

Briefing to Incoming Minister 2023

Government action needed for
dementia mate wareware crisis



Dementia care in Aotearoa New Zealand: another looming health crisis

Aotearoa New Zealand faces another looming health crisis. Government knows about it but has been extremely slow to act. This health crisis centres on the rapidly growing prevalence of dementia mate wareware, and the totally inadequate Government support/funding for the dementia mate wareware sector over many years.

There is no treatment or cure for dementia mate wareware.

It is such a global health threat the World Health Organization produced a [report](#) urging Governments around the world to have a plan for dealing with it.

By 2050, the number of New Zealanders living with dementia mate wareware will raise to 170,000 and it will cost the country nearly \$6 billion a year. It will hit our Māori, Pacific, and Asian communities hardest, creating major health equity issues.

But we can stem the worst impacts. To do that, Government must act now and do these two things urgently:

- Implement and fund the Dementia Mate Wareware Action Plan (the Plan) to reduce the rapidly growing incidence of dementia mate wareware among New Zealanders and provide better support for those diagnosed with the condition.
- Provide \$9 million per year to stabilise community dementia mate wareware support services. Many of these services are on the brink of financial collapse.

Our thoughts are with people affected by Cyclone Gabrielle and the flooding in Auckland. We are especially concerned for people with dementia mate wareware.

For people with dementia mate wareware, natural disasters can be confusing and distressing, and add significantly more anxiety to an already stressful health situation. As an example, [people with dementia whose homes were damaged](#) are likely to experience more severe declines in cognitive functioning as a result.

The recent natural disasters have also totally disrupted the community-based dementia mate wareware services that so many Kiwis living with this condition rely on every day. Those services, which were already underfunded and under extreme pressure, provide a much-needed source of local support to some of our most vulnerable citizens.

So many lives have been upended by these tragic events. But the New Zealanders living with dementia mate wareware are often among those who have been most severely affected. And they need our help more now than ever.

The current situation

Several important first steps in addressing this big and growing problem have been made in the past eighteen months. But there is so much more that is desperately needed.

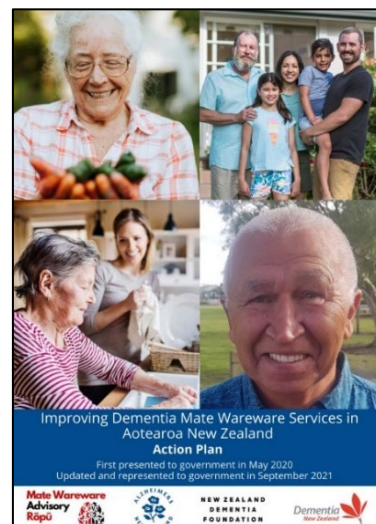
“ ... we know that we could be doing more, we know we could be doing better, and we know we could be reaching further but at the moment we’re doing the best we can. We’re spreading the margarine on the toast as thin as we can to cover as many slices of bread as we can ... but we could be doing a lot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

Manager, Alzheimers South Canterbury

Dementia Mate Wareware Action Plan

Alzheimers NZ co-authored [The Dementia Mate Wareware Action Plan](#) which was endorsed by Cabinet in 2021. The Plan has four priority areas:

- Reducing the incidence of dementia mate wareware.
- Better supporting those living with it, and their care partners.
- Building dementia mate wareware friendly and inclusive communities.
- Strengthening leadership and capability across the sector.



Implementation of the Plan would meet obligations for Aotearoa under [the Global action plan on the public health response to dementia 2017 – 2025](#). While the Plan received Cabinet endorsement, Government has yet to fully implement or fund it. Tens of thousands of New Zealanders have a reduced quality of life as a direct result.

Budget 2022

Budget 2022 provided \$12 million of funding over four years to undertake four post-diagnostic support trials, fund dementia mate wareware navigators, and provide some respite for carers.

The Dementia Mate Wareware Governance Ecosystem – Te Pūnaha Mana Whakahaere mō te Mate Wareware

The [Dementia Mate Wareware Leadership and Advisory Group](#) - Te Whakaruruhau mō te Mate Wareware and the Dementia Mate Wareware Network - Te Tūhononga mō te Mate Wareware have been established to provide advice to Government about future care and support for people and whānau with dementia mate wareware. They are now considering draft advice on the Budget 2022 dementia mate wareware projects.

Community support services on brink of collapse

In its Budget 2022 advice to Government, Alzheimers NZ called for the urgent provision of \$9 million per year to prop-up massively under-funded community dementia care services. Right now, these services, which support tens of thousands of Kiwis, are inadequate and under immediate financial threat.

These organisations deliver essential services. Referral to them is a core part of each former DHB's Cognitive Impairment pathway. But on average, Government funding for these services is just \$1.10 per person per year.

