



Presbyterian Support
New Zealand

Position on Dementia / Mate wareware

Executive Summary

Presbyterian Support calls for the following actions:

- Increase existing supports and provide new ones for carers. This includes making respite funding more flexible across the diverse population of carers and investing more into respite to improve carer wellbeing.
- Provide more effective Dementia / Mate wareware navigation support services, with specific attention paid to adequately supporting older people who live alone.
- Improve people's access to appropriate Primary Care support. We must enable greater access to diagnostic testing, particularly older Māori and Pacific peoples, and provide post-diagnosis support to equip people to live their best possible lives.
- Strengthen leadership and partnership capability across the sector and ensure Māori leadership is engaged in the design and implementation of Mate wareware funding models and services.
- Through strengthened leadership and partnership, improve the design, quality, and availability of existing community and home-based services.
- Ensure that information about Dementia / Mate wareware is freely available, in accessible formats, and accessible in Te Reo Māori.
- Improve understanding of Mate wareware and ageing in Māori communities, supporting Māori initiatives, and in Pacific communities, supporting Pacific initiatives.
- Develop and implement a workforce strategy that addresses both the immediate capacity and capability issues, and the long-term growth needs of the aged care sector, to adequately serve all those we anticipate will develop Dementia.
- Implement the advanced care planning strategy which encourages people and health professionals to talk about advance care plans for health and end of life cares.
- Review and prioritise Mate wareware service planning inside the Healthy Ageing Strategy 2016,¹ He Oranga Kaumatua 2019-2034,² with the actions from "Improving dementia mate wareware services in Aotearoa New Zealand: Action Plan" 2021.³

We also encourage the government through their contact with local councils to:

- Consider how communities support people to plan for their later years to achieve greater personal control over their Dementia journey.
- Continue to raise awareness of the impact of loneliness and social isolation on older people.
- Through strengthened leadership and partnership, design future community environments that make it easy for older people everywhere to be socially connected and remain within their homes and preferred environments for longer.

¹ Healthy Ageing Strategy, Ministry of Health, 2016.

² Better Later Life: He Oranga Kaumatua, 2019-2034, A strategy for making the future better for New Zealanders as we age.

³ Improving Dementia Mate Wareware Services in Aotearoa New Zealand: Action Plan, Alzheimers New Zealand, Dementia New Zealand, New Zealand Dementia Foundation, Mare Wareware Advisory Rōpū, 2021

What is Dementia / Mate wareware?

Dementia is the term used commonly around the world when a person experiences a gradual loss of brain function due to physical changes in the structure of their brain.⁴ It is not a normal part of ageing but a condition that gets worse over time and is usually diagnosed only when it begins interfering with a person's ability to function in daily life. In Aotearoa New Zealand the equivalent word in Te Reo is Mate wareware. Presbyterian Support staff try to use both terms interchangeably, depending on who they're communicating with.

Dementia is caused by several different disease processes and has a range of associated risk factors. In Te Ao Māori however, Mate wareware may not be considered to be an illness or a disease but rather as part of a spiritual journey and a normal part of somebody's preparation for joining tūpuna.⁵ We hold that health staff and professionals supporting older people with dementia should adopt this cultural understanding so that they are less likely to frame the condition in a negative way for those they serve.

In Te Wai Pounamu, PSUSI host an Enliven Harakeke Club for people with Mate wareware which proves valuable both to the members and their whānau carers. The programme is run as a Day Programme and members usually attend one day a week.

"I don't need to be concerned if Harry* is OK as I know he is being well cared for," says the wife of one member who has attended now for almost a year. "Having people come into our home doesn't work for us, so the Day Programme is the perfect solution."

Carers have a chance to connect with carers of other club members and appreciate this community of support.

"It's really good to be able to talk with staff and other carers, who understand the world that is 'living with dementia'."

**The name of our Harakeke Club member has been changed for privacy*

Common types include Alzheimers Disease, Vascular Dementia, Lewy Body Dementia, Frontotemporal Dementia, Alcohol Related Dementia, and a person can have more than one type of Dementia.⁶ Healthcare and social support is usually sought once conditions affect memory, behaviour, thinking and social abilities severely enough to interfere with one's activities of daily living and social autonomy.⁷

There are large health and social costs for the person with Dementia, including lost quality of life, a shortened lifespan, and the impact their condition has on their family and friends. In a 2016 report of Manatū Hauora,⁸ Mate wareware was one of the top four leading causes of health loss for people aged over 75 years and in 2020 over one quarter of all who died in Aotearoa New Zealand had a diagnosis of dementia at the time of death.⁹ It is a significant health issue that impacts the person with Mate wareware as well as their whānau.

⁴ Manatū Hauora, 2021. <https://www.health.govt.nz/your-health/conditions-and-treatments/diseases-and-illnesses/dementia>.

⁵ <https://www.matewareware.co.nz/maori-understanding>

⁶ Manatū Hauora, 2021. <https://www.health.govt.nz/your-health/conditions-and-treatments/diseases-and-illnesses/dementia>.

⁷ World Alzheimers report, 2021: Journey through the diagnosis of dementia, Alzheimer's Disease International. <https://www.alzint.org/resource/world-alzheimer-report-2021/>

⁸ Manatū Hauora / Ministry of Health, 2016. Health Loss in New Zealand 1990 – 2013: a report from the New Zealand Burden of Diseases, Injuries and Risk Factors Study. Published 4 August 2016

<https://www.health.govt.nz/publication/health-loss-new-zealand-1990-2013>

⁹ University of Auckland, 2021. Dementia Economic Impact Report 2020. <https://cdn.alzheimers.org.nz/wp-content/uploads/2021/09/Dementia-Economic-Impact-Report-2020.pdf>

At Presbyterian Support our Enliven services provide a range of Aged Residential Care (ARC) and community supports across New Zealand, including the provision of social programs and care for individuals with Mate wareware. As such, we have an extensive appreciation of the impact of Dementia on individuals, whānau and communities.

Our view is that not enough is being invested by government nor provided in communities across Aotearoa New Zealand, for those experiencing this life altering condition. We see little collaboration between the Aged Care Sector, Community Supports and government to ensure equitable continuity of care for those experiencing Mate wareware. Some navigation and support services are presently provided by charitable and not-for-profit organizations, but this is often without sufficient funding and support to truly meet the health needs continuum for all people with Dementia and their families.

In Tauranga, PSN has introduced Enliven Plus, a Dementia-specific service, that amongst other things provides navigation and in-home education for the whānau of those with Mate wareware as well as a high level of social connectedness that opens up the world and reduces stigma. Respite for the family carer is a key component of the PSN Enliven Plus service, but as this programme does not fit the current funding model it has to be a private service and therefore limited only to those who can afford it.

More attention needs to be paid by our leaders to the fact that almost 1 in 10 (9%) of all diagnosed with Dementia are under 65.¹⁰ Given that our population is ageing and the rates of Dementia are growing rapidly, we hold that there should be more proactive collaboration with our Sector and greater investment from our government to adequately meet the Mate wareware needs of all communities across Aotearoa equitably.

Inequalities in prevalence and Te Tiriti o Waitangi

Mate wareware is more common in people over 65 but research indicates Māori and Pacific peoples show symptoms at a younger age than non-Māori/Pacific, and Pacific peoples present with more advanced symptoms when they first seek a memory service.¹¹ In 2020, Dementia was estimated to affect almost 70,000 people in Aotearoa New Zealand. Most of these people were over 65 years old, with a prevalence among over-65's of 8%.¹² Māori and Pacific people however have higher rates of diagnosed Mate wareware than other groups in Aotearoa.¹³

Longer life expectancy means that more people will be at risk of Dementia during their lifetime. By 2050, an estimated 10.8% of over-65's will be diagnosed with Mate wareware – the increase being due to more people living into late old age. By 2050 Aotearoa NZ will have over 165,000 people living with Dementia.¹⁴

The Crown has an obligation to protect Māori as a Tiriti partner and has a direct role to play in delivering targeted and robust solutions to hauora Māori. To date however the expertise and

¹⁰ University of Auckland, 2021. Dementia Economic Impact Report 2020. <https://cdn.alzheimers.org.nz/wp-content/uploads/2021/09/Dementia-Economic-Impact-Report-2020.pdf>

¹¹ Callum, S. et al., 2018. Do community-dwelling Māori and Pacific peoples present with dementia at a younger age and at a later stage compared with NZ Europeans? International Journal of Geriatric Psychiatry, Volume 33, Issue 8 pp1098-1104. <https://onlinelibrary.wiley.com/doi/abs/10.1002/gps.4898>

¹² University of Auckland, 2021. Dementia Economic Impact Report 2020. <https://cdn.alzheimers.org.nz/wp-content/uploads/2021/09/Dementia-Economic-Impact-Report-2020.pdf>

¹³ Chueng, G. et al., 2022. Dementia prevalence estimation among the main ethnic groups in New Zealand: a population-based descriptive study of routinely collected health data. BMJ Open, doi:10.1136/bmjopen-2022-062304.

