

Briefing to the Incoming Minister November 2023

Government action needed for urgent
dementia problem



The urgent dementia health care problem in New Zealand

Dementia is a major and growing health care problem for New Zealand. It has significant consequences for individuals and families, the health system, and the economy. With no clinical breakthroughs, an ageing population, and unprecedented growth in the number of people living with dementia, this crisis has our country in its grip.

We therefore welcome the provisions in the Coalition Government to improve the lives of our seniors, particularly in the area of funding for care and dementia beds that New Zealand needs now and the future.

Our Briefing outlines three key actions by Government that would do much now to support this work and stem the worst impacts of this escalating situation.

Our **first recommendation** is that Government fully fund and implement the [Dementia Mate Wareware Action Plan](#). This evidence-based Plan provides a sustainable approach to addressing the dementia challenge and relieving the pressure on the health system.

Our **second recommendation** is that in Budget 2024, Government provide funding of \$127.3 million over the three years 2024-2026 to Alzheimers and Dementia organisations through nationally consistent contract(s) to deliver community-based services to 37,400 families.

Our **third recommendation** is that Government prioritise development of a health strategy and plan for an integrated continuum of care for older people.

These three actions will benefit the country significantly by:

- Reducing the number of people living with dementia in future.
- Providing better and more equitable support for those with dementia now.
- Relieving pressure on the health system.
- Reducing the future cost of dementia to Government.

The facts

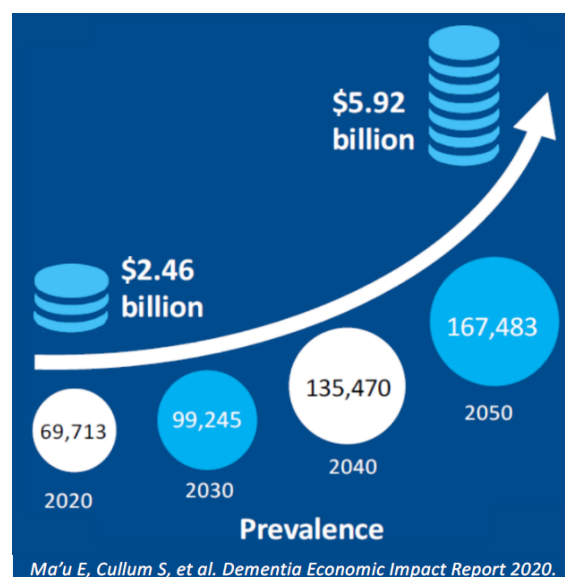
1. Rapid increase in dementia prevalence

New Zealand is only halfway towards our peak 'ageing bulge' in 2050. Our 'dementia crisis' is well and truly here, and the impacts will increase in the next 25 years.

An [estimated 170,000 people](#), or nearly three per cent of the total population, will be living with dementia by 2050, most of whom will be over 65. This represents an increase of 240 per cent from 70,000 people in 2020. Numbers will increase at a faster rate in Māori, Pacific Peoples, and Asian communities as those populations are ageing at a faster rate than the general population.

More recent research suggests that because dementia often goes unreported and undiagnosed, this figure is likely underestimated by 12-15 per cent. This means there will be 100,000 people with dementia by 2025, and 20,000 new cases per year and 220,000 people with dementia by 2050.² This is in contrast to some other western countries that are seeing a decline in the numbers of people with dementia as their cardiovascular health improves and the rates of obesity and diabetes decline.

This is creating significant challenges for our health system and demands on our economy. Dementia is a major cause of disability and loss of independence among older adults, affecting memory, cognitive abilities, and behaviour.



² Ma'u E, Estimating Dementia Incidence & Prevalence in Aotearoa. Auckland, New Zealand. 2023. Presented at the Alzheimers NZ Repositioning Dementia Conference 21 September 2023.

2. Dementia causes a big economic impact

It is estimated that dementia costs our economy \$2.5 billion in 2020, an increase of 43 per cent from \$1.7 billion in 2016. It will reach almost [\\$6 billion by 2050](#) in today's dollars if nothing changes.

3. Services are inequitable, creating pressure on the health system

Rapidly growing demand for services from local Alzheimers and Dementia organisations far outpaces Government funding for those services. As a result, only 13 per cent of people with dementia are able to get support and around 30,000 people are currently missing out on the help they need. Because services are fragmented, inconsistent, and inequitable, they result in major health inequities particularly for Māori, Pacific Peoples, and Asian communities as well as those living in rural areas.

Most people also struggle to get a diagnosis, with global research suggesting that at best only [50 per cent of people with dementia](#) receive a formal diagnosis which is a key gateway for getting help and support. These gaps will only grow as New Zealand's population continues to age.