As a result of skyrocketing demand and woeful funding many of these services have already reduced the support they provide. Some face financial collapse. [Published data](#) reveals as many as 27,000 New Zealanders with dementia care services cannot get the community support they need and that will only get worse as our population continues to age.

The collapse of these services is not a long run issue, it is happening now. While the funding requirement is modest, the impact on thousands of older and vulnerable Kiwis is tremendous.

“We’re trying to be as sustainable as we can but things are looking grim, really ... so if we’re in a crisis now – what’s that going to look like down the track? Growth is increasing, funding’s not, so that gap’s just getting bigger and bigger. Things are looking pretty tough for financial stability and carrying on, and that’s a real risk for our local community cause we’re it.”
Manager, Alzheimers South Canterbury

Background and key facts about dementia mate wareware in Aotearoa

1. Rapid increase of the number of people living with dementia mate wareware

The [Dementia Economic Impact Report 2020](#) (DEIR 2020) estimated the number of Kiwis with dementia mate wareware grew by nearly 12 percent to 70,000 people in 2020 - from approximately 62,000 people in 2016. The risk of dementia mate wareware increases with age. The number of people living with dementia mate wareware increase at a rapid rate among Māori, Pacific, and Asian populations.

Dementia mate wareware impacts more women than men, about 30 percent higher. 90 percent of people living with dementia mate wareware are over 65 with Alzheimer's disease is the most common form, affecting around two-thirds of people living with dementia mate wareware.

2. Dementia mate wareware causes a big economic impact

The [DEIR 2020](#) shows that dementia mate wareware cost our economy \$2.5 billion in 2020. This is an increase of 43 percent between 2016 and 2020. It is likely to reach almost \$6 billion by 2050 in today's dollars. Aged residential care accounts for half of the economic cost of dementia mate wareware borne by government (\$1.21 billion).

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

Demand for community-based dementia mate wareware services has far outpaced Government funding. As a result, Māori, Pacific peoples, cultural minorities, people with young onset, people with disabilities, and people living in rural areas face inequitable services.

Without help from community services, people with dementia mate wareware are likely to experience a faster decline of their cognitive function, more acute events and admissions to secondary services, increased lengths of stay, failed discharges, increased need for aged residential care and for higher levels of that care, and health system harms, especially falls and medication harms.

Lacking access to these services also makes people living with dementia more aware seek support in public hospitals. This exacerbates hospital wait lists, compounding already significant problems for the wider health system. Investing in community services would alleviate these issues.

4. Whānau struggle to support their loved ones with dementia more aware

People living with dementia more aware and their whānau face significant financial impacts from the increased cost of living, health and social care, and from reduction or loss of income. Care partners provide over [one million hours of unpaid](#) care every week and [about one million whānau carers are struggling](#), under pressure and do not feel valued. Respite care is also limited and inflexible, adding to care partner stress.

5. Human rights are ignored or overlooked

People living with dementia more aware are often denied the ability or the opportunity to make their own decisions. They face considerable stigma and discrimination which creates even more barriers to accessing services and support. There is a limited approach to establishing dementia more aware and age friendly communities.

6. Covid-19

We are only now seeing the impact of withdrawal of services during Covid-19 and since due to staff shortages. People living with dementia more aware were isolated and lonely, many experienced more rapid cognitive decline than they would have otherwise, and carers were unsupported and stressed.

7. Cyclone Gabrielle and natural disasters

Natural disasters are distressing for anyone, but they are particularly daunting for people with dementia more aware. They are already struggling with their daily lives and vulnerable, and the recent events may have forced them to evacuate and found themselves homeless. [People with dementia whose homes were more damaged](#) experiencing more severe declines in cognitive functioning.



Appendix 1: Who is Alzheimers NZ?

Alzheimers NZ is the lead organisation at a national level representing people and whānau living with dementia mate wareware.

People living with dementia mate wareware are at the centre of everything we do – our work is shaped by [the Dementia Declaration](#) and advice from the Alzheimers NZ Advisory Group.

Our role includes raising awareness of dementia mate wareware, providing information and resources, advocating for high quality services, providing practical tools to support a dementia mate wareware friendly Aotearoa New Zealand, and promoting research.

Alzheimers NZ was established in 1986. We support local Alzheimers NZ organisations throughout Aotearoa 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 mate wareware. These services include but are not limited to:

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

We can't do it alone

Partnership is at the heart of everything we do. We're members of:

- New Zealand Carers' Alliance (Chief Executive Catherine Hall is Co-Chair)
- Neurological Alliance (Chief Executive Catherine Hall is Chair)
- Health Coalition Aotearoa
- Federation of Primary Health
- New Zealand Coalition to End Loneliness (founding members)



A dementia friendly New Zealand Aotearoa

He aro nui ki te hunga mate wareware

www.alzheimers.org.nz

04 387 8264

Level 1, 15 Dixon St, Te Aro, Wellington 6011

admin@alzheimers.org.nz

Charity registration number CC 21026

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