

# Dementia Mate Wareware Action Plan

2026-2031







### **Contents**

About this Plan	
The context	2
Economic challenges	2
System pressures	3
The Plan	4
Vision	5
Scope	6
Priority actions	8
Plan at a glance	11
What's behind this Plan	12
The history of this Action Plan	12
Continuing important work	14
Evidence base for this Action Plan	15
Links to other strategies and plans	17
Explanation of key terms	18

**Mate Wareware:** The authors adopted mate wareware as the preferred te reo Māori for dementia in 2020 based on the work of kaupapa Māori researchers (Dudley et al, 2019). Using this term recognises that dementia mate wareware is a health condition and not a normal part of ageing.

**Layout:** This Action Plan uses plain English and a minimum of size 14 font.

# **About this Plan**

Dementia mate wareware is not a future problem – it is happening now. The government and the health system must make important choices about how to respond. The decisions that are made in the next few years will affect people, families and whānau who live with dementia mate wareware. These decisions will also affect the whole health system and Aotearoa New Zealand's future.

Government endorsed the first Dementia Mate Wareware Action Plan (2020–2025) and the Action Plan gained wide recognition and acceptance. But today, it is even harder for people living with dementia mate wareware to get the help they need, and the number of people living with dementia mate wareware continues to grow. The first Plan's work is not complete, so this refreshed Action Plan continues the mahi.

The development of this refreshed Action Plan 2026–2031 has been led by Alzheimers New Zealand, Dementia New Zealand, the New Zealand Dementia Foundation, and the Mate Wareware Advisory Rōpū, with considerable input from across the sector. It sets out five immediate priority areas and a clear five-year roadmap for government and the health system to act. Now is the time for decisive action and we call on the government to make the funding and policy changes needed to support the growing number of New Zealanders living with dementia mate wareware.

Matthew Croucher

Chair, NZ Dementia Foundation

Frances Blyth

Chair, Dementia NZ

Cheryl Collier and

Treasure Thomas-Egglestone

Kaiwhakarite

Mate Wareware Advisory Ropū

Teresa Wall

Chair, Alzheimers NZ

L. Wah.

# The context

# **Economic challenges**

The successful implementation of this refreshed Action Plan requires sustained government investment. Its success depends on government supporting its endorsement with adequate, dedicated and sustainable funding for each priority action.

Dementia mate wareware is one of the most significant challenges of our ageing population. It has a profound impact on individuals and their families and whānau, as well as the health system and the economy. Demand for services will continue to grow as the population ages.

The number of people living with dementia mate wareware is expected to more than double, from an estimated 83,000 in 2025 to around 170,000 by 2050.<sup>1</sup> Health inequities further complicate this picture with the number of people living with dementia mate wareware projected to increase at a faster rate in Māori, Pacific peoples, and Asian communities.

The economic cost of dementia mate wareware is also growing. Currently estimated at \$2.4 billion, this figure is expected to reach almost \$6 billion (in 2020 dollars) by 2050. Delayed action will make these challenges significantly harder and more expensive to address.

Ageing remains the most significant risk factor. By 2028, it is estimated that more than one million New Zealanders will be aged 65 years and over.<sup>2</sup>

Health system planning and investments have not kept pace with the growing need. Services for people living with dementia mate wareware are under increasing strain. Current approaches are not sufficient to meet the scale of future demand. The next page shows a summary of these pressures.

<sup>1</sup> See the Dementia Economic Impact Report 2020, reference on page 15.

<sup>2</sup> See Stats NZ, reference on page 16.

# **System pressures**

### Help is hard to get

Major gaps exist across the dementia mate wareware journey. It is estimated that half of people living with dementia mate wareware have not got a diagnosis and a third of those diagnosed do not have community-based support.

Family and whānau struggle to get support, and experience greater levels of depression and poorer health than the general population.

Stigma and discrimination continue to create barriers to accessing services and support.

### Support is uneven

Māori as tangata whenua face higher risks for developing dