOs, clinicians, academics and providers.

3. Build accepting and understanding communities

Dementia/ age friendly communities would:

- greatly improve social inclusion;
- reduce stigma and isolation; and,
- make it easier for people to get the support they need.

4. Strengthen capability across the sector

The dementia sector needs consistent and equitable services of a high standard; effective leadership; and, a strong focus on capability.

The draft NZ Dementia Plan includes the *Six Simple Steps Solution* that Alzheimers NZ has promoted previously. The plan will be finalised by the end of 2019.

Urgent priorities for Budget 2020

It is the second objective (*Supporting people to live well*), that we urge Government to concentrate on in Budget 2020. What is required as a priority in that Budget is for all District Health Boards (DHBs) to commission and/or deliver equitable, tailored and quality assured support services. This includes:

1. At least 12 months post-diagnosis support to equip people to live well through services provided by the local dementia-specific NGO (indicative cost \$5 million per year).
2. Dementia navigation services for all people affected by dementia in their districts (indicative cost \$10 million per year).
3. Flexible, available and accessible respite services so care partners can take a break. The report *Respite In New Zealand: We must do better* outlines eight non-costed steps Government must take to address the problems with respite care (cost to be confirmed).

Dementia: health system changes are urgent

Dementia is a rapidly escalating health priority and is one of the 21st century's greatest health challenges. There is no treatment or cure, and none is

currently on the horizon.³ The current services are not capable of meeting the need. Those living with dementia who devised the *Dementia Declaration* did so in response to this deleterious situation.

Aotearoa is required to act on dementia as part of our commitment to the World Health Assembly *Global action plan on the public health response to dementia 2017* which prioritises improving awareness of dementia; reducing the risk of dementia; diagnosis, treatment and care; support for dementia carers; strengthening information systems for dementia; and research and innovation.

Even in the absence of this international commitment, immediate action is essential as dementia is creating major human, social, health, workforce and economic costs for New Zealand. Government must act because dementia is challenging our health system:

1. Availability of and access to services is inequitable

Access to appropriate dementia services is inequitable across specific groups such as Māori, Pasifika, ethnic minorities (particularly refugees), people living alone, and people living with young-onset dementia, deafness, intellectual disability, or neurological or psychiatric illness; and, across urban-rural and DHB boundaries.

2. Current gaps make service improvement urgent

There are gaps across the dementia journey which include:

- **Pre-diagnosis:** stigma is rife, health literacy is poor, there is no dementia prevention plan.
- **Timely diagnosis:** workforce capability to deliver diagnoses is inadequate; support and care planning is also inadequate.
- **Living well:** respite care is limited and inflexible; funded NGO-led living well programmes are urgently needed.

³ The *Lancet* "Commission on Dementia"; led by Professor Gill Livingston with contributions Claudia Cooper, Sergi Costafreda, Jonathan Huntley, Rob Howard, Naaheed Mukadam, Vasiliki Orgeta, Liz Sampson and Andrew Sommerlad, (2017).

- **Minimising symptoms:** services are limited to medical solutions and disability support.
- **Dying with dementia:** greater synergy between palliative and dementia sectors is urgently needed.

3. Dementia is an important hidden player in the wider health system

Dementia has multiple impacts in terms of acute hospital presentations, lengths of stay, failed discharges, need for aged residential care and for higher levels of that care, and health system harms, especially falls and medication harms. Dementia-associated health and social care costs almost matches the combined costs of cancer, heart disease and stroke.⁴

4. Population growth makes service development urgent

The number of New Zealanders living with dementia is growing rapidly. There were estimated to be around 62,000 New Zealanders living with dementia in 2016. This is expected to rise to 102,000 by 2030. By 2050 the number of people living with dementia is expected to have almost tripled to 170,000. Most have family/whānau also affected by the diagnosis.

Economic costs of dementia are likely to increase at an average rate of over \$250,000 per day (\$2016) between now and 2040. Dementia is the key reason people enter aged residential care, and care of older people is likely to account for 50% of DHB expenditure by 2025/6.

5. 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 will be expensive, and the system is not geared to respond.

Alzheimers NZ can help

Alzheimers NZ works at a national level to represent people living with dementia. Our focus is building a dementia friendly New Zealand by raising awareness of dementia, providing information and resources, advocating for

⁴ Luengo-Fernandez, R., et.al, (2010). Dementia 2010: The prevalence, economic cost and research funding of dementia compared with other major diseases. A report produced by the Health Economics Research Centre, University of Oxford for the Alzheimer's Research Trust. Cambridge: Alzheimer's Research Trust.

high quality services, and promoting research. Our patron is distinguished Professor Sir Richard Faull.

Our work programme focuses on four key components:

1. Strengthening the voice of people affected by dementia;
2. Supporting people affected by dementia to live well;
3. Lifting the quality of care and of support; and,
4. Building resources, readiness and capability.

Alzheimers NZ was established in 1986. Between us and our frontline member organisations we have a wealth of expertise and experience that, importantly, includes knowledge gained by working for many years with people living with and affected by dementia, including those who crafted the Dementia Declaration.

We are also well connected to dementia organisations internationally, giving us a global perspective on how other countries are dealing with the Dementia Challenge.

Our background and our networks enable us to construct and deliver meaningful, evidence-based recommendations for addressing a problem that will have significant consequences for us as a country and a community.

The best solutions are found when government and not for profits work well together. Funding remains a significant issue for non-profit organisations and has important implications for our capability, capacity and ability to innovate.

People/ families affected by dementia all rely on community and home-based services provided by Alzheimers and Dementia organisations around the country. Although recent reports estimate Government funds less than two thirds of the cost of delivering essential social services (Jenkins); in our sector, funding through DHBs only covers around 30 percent of the costs of providing those services.

Alzheimers NZ has many successes, and we work with governments of all shades. However, our resources are limited, and we do not create public policy. We are dependent on you, our politicians, to act on our recommendations and to implement them as part of public policy directives that will help support thousands of the most vulnerable Kiwis who are in desperate need.

Appendix: 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 Alzheimer's 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 whiwiringa, 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 pūaroha, 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.



Karapotingia 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.