4. Funding is adequate

Total funding for community-based dementia services is currently a very modest \$11.8 million across the 17 local Alzheimers and Dementia organisations. Only 58 per cent of which is contributed through Health New Zealand - Te Whatu Ora contracts. That means Health New Zealand - Te Whatu Ora contracts contribute around just over half of the funding used to support only 13 per cent of the people who need services.

Funding also does not cover costs. Operating costs for Alzheimers and Dementia organisations have increased 16 per cent from 2018 to 2022 while over this same time, revenue has increased by only eight per cent.

5. Families struggle to support their loved ones with dementia

The 2020 research estimates that care partners and families provided over [one million hours of unpaid care](#) to people with dementia at an estimated cost of \$1.19 billion every week. [Carers find it difficult to get help](#), are more likely to experience mental health issues, and [experience more stress](#) than those caring for people without cognitive impairment.

6. Human rights are ignored or overlooked

People with dementia are often denied the ability and the opportunity to make their own decisions. They face stigma and discrimination which creates even more barriers to accessing services and support and exercising their human rights.

Our ageing population

New Zealand's ageing population is the biggest demographic shift in decades and has implications for the economy, health, and social systems. By 2034, more than [one in five New Zealanders will be aged 65 years or over](#) or approximately 1.2 million people.

There is an urgent need for a clear health strategy and plan for an integrated continuum of care for older people. Older people are the largest users of the health system such as hospital and specialist services, primary care, and community-based support.

With the current inconsistent and inequitable funding eligibility and access arrangements, older people are falling between the gaps in the system. This results in older people experiencing more acute events and admissions to secondary services, increased lengths of stay, failed discharges, an increased need for aged residential care and/or higher levels of that care, and increased health spending.

Older people deserve to be treated with respect like everybody else. Not having access to appropriate health services has severe implications for older people in terms of their physical and mental health, their quality of life, and their enjoyment of their human rights.

“...we know that we could be doing more, we know we could be doing better, and we know we could be reaching further but at the moment we're doing the best we can. We're spreading the margarine on the toast as thin as we can to cover as many slices of bread as we can... but we could be doing a lot more.”

Manager, Alzheimers South Canterbury

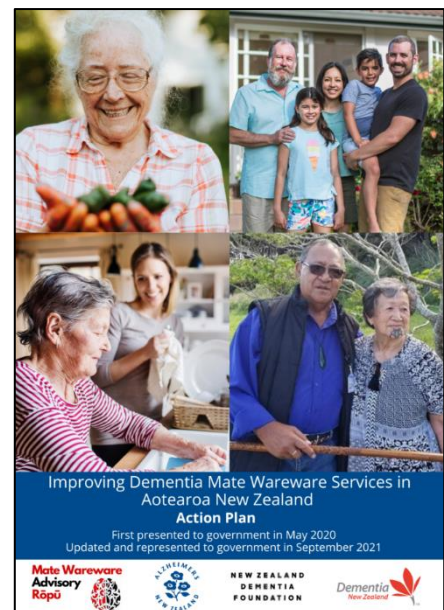
The current situation

Several important first steps have been taken to address this urgent and growing problem.

Dementia Mate Wareware Action Plan

Alzheimers NZ and Dementia NZ co-authored the [Dementia Mate Wareware Action Plan](#) (the Plan) along with the New Zealand Dementia Foundation and the Mate Wareware Advisory Rōpū. The Plan was endorsed by Cabinet in 2021 and has four priority areas:

1. Reducing the incidence of dementia.
2. Better supporting those living with it, and their care partners.
3. Building dementia friendly and inclusive communities.
4. Strengthening leadership and capability across the sector.



Implementing the Plan would meet New Zealand’s obligations under [the WHO’s Global action plan](#) on the public health response to dementia 2017 – 2025.

Budget 2022

There is currently a short-term focus on addressing the long-term challenge of dementia in New Zealand. Te Pae Tata [Interim New Zealand Health Plan 2022](#) commits to implementing the Dementia Mate Wareware Action Plan. However, Budget 2022 provides funding for only \$12 million over four years for a governance ecosystem along with funding for seven four-year initiatives spanning post-diagnostic community support and respite services.

These developments are welcome, but they do not address the significant unmet need for community-based dementia services or respond to the stark reality that core community-based services are significantly under-resourced.

Benefits of our recommendations

1. Improved community-based dementia support services

Supporting people with dementia, their family and care partners to live their best possible lives is one of four key objectives of the Plan. Actions under this objective are equitable, tailored, person-directed, person-centred, and culturally appropriate. They include post-diagnostic support, navigation, family care support, Cognitive Stimulation Therapy, and information.

