HEALTH & DISABILITY COMMISSIONER
TE TOIHAU HAUORA, HAUĀTANGA

August 19, 2024

Hon Sam Uffindell MP
Chair
Health Select Committee
By email: health@parliament.govt.nz

Aged Care Commissioner Submission on the inquiry into the aged care sector's current and future capacity to provide support services for people experiencing neurological cognitive disorders

Tēnā koe Minister Uffindell,

Thank you for inviting comment on the inquiry into the aged care sector's current and future capacity to provide support services for people experiencing neurological cognitive disorders.

As Aged Care Commissioner, I advocate for quality improvement in health and disability services for older people, provide greater oversight of sector and system reforms and support the Government's commitment to Te Tiriti o Waitangi. My role includes assisting older people and whānau to have more confidence in the quality and safety of health and disability services and to highlight issues and improvements, including for people with cognitive conditions. As Deputy Commissioner to the Health and Disability Commissioner, I am a statutory decision-maker on complaints (including formal investigations) about care provided to older people, and whether their rights have been breached under the Code of Health and Disability Services Consumers' Rights (the Code).

I welcome the Health Select Committee's focus on people with neurological cognitive conditions, including dementia mate wareware. This is a focus of my recent report, Amplifying the Voices of Older People Across Aotearoa New Zealand (March 2024). My report outlined twenty recommendations, including a call to review the: prevention, diagnosis and treatment of dementia mate wareware and cognitive conditions; funding model for services across the continuum of care for priority populations, including people with dementia mate wareware, to ensure there is sustainable and accessible, quality aged care services available into the future.

Submission

I have summarised some of the key findings from my report, as they relate to your stated terms of reference, for your consideration:

1. Appropriate services for people with neurological cognitive disorders across the care continuum including from home and community care to residential care, to palliative care.

Planning for our rapidly ageing population, with an increasingly complex health and disability profile and ethnic/cultural demographic diversity, includes preparing our health and disability system for a rising prevalence of cognitive conditions. Four out of five people in New Zealand know or have known someone with dementia mate wareware[1] and dementia mate wareware impacts approximately 30% more women than men.

There is a need for a targeted, resourced strategy and action plan to deliver health and disability services for older people across an integrated continuum of care with a focus on neurological cognitive conditions.[2]

To ensure services are appropriately delivered, consideration should be given to:

- **Quality discharge planning by hospitals** for improved transitions of care for older people with cognitive conditions, from hospitals to home and community support (HCSS) and aged residential care (ARC). Effective discharges can be supported by hospital-based social workers specialising in cognitive health and with coordinated care plans so people can age well in place at home for as long as possible or in ARC.[3]
- **Declining ARC beds especially at the two levels of care – dementia mate wareware and specialist dementia mate wareware (psychogeriatric)**. I am concerned about the lack of dementia care beds in several regions and the impact on older people and their whānau. We urgently need a commitment to provide accessible, affordable/equitable ARC beds at all levels, especially the two levels relevant to dementia mate wareware.[4]
- **The gap in kaupapa Māori aged care services for people with dementia mate wareware and psychogeriatric care** needs to be addressed. This is a major concern especially in regions/rural areas with no dementia and psychogeriatric ARC.[5]
- **Preventative actions to reduce dementia mate wareware**, including increasing hearing aid subsidies and funding schemes (given the links between hearing loss and dementia mate wareware), and public health action including social connection programmes.[6] This includes building on the promising work under the Dementia Mate Wareware Action Plan to address loneliness, which is a risk factor for cognitive decline, including investing in locally led, kaupapa Māori and kaupapa kaumātua programmes.[7]

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[1] Alzheimers' NZ (2024). Facts and figures. Available at: https://alzheimers.org.nz/explore/facts-and-figures/#:~:text=Four%20out%20of%20five%20New,men%20%E2%80%93%20around%2030%25%20higher.
[2] Amplifying the Voices of Older People Across Aotearoa New Zealand (March 2024) Recommendation 1.
[3] Ibid. Recommendation 2.
[4] Ibid. Recommendation 6.
[5] Ibid. Recommendation 7.
[6] Ibid. Recommendation 13.
[7] Ibid. Recommendation 14

- **Minimising chemical restraint and improving quality of care and safety** for people with cognitive conditions, including early onset dementia mate wareware, who deserve safe, secure care balanced alongside dignity and human rights.
- **Support for whānau carers (both paid and unpaid),** who themselves are an ageing population with rising prevalence of cognitive conditions. There has been no update to Mahi Aroha | the New Zealand Carers' Strategy Action Plan of 2019-2023. I would hope to see an intentional and aligned focus on carer support and respite relief in:
    - Updates to Mahi Aroha.
    - The upcoming Health NZ Te Pae Tata Plan and Workforce Plans.
    - The Healthy Ageing Strategy.
    - Better Later Life Strategy and Action Plan.
    - Existing and forthcoming Pae Ora health strategies e.g. proposed strategy on mental health.