¹⁴ University of Auckland, 2021. Dementia Economic Impact Report 2020. <https://cdn.alzheimers.org.nz/wp-content/uploads/2021/09/Dementia-Economic-Impact-Report-2020.pdf>

strategic focus for Māori wareware has been led outside government, such as the Māori wareware advisory group to Alzheimers NZ, Dementia NZ and the New Zealand Dementia Foundation. We support a Sector-led approach, particularly when its prioritisation of adequate engagement with Māori researchers and specialists is strong. Nevertheless, as the service-population grows due to our ageing population and due to the insufficiency of government funding for Aged Care generally, the focus necessary in meeting Te Tiriti expectations for older Māori is often unable to be met by providers.

Māori and Pacific kaumatua and their whānau therefore struggle to find services that meet their needs. Māori people aged over 65 are underrepresented in ARC facilities and a major reason for this is a perceived lack of Kaupapa Māori services and Māori cultural norms in ARC.¹⁵ The same principle

Together with whānau our Enliven services face an array of challenges meeting care needs for people with Māori wareware. The most significant challenges are primary stressors and the level of cognitive decline.

Primary stressors can include behavior problems, which can lead to burden, depressive symptoms and physical health issues for the caregiver. These behavioral problems can range from day and nighttime wandering to emotional outbursts and inappropriate behavior. The level of cognitive decline has a significant impact on both caregivers and provider capacity. During the moderately severe cognitive decline stage (stage 5) for example, people require assistance with activities of daily living, and memory will often be noticeably impaired.

Unfortunately, there are often no affordable services available to support this level of care where people are located.

It may be necessary for someone to leave their home but for providers it is crucial to ensure that the needs of other residents are also met and that they are protected from any potential harm to them and staff. Many of our facilities currently face staff shortages and so we must carefully evaluate the risks associated with accepting residents and balance that with the risk of harm that might be caused to staff and other residents in the facility.

applies to non-residential community services. Many services for people with Dementia may not be culturally appropriate, nor appreciative of the needs of Māori, nor other ethnic populations of Aotearoa.

The number of Māori people over the age of 65 has grown by 109% and population projections suggest that from 2013 to 2038, the absolute number of Māori in the 65+ age group will increase by over 350%, from 34,500 to 125,900 people.¹⁶ It is important that this rapidly growing group can access the services they need. This is also important for the families of older people who need support. As the care for older Māori and Pacific people often falls to whānau members, it is essential that families can access culturally appropriate community services for Māori wareware. The burden of unpaid care is far higher in Māori (11% higher than European), Pacific (12% higher) and Asian whānau carers (21% higher).¹⁷

As providers we want to get this right. We understand the need to pay particular attention to the interests of Māori and to be guided by Te Tiriti o Waitangi as a founding document of our country. Government's current Healthy Ageing Strategy too, recognizes that inequities in health need to be reduced, and in particular for Māori and Pacific people. However, community services struggle to meet Te Tiriti expectations due to insufficient funding from government. We need financial backing that recognizes not only the challenging journey of Dementia, but also the need for services that allow

¹⁵ Ibid

¹⁶ Older Māori and aged residential care in Aotearoa. Hikaka, J., & Kerse, N., 2021. Report prepared for Health Quality & Safety Commission New Zealand.

¹⁷ University of Auckland, 2021. Dementia Economic Impact Report 2020. <https://cdn.alzheimers.org.nz/wp-content/uploads/2021/09/Dementia-Economic-Impact-Report-2020.pdf>

Māori kaumatua and their whanau to “see, hear and feel the presence of Māori cultural values and practices”.¹⁸

Introducing Māori cultural values and practices into services that are currently monocultural / Pakeha-centric, and embedding these effectively, requires the investment of time and resources. We need a Māori health action plan for Mate wareware, adequately supported and funded by the government.