Improving access to community-based dementia services will contribute to achieving equitable health outcomes for people with dementia particularly among Māori, Pacific Peoples, and rural communities.

2. Community-based dementia services provide important economic benefits

Providing support for people with dementia and their care partners in communities will have positive economic impacts such as:

- [Reducing the costs](#) of residential care, pharmaceuticals, and primary and secondary health services by enabling people with dementia to live independently for longer.
- [Increasing the productivity](#) of care partners and improving their wellbeing, by reducing stress and the burden on them, and improving access to respite and support services.
- [Increasing the wellbeing](#) of people with dementia and their care partners by promoting participation and inclusion in their communities.

Research shows that delaying entry to residential or hospital level care has a significant economic impact. The [cost benefit ratio](#) of caring for an individual living with dementia in the community compared to providing care in aged residential care is 4:1.

Community-based Alzheimers and Dementia organisations play an important role in creating positive impacts in communities by educating people about dementia and creating supportive environments for those living with dementia. They also play a critical role in addressing health inequity and protecting the rights of people with dementia and their carers.

3. Fair funding for community-based Alheimers and Dementia organisations will build a sustainable and competitive sector

Community-based Alheimers and Dementia organisations have a known and trusted brand and a strong community presence, as well as a proven history of responsive support services and innovative programmes that help people navigate the dementia journey. These local organisations have also demonstrated the capability to manage their finances prudently, including managing rising costs, through merged roles, use of volunteers, and additional fundraising.

However, our local organisations are now at breaking point with no capacity to absorb further costs. Nor can we rely on goodwill and philanthropy any longer.

Fair funding for community-based Alheimers and Dementia organisations will enable them to continue to play a lead role in localities, and in the dementia sector, in supporting new providers and services as they emerge over time.

4. Standard service contracts help ensure national consistency

Nationally consistent contracts will deliver comprehensive cost-effective services aligned with research and best practice, the Dementia Mate Wareware Action Plan, and [Pae Ora \(Healthy Futures\)](#). Using the population-based standard contracts will help Te Whatu Ora manage contracts more efficiently and ensure the equitable and sustainable services are offered consistently nationwide.

Risks of not acting on our recommendations

Without these changes dementia will continue to create growing pressure on primary and secondary health services, and aged residential care at significant cost to the overall system.

People with dementia and their families will continue to miss out on services and as a result, they will experience a faster decline of their cognitive function, more acute events, and greater risk of health system harms.

Local Alzheimers and Dementia organisations will continue to struggle to respond to the increasing demand and the inequities across the system. Some services may fail, thus reducing the capacity and capability in the sector at a time when demand is rapidly increasing.

New providers are unlikely to enter a market where contracting arrangements are neither fair nor sustainable.

These issues present significant equity challenges because failure to act on our recommendations will also harm Māori and Pacific Peoples living with dementia because they are ageing at a faster rate than the general population.

There will be little, if any, flexibility, or resilience in the sector in future to absorb unexpected external challenges and costs, such as those experienced with the COVID-19 pandemic.

Lastly, given the current workforce challenges to attract and retain staff, and the fact that staff represent the single largest cost, any further reduction in staffing, either in numbers or in skills, will further limit responsiveness to meeting demand and to extending service coverage reach across New Zealand.

Appendix 1: Who is Alzheimers NZ and Dementia NZ?

Alzheimers NZ and Dementia NZ are lead organisations in the dementia sector working collaboratively to represent people and their families living with dementia and advocate for high quality and equitable services.

Together, we provide community-based dementia services throughout New Zealand through 13 Alzheimers NZ and four Dementia NZ organisations.

Alzheimers NZ

Alzheimers NZ is a not-for-profit organisation established in 1986. We work nationally to raise awareness of dementia, deliver high-quality dementia education, advocate for more and better services, provide information, provide practical tools to support a dementia friendly New Zealand, and promote research.

People living with dementia are at the centre of everything we do. Our work is shaped by the Dementia Declaration and advice from the Alzheimers NZ Lived Experience Advisory Group.

Local Alzheimers organisations provide navigation, support, education, and information so people living with dementia can live their best possible lives with dignity.

Dementia NZ

Our vision is 'Helping people to live their best possible lives', with a focus on three priority areas, promoting brain health; providing a range of community-based services for people living with dementia, their carers and whānau; and advocacy and policy.

At the heart of what we do is the provision of quality services to support the person living with dementia and their whānau, so the person can continue to live a fulfilling life following a mate wareware-dementia diagnosis.



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.