2. The funding model, amount of funding available, including best practice and international examples of funding models.

Funding models need to support person-centred service delivery, be sustainable and better reflect the actual cost of delivering quality care across the continuum of care.

I note specifically:

- HCSS and ARC urgently need sustainable funding as critical partners in the health system serving older people and to reduce pressure on hospitals.[8]
- Planning and funding need to provide for geographically equitable access to acute and long-term care that is culturally safe and community-based where possible.[9]
- Action on workforce shortages, including ensuring pay parity for HCSS and ARC staff included in the Health NZ review and other workforce and funding decisions.[10]

I would welcome consideration of funding, as aligned to the plans noted on page 2, allocated to preventative primary and community care on maintaining cognitive health, such as those in the Dementia Mate Wareware National Action Plan[11] which look to address risk factors for cognitive decline including hearing loss and loneliness.[12]

A useful example from Denmark is community funding to better equip communities to become dementia friendly, through the use of dementia friendly décor and design in ARC

[8] Ibid. Recommendation 5.
[9] Ibid. Recommendation 6.
[10] Ibid. Recommendation 5.
[11] Ibid. Recommendation 14.
[12] Ibid. Recommendation 13.

housing/assisted living facilities and hospitals, and permanently funding a national knowledge centre to expand research on dementia mate wareware.[13]

3. Resources available and the ability for the health system to provide appropriate care and what support enables 'ageing in place', including for priority populations.

At present, there is a shortage of community-based dementia mate wareware services. This means approximately 30,000 people do not get access to the level of care that they need (also reported by Alzheimers NZ).[14] Although our national health service was established with a view to address regional disparities in service delivery, I note with concern that service availability for dementia mate wareware remains variable across the country. Appropriate services for people with neurological cognitive disorders need to be available across the care continuum, including from home and community care to residential care, through to palliative care.

In order to enable people with dementia mate wareware to live safely at home for as long as possible, HCSS needs to be resourced to adequately provide the supports for daily cares, as required. People living alone or with a spouse who also has a need for health and disability services, or who live in a rural area with no dementia mate wareware services, are particularly disadvantaged. The impact of a lack of regular and trusted support is profoundly distressing, leads to a loss of dignity and can contribute to deteriorating health. Urgent consideration to address this would be welcomed and I direct you to the following report recommendations:[15]

- The need for long-term nationally consistent flexible funding models nationwide.
- Models of care and funding that support access and choice in HCSS for rural and Māori communities.
- Addressing 'age' as a cut-off point of 65, to demarcate access for disabled people as they age from disability to mainstream older people's services.
- Exploring digital technology to expand services.
- Investing in innovative models of care e.g. consistent community-based acute models of care to prevent and treat cognitive conditions.

Kaumātua and whānau Māori

Kaumātua, who hold mana within their whānau, hāpū and iwi, may find it challenging to:

- Acknowledge symptoms of dementia mate wareware.
- Be informed on cognitive/neurological health and services available.

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[13] [13] Government of Denmark, (2017). A Safe and Dignified Life with Dementia: Denmark National Action Plan 2025 – English Summary. Available at: https://www.alzheimer-europe.org/sites/default/files/2021-10/Denmark%20National%20Action%20Plan%202025%20-%20English%20Summary.pdf

[14] Alzheimers NZ UPR submission.

[15] Amplifying the Voices of Older People Across Aotearoa New Zealand (March 2024) Recommendation 16 (b-f)

- Access assessment and diagnosis.
- Get the support and education they need to enhance quality of life and wellbeing.

Of particular concern to kaumātua whom I met with, was the ability to continue to care for mokopuna and fulfil their whānau duties as intrinsic to their own health and wellbeing.

Positive ageing for kaumātua means freedom to exercise tino rangatiratanga and mana motuhake. Tino rangatiratanga is the primary way for kaumātua and Māori relationships to thrive. An example of mana motuhake is the kaumātua- and Māori-led services Taurite Tū and Kaumātua Mana Motuhake Poi[16].

I support the recommendations outlined in research commissioned by Te Tāhū Hauora | the Health Quality & Safety Commission (HQSC), affirming a need to support and adequately resource the development of kaumātua-led ARC and kaupapa Māori care models that deliver services for people with similar clinical care needs.[17] These would include consideration of the following:

- Tikanga Māori: including te reo Māori | the Māori language and Māori values, must underpin care models by involving and resourcing appropriate expertise.
- Policy: ensuring a pro-equity policy in ARC settings and monitoring ARC access and quality outcomes for Māori.
- Workforce: developing an ARC workforce to deliver culturally safe care to kaumātua that is equitably resourced and where both cultural and clinical skills are valued and remunerated appropriately.
- Commissioning and funding: ensuring flexibility in contracting ARC services so that ARC accommodates more than just clinical needs.

