



# **Our recommendation for Budget 2025**

Dementia is a major health and social challenge in New Zealand, affecting individuals, families, the health system, and the economy. Its already significant impacts will only get worse as our population ages.

Most people living with dementia live at home for most of their time after receiving the diagnosis. They want to remain independent and manage their health for as long as possible. But many find it hard to access the few available health services. Of the estimated 73,000 New Zealanders living with dementia in 2023, around 30,000<sup>1</sup> – about the size of a Blenheim or Queenstown – are missing out on essential community-based dementia support because these organisations are under-funded.

None of this is unexpected, ageing is the most significant risk factor for dementia, and we have long been aware of New Zealand's ageing population. The substantial impact of dementia on our health system and economy is also not surprising.

What is surprising is that 'the system 'has not adequately planned for the impact of New Zealand's ageing population, and little or no action is being taken to address the existing unmet need, or prepare for the rapid increase in need for these services that is on its way.

Funding and implementing the <u>Dementia Mate Wareware Action Plan</u>, which provides an evidence-based blueprint for Government to mitigate the impacts of the rising dementia numbers, will help you to:

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

\_

<sup>&</sup>lt;sup>1</sup> Based on the most recent estimates around 73,000 people have dementia in 2023. 9300 receive services from local Alzheimers and Dementia organisations, 26,000 are in residential care, and if 20 per cent are able to pay for their services and/or receive them from one of the pilots, there are still 30,000 not getting help. Note, more recent research suggests that report <u>underestimates prevalence by 12 to 15 per cent</u> which means these numbers likely underestimate the unmet need.

In the meantime, our recommendation for Budget 2025, should you be invited to submit a business case, includes provision for \$127.3 million over three years for Alzheimers and Dementia community-based organisations to support 37,400 families.

#### This funding will:

- Stem the immediate effects of the dementia challenge and help deliver on the Government Policy Statement on Health 2024-2027 that prioritises sustainability and quality in health services for older people.
- Support the goal of the Aged Care Services and Funding Models Review to provide services that help older people live well, age well, and have a respectful end of life in age-friendly communities.
- Help reduce the health burden in New Zealand and bridge existing gaps, allowing the core sector to focus on priorities such as digitalising the system, enhancing primary care, building more aged residential care beds.

#### The facts

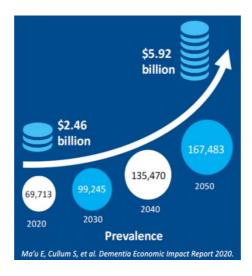
## 1. Rapid increase in dementia numbers

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

The <u>Dementia Economic Impact Report 2020 (DEIR 2020)</u> shows that by 2050, an estimated 170,000 New Zealanders, or nearly three per cent of the total population, will be living with dementia. This represents a staggering 240 per cent increase from the 2020 estimate. The numbers will increase at a faster rate among Māori, Pacific Peoples, and Asian communities because these populations are ageing at a faster rate than the general population.

Dementia often goes unreported and undiagnosed. Recent research suggests the current estimated dementia prevalence in New Zealand is likely <u>underestimated by 12-15 per cent</u>. This means there could be approximately 100,000 people living with dementia by 2025, with 20,000 new cases each year, and a projected total of 220,000 people living with dementia in New Zealand by 2050. In contrast, some western countries are seeing a decline in the numbers of people living with dementia because their cardiovascular health is improving, and rates of obesity and diabetes are declining.

This increase in the number of New Zealanders living with dementia is putting major strain on our health system and economy. Dementia is a major cause of disability and loss of independence among older adults, affecting memory, cognitive abilities, and behaviour.



#### 2. Dementia causes a big economic impact

The <u>Dementia Economic Impact Report (DEIR) 2020</u> estimated that dementia cost our economy \$2.5 billion per year in 2020, an increase of 43 per cent from \$1.7 billion per year in 2016. If nothing changes, dementia will likely cost our country nearly \$6 billion per year by 2050.

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

Rapidly growing demand for services from the 17 local Alzheimers and Dementia organisations far outpaces Government funding for those services. Around 36,500 people are not formally diagnosed<sup>2</sup> and at least 30,000 people living with dementia miss out on essential community-based dementia support<sup>1</sup>. 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.

#### 4. Funding is inadequate

Total funding for the 17 Alzheimers and Dementia organisations is currently a very modest \$11.8 million<sup>3</sup>, only 58 per cent of which is contributed through Health New Zealand - Te Whatu Ora contracts. That means these contracts contribute just over half the funding used to support under 20 per cent of those who need help.

Funding does not cover costs or meet delivery expectations within current contracts. While operating costs for Alzheimers and Dementia organisations increased 16 per cent from 2018 to 2022, revenue rose only eight per cent.

This limits their ability to absorb further costs. It also makes it harder to attract and retain a workforce, given the pay gap that exists with Health NZ - Te Whatu Ora-employed registered health professionals, and rising inflation.

Moreover, low cash reserves and inadequate infrastructure limit their ability to respond to challenges such as the COVID pandemic and hinder investments in areas such as telecommunications, IT, service improvement and innovation.