The Impact of Dementia / Mate wareware

As we age, we should maintain a sense of purpose and value, adapting to change, and participating in our communities. We should all feel and be safe, living free from abuse, neglect, stigma and discrimination. This applies to people with Dementia too. Maximising the health, independence and wellbeing of people with Mate wareware is a key part of ensuring their quality of life.

Families instead end up paying the economic, social and mental health consequences of insufficient and inadequate health services for their older family members. Family (unpaid) carers of those with Dementia experience lower employment rates than the general population: 30% of carers in the 2022 Carers Report Aotearoa indicated they were unable to undertake paid work due to their caring responsibilities, and more than 50% gave up paid employment or reduced working hours to enable them to provide care.¹⁹ This has many flow-on impacts inside households, including the risk of abuse and neglect and higher levels of stress when meeting the rising costs of living.

In 2020 there were over 1 million hours of unpaid care provided to people with dementia, primarily provided by family, which would cost \$1.19 billion if it were provided by paid carers.²⁰

There are large health and social costs of course for the person with Mate wareware also, including lost quality of life, a shortened lifespan, and the stress caused when considering the impact their condition has on their family and friends. In 2016 the Ministry of Health reported Dementia was one of the top four leading causes of health loss for people aged over 75 years.²¹

People living alone.

At our Enliven services we see how older people living alone who develop Dementia are especially vulnerable and in need of support.²² It is estimated that by 2034 people aged 65+ will make up 55%

There is limited availability of training for general health care professionals in the care of Mate wareware. Historically speaking the workforce has been under-appreciated, resulting in insufficient investment in long-term care services and support. This leaves a shortage of well-trained direct care workers. These challenges need to be tackled to improve the overall quality of healthcare services and support for people with Dementia.

There is an inadequate supply of specialists who possess the necessary expertise to provide proper treatment and train the next generation of practitioners. There is also limited availability of training for face-to-face general healthcare professional in the best practices of Dementia care. We are left with a shortage of well-trained direct care workers, which leads to not enough providers being trained for the growing number of patients.

Misdiagnosis and mistreatment become significant issues in aged care, particularly in rural communities where a lack of healthcare workers leads to under-served portions of the population.

¹⁸ Hikaka & Kerse, 2021. Report prepared for Health Quality & Safety Commission New Zealand.

¹⁹ The State of Caring in Aotearoa: A report for Carers NZ and the Carers Alliance, 2022.

²⁰ University of Auckland, 2021. Dementia Economic Impact Report 2020. <https://cdn.alzheimers.org.nz/wp-content/uploads/2021/09/Dementia-Economic-Impact-Report-2020.pdf>

²¹ Manatū Hauora / Ministry of Health, 2016. Health Loss in New Zealand 1990 – 2013

²² In one regional example, one third of PSN’s Enliven Plus clients live alone.

of all people living alone.²³ People are having fewer children;²⁴ and it is becoming more common for families to be geographically dispersed, rather than living close to elderly relatives. This means that with every generation, more older people will be living alone without the option of support from nearby whānau. A healthy ageing strategy needs to consider specifically how government is to adequately support older people living alone who develop Mate wareware.

Whānau

In our experience family members want to be actively part of the care of a loved one with Dementia. When there is inadequate community support however, these carers may suffer negative health/injury consequences of their own and struggle financially as a result.

Direct care workers have become essential in Dementia care as they are well-positioned to implement non-pharmacologic interventions for behavioral and psychological symptoms. They also educate and support whānau carers and observe and record changes to clinical team members. Compensation, opportunity, and support are some of the factors that attract and retain direct care workers in the field, including good wages, benefits, fulltime schedules with no mandatory overtime, excellent training, participation in decision-making, career advancement, supportive supervisors and resources to resolve barriers to work. To improve the care for people with Mate wareware from at-risk populations, several changes to healthcare practice are necessary. An interpersonal team with Dementia care expertise, along with a family/whānau liaison, can better meet the complex medical, psychological and social needs of these patients than a single practitioner working in silo. Family caregivers should also be viewed as an essential member of the caregiving team.