Pacific matua

Pacific matua play an important role in aiga/kāinga/Pacific families, in sharing beliefs, knowledge, and values, and also having a key role in raising grandchildren. Faith and religion are important aspects to consider when addressing cognitive health for Pacific peoples.

We support the need to collect more data on the health journeys of Pacific matua, including those with dementia mate wareware, as outlined in Te Mana Ola | Pacific Health Strategy under Pae Ora, as well as progressing the development of culturally safe diagnostic tools for Pacific peoples.

Culturally appropriate information and services provided in Pacific languages to support matua and their fanau to increase awareness of and access to the appropriate support for cognitive conditions would ensure that people are well informed about their health, pathways and treatment options available to them. I support workforce development plans to train

[16] Amplifying the Voices of Older People Across Aotearoa New Zealand (March 2024). Pg 27.
[17] Health Quality and Safety Commission | Te Tahū Hauora (2021) Older Māori and aged residential care in Aotearoa. Available at: https://www.hqsc.govt.nz/assets/Our-work/Improved-service-delivery/Aged-residential-care/Publications-resources/Older_Maori_and_ARC_report_Dec2021_final.pdf

more Pacific kaimahi | staff and ensure the non-Pacific workforce are trained in cultural safety.[18]

Tāngata whaikaha | disabled people

The rights, will and preferences of disabled people with dementia mate wareware under the Convention on the Rights of Persons with Disabilities and Enabling Good Lives (EGL) approach, especially those aged 50 plus in ARC homes, need to be taken into consideration.

Intellectually disabled (ID) people show much higher rates of dementia mate wareware than the general population.[19]

In addition, the average age of onset for dementia mate wareware for people with Down Syndrome occurs much earlier, in their 50s, with approximately 50% living with dementia mate wareware by the time they are 60 years of age.[20] It is estimated that up to 80% of people with Down syndrome aged 65 and older have dementia mate wareware, which is nearly six times the percentage of people aged 65 plus who do not have Down Syndrome.[21]

Tāngata whai ora | people seeking wellness

A thirty-year analysis of 1.7 million New Zealanders found that mental health conditions are an underappreciated category of modifiable risk factors for dementia mate wareware.[22] This means that people who have mental health conditions and who receive appropriate support early in the life course of their mental health condition have a lower risk of developing dementia mate wareware or other neurodegenerative conditions, and experience a better quality of life in older age than those that do not get early support. I would recommend that any future mental health strategy to be developed, consider the express needs of people with mental health conditions with a view to, including plans for reducing risk of neurological and cognitive decline through preventative/early intervention programmes and support services.

4. The process of applying for funding and care resources.

Processes of applying for funding and care must be streamlined and person-centred so they are easy to understand and accessible. I recommend consideration is given to connector/single point of contact roles located in primary care who can assist with the

[18] Amplifying the Voices of Older People Across Aotearoa New Zealand (March 2024). Recommendation 3.
[19] IHC (2024). From Data to Dignity: Health and Wellbeing Indicators for New Zealanders with Intellectual Disability. Available at: https://cdn.prod.website-files.com/628455c1cd53af649dec6493/6584cc68cbd28550e09d0397_Full_IDI%20report_final_web.pdf
[20] Dementia NZ, Down Syndrome and Dementia Factsheet. Available at: https://dementia.nz/down-syndrome-and-dementia/#:~:text=The%20average%20age%20of%20onset,and%20at%20an%20earlier%20age.
[21] McCarron, M., P. McCallion, E. Reilly, P. Dunne, R. Carroll, and N. Mulryan, A prospective 20-year longitudinal follow-up of dementia in persons with Down syndrome. *J Intellect Disabil Res*, 2017. **61**(9): p. 843-852.
[22] Richmond-Rakerd LS, D'Souza S, Milne BJ, Caspi A, Moffitt TE. Longitudinal Associations of Mental Disorders With Dementia: 30-Year Analysis of 1.7 Million New Zealand Citizens. *JAMA Psychiatry*. 2022;79(4):333–340. doi:10.1001/jamapsychiatry.2021.4377

navigation of access to appropriate funding.[23] This approach has been successful in other contexts, such as ACC Wayfinders and MSD community connectors.

Australia's aged care funding taskforce recommendations (taskforce recs) may provide useful guidance on this matter, and in particular I recommend the sections on: supporting people to age well in place (taskforce rec 1); and balancing government funding and participant contributions (taskforce recs 2-6).[24]

5. Appropriate and sustainable asset thresholds for people with neurological cognitive disorders

Whilst my role is focused on quality improvement in health and disability care for older people, the issues of most concern for older people after their health are housing security and income/cost of living.

Lack of accessible housing is a critical issue of concern for older disabled people. We know that accessibility accommodations to homes (eg rails, ramps) utilising universal design principles can delay cognitive decline, keep people safely in their homes longer and improve quality of life for disabled people as they age.[25] As such, I would recommend consideration is given to ensuring a supply of accessible housing and more timely funding is available for housing modifications to support accessibility.

6. Process for diagnosing neurological cognitive disorders and the effects of diagnoses on funding and treatment.

Dementia mate wareware remains under-recognised and under-diagnosed, despite being a common late-life neurodegenerative condition.[26] It is estimated only 20-50% of people receive a formal diagnosis.[27]Aotearoa New Zealand could adopt a similar approach to Denmark in developing a National Dementia Action Plan 2025 which aims for 80% of people with dementia mate wareware to have a diagnosis.[28]

I would like to see measurable progress on lifting diagnosis rates of people with dementia mate wareware, as well as the essential post-diagnosis funding and treatment, in order for people to age with dignity, especially in localities that currently have limited post-diagnosis services. Support for primary care to assist in timely diagnosis is essential.

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[23] Amplifying the Voices of Older People Across Aotearoa New Zealand (March 2024). Recommendation 9.
[24] Australian Government (2024) Final report of the Aged Care Taskforce.
[25] New Zealand Disability Support Network, 'Accessible housing for disabled people living in Aotearoa New Zealand- Executive Summary.' Available at: https://nzdsn.org.nz/wp-content/uploads/2022/11/20221109-Housing-paper.pdf
[26]Cheung G, To E, RiveraRodriguez C, et al. Dementia prevalence estimation among the main ethnic groups in New Zealand: a population-based descriptive study of routinely collected health data. BMJ Open 2022;12:e062304. doi:10.1136/ bmjopen-2022-062304, [Cheung et al].
[27] Alzheimers NZ, (2024), Submission to the Universal Periodic Review for New Zealand. Available at: https://cdn.alzheimers.org.nz/wp-content/uploads/2024/05/Alzheimers-NZ-submission-UPR-2024.pdf [Alzheimers' NZ UPR submission].
[28] Government of Denmark, (2017). A Safe and Dignified Life with Dementia: Denmark National Action Plan 2025 – English Summary. Available at: https://www.alzheimer-europe.org/sites/default/files/2021-10/Denmark%20National%20Action%20Plan%202025%20-%20English%20Summary.pdf

My report profiles the MANA tool launched in December 2023 as a culturally safe diagnostic tool for kaumātua and whānau Māori. To assist with increasing rates of diagnosis, support to enable MANA to be available for use nationwide would be welcomed. There are opportunities to similarly adopt culturally safe and rights based diagnostic tools for: Pacific, Asian and MELAA communities; Rainbow and takatāpui peoples; and our increasingly diverse ageing population.

7. Projections for future needs for people with neurological cognitive disorders.

More accurate projections of the future needs of people with cognitive conditions, especially dementia mate wareware, will assist with improved planning and targeting resourcing.

New Zealand research (2022) estimates that dementia prevalence is around 3.8-4.0% for people aged 60 plus, and 13.7-14.4% among those aged 80 plus[29] (the latter is the fastest-growing age group in our population).[30] These rates are higher than the Dementia Economic Impact Report 2020 which estimates 170,000 people living with dementia mate wareware by 2050, up from around 70,000 people diagnosed in 2020 at a current cost to the economy of $2.5 billion.

The Dementia Economic Impact Report states that around half of the cost to the economy of dementia mate wareware is provided by ARC and borne by the Government ($1.21 billion). The report states that by 2050, dementia mate wareware will cost our economy nearly $6bn in today's currency.[31] This cost projection is even higher if the prevalence data in the 2022 research is applied and if the 80 years plus age group continues to be the fastest growing age group in our population.[32]

The focus on ensuring that the holistic care needs for people with neurological conditions including dementia mate wareware is well planned for and resourced appropriately for the future is welcomed.

Thank you for considering the issues highlighted in this submission and I would welcome the opportunity to discuss these matters further with the Committee.

Ngā mihi,

Carolyn Cooper
Aged Care Commissioner

[29] Cheung et al.
[30] See: https://www.stats.govt.nz/information-releases/2023-census-population-counts-by-ethnic-group-age-and-maori-descent-and-dwelling-counts/.
[31] Ma'u E, et al. Dementia Economic Impact Report 2020. Auckland, New Zealand: University of Auckland. 2021.
[32] Cheung et al.