# 5. Families struggle to support their loved ones with dementia

The 2020 research estimates care partners and families provided over <u>one million</u> <u>hours of unpaid care</u> to people living with dementia every week. It equals 52.7 million hours per year, at an estimated cost of \$1.19 billion.

<sup>&</sup>lt;sup>2</sup> The <u>ADI report</u> indicates at best 50 per cent of people living with dementia do not receive a formal diagnosis. Based on this estimate, approximately 36,500 people or half of 73,000 people living with dementia in NZ (2023) are not formally diagnosed.

<sup>&</sup>lt;sup>3</sup> 'Fair funding for community-based dementia services,' a business case jointly developed by Alzheimers NZ and Dementia NZ. 2023.

Families and carers are also under greatly <u>increased stress</u> and find it difficult to get help. They experience significant health inequity and many have a <u>health</u> <u>condition, disability or mental health condition of their own</u> and often neglect their own health.

#### Recommendations

Our recommendation for the Budget 2025 is to:

1. Provide \$127.3 million over the three years for Alzheimers and Dementia community-based organisations to support 37,400 families.

We have developed a Business Case, 'Fair funding for community-based dementia services', which costs this comprehensive service. It also aligns with Pae Ora – Healthy Futures and the Dementia Mate Wareware Action Plan. The Business Case was provided to Health NZ - Te Whatu Ora, and the Minister and Associate Minister of Health in late 2023.

The Business Case model is designed to allow people with dementia to live at home independently for longer. It benefits Government by supporting a shift away from high cost residential and hospital services to more local, community-based services. Delaying entry to care has a significant economic impact - indicating a benefit cost ratio of 4, which means it is four times more cost effective to keep people at home. This reduces the impact of dementia on the health system, provides economic benefit, and helps build a sustainable sector.

The cost to deliver this Business Case model is \$11.11 per day. This compares more than favourably to the cost of aged residential care at \$373 per day and a hospital level bed at \$1,700 per day.

## The benefits of implementing our recommendations

## 1. Improved community-based dementia support services

Providing fair funding for, and improving access to, community-based dementia support services will generate a lengthy list of benefits:

- Help ensure these vital services are sustainable for the long-term.
- Contribute to achieving equitable health outcomes for people living with dementia, particularly among Māori, Pacific Peoples, and Asian communities as well as those living in rural areas.
- Ensure business continuity, enabling local organisations to build on their experience and the community's trust in them and scale up their existing community-based support services.

# 2. Community-based dementia services provide important economic benefits Providing support for people living with dementia and their care partners in communities will have positive economic impacts such as:

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

Note these benefits rely on timely diagnosis of dementia. Timely diagnosis is essential to help people living with dementia and their families understand the condition, access necessary support services, and make informed care decisions. Increased financial support allows healthcare providers to invest in training, resources, and technologies that help with early detection and accurate diagnosis.

# The impact of simply maintaining the status quo

Implementing our recommendations will create a more responsive healthcare system that addresses the fast-growing impacts of dementia and supports people with this health condition to enjoy better health and well-being.

On the other hand, simply maintaining the status quo in the dementia sector will create a number of significant and long-term consequences that could easily be avoided.

 It will make an already difficult health journey even harder for people living with dementia.

- Dementia continues to add unnecessary pressure on health services, resulting in significant and growing costs for the overall system.
- People and their families will continue to miss out on services. They may use more expensive options like rest homes and hospital care, putting those sectors under added pressure and creating additional costs.
- Local Alzheimers and Dementia organisations will continue to struggle to meet the increasing demand and address health inequities.
- New providers are unlikely to enter a market with unfair and unsustainable contracts.
- The dementia sector will lack the flexibility and resilience to deal with unexpected external challenges, such as experienced during the COVID-19 pandemic.
- Current workforce challenges in attracting and retaining staff will worsen, making it harder to meet demand and expand services.

#### Conclusion

The number of New Zealanders living with dementia is growing exponentially, and 'the system' is nowhere near prepared to handle the impacts of this health condition on our social, financial and health systems.

Government needs to act urgently, and New Zealand's 17 Alzheimers and Dementia organisations are an efficient and effective solution.

They have the frameworks, systems, experience and expertise, that if appropriately funded, would enable them to play a much larger and more strategic role in caring for older New Zealanders who would otherwise have to seek care and support in either aged care facilities or hospital-level care.

The dementia sector wants to partner and engage with Government to better manage – and reduce – the major impacts associated with the rapidly rising number of New Zealanders who are going to be affected by dementia.

## **Appendix 1: Who are 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 New Zealand**

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.

Through the Dementia NZ Affiliate network we provide quality services to support the person living with dementia and their whānau, so the person can continue to live a fulfilling life following a dementia diagnosis. To achieve this goal, Affiliates employ skilled registered health professionals and support staff.



# A dementia friendly New Zealand Aotearoa He aro nui ki te hunga mate wareware

alzheimers.org.nz

04 387 8264 Level 1, 15 Dixon St, Te Aro Wellington 6011

admin@alzheimers.org.nz

Charity registration CC 21026



#### Helping people to live their best possible lives

dementia.nz

0800 444 776

Dementia New Zealand operates nationally using a virtual office system

info@dementia.nz

Charity registration CC 54078

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.