Carers of family members with Mate wareware report experiencing loneliness, depression and anxiety at significantly higher levels than the general population, according to the 2022 Carers Report Aotearoa. Carers need respite to be able to care for themselves, 'recharge' and connect with other people. Lack of in-home and care-based respite is a leading problem within Dementia services, with 90% of carers indicating in 2022 they had much less access to respite than was available to them prior to the commencement of the Covid pandemic.²⁵

The NZACA indicates a shortage of aged care beds presently, and a need to grow by more than a third over the next 10 years. These figures only suggest the situation will continue to compound as the population in Aotearoa continues to age. More needs to be done to listen to older people and their support carers about how and where they want to be cared for, with more than lip-service paid to a holistic approach inside our aged care and home-based systems.

Actions to date

Our position is that Aotearoa New Zealand needs a Healthy Ageing Strategy that has specific focus on Dementia / Mate wareware, through the lens of Te Tiriti o Waitangi. This is already an urgent need, but it will become increasingly important as more of our population live into late old age and become vulnerable to the condition and a growing proportion of them Māori. A clear strategy implemented through specific actions is crucial to protect the welfare of everyone in Aotearoa's society as we age.

²³ Better Later Life: He Oranga Kaumatua, 2019-2034, A strategy for making the future better for New Zealanders as we age.

²⁴ New Zealand's birth rate lowest on record, deaths drop in 2020: Stats NZ 2021.

<https://www.stats.govt.nz/news/new-zealands-birth-rate-lowest-on-record-deaths-drop-in-2020>

²⁵ The State of Caring in Aotearoa: A report for Carers NZ and the Carers Alliance, 2022.

The government is aware of the impact of Dementia but is still to undertake a NZ prevalence study, nor hold national data on New Zealanders diagnosed with dementia, using overseas data to estimate prevalence in NZ.²⁶ Government accepts that Mate wareware is under-recognised and underdiagnosed,²⁷ but leaves the current and projected numbers underestimating Aotearoa's actual numbers. In 2014 the government recognised that the population of older people in Aotearoa was growing, and along with this, the increasing numbers experiencing Mate wareware. Outlined in its Ministry of Health paper 'Improving the lives of people with dementia',²⁸ intentions for the three years to 2017 specifically promised to:

- implement a nationally consistent approach to dementia care.
- increase dementia awareness.
- reduce the risk of dementia.
- increase access to a timely diagnosis of dementia.
- provide navigation of services and increase the quality of information and education.
- increase the ability of people with dementia to remain living at home.
- increase the quality of information and education for the workforce.
- develop dementia-friendly health and social support services.
- provide respectful and supportive end-of-life care.

We are grateful that reviews during this time resulted in the establishment of an Aged Care Commissioner to provide oversight of the Sector. This improved confidence and quality in aged care services and helped to protect the rights of those experiencing life changing conditions. The association of this role with the Health and Disability Commission, enabling independence from government, is also appreciated. The Commissioner's support for the Dementia Mate Wareware Action Plan as launched by Alzheimers NZ is also valued.

It is important to note, however, that a number of the promises made, as well as actions specified in the supported Dementia Mate Wareware Action Plan, continue to go unfulfilled. We acknowledge that Covid-19 has impacted the focus and financial aspirations of government. However, the impact of Covid-19 on our older people through isolation, reduction of services, reduced access to diagnosis, a lack of respite for short- and long-term relief, and the loss of some services completely, continues to compound the issues faced in our older population.

Conclusion

An ageing population means that maximising the health, independence, and wellbeing of people with Dementia is a key part of ensuring the good health of all New Zealanders. We have so much more to do to make this a reality.

We call on government to provide adequate financial support to ensure the safety and wellbeing of those experiencing dementia, and the Sector's capability to partner effectively with their whānau to provide care that meets all their cultural needs.

²⁶ Living with Dementia in Aotearoa (LiDiA): A Feasibility Study for a Dementia Prevalence Study in Māori and Non-Māori Living in New Zealand. Martinez-Ruiz, et al., 2023.

<https://journals.sagepub.com/doi/10.1177/14713012231173012>

²⁷ Chueng, G. et al., 2022. Dementia prevalence estimation among the main ethnic groups in New Zealand: a population-based descriptive study of routinely collected health data. *BMJ Open*, doi:10.1136/bmjopen-2022-062304.

²⁸ Improving the lives of people with dementia: Ministry of Health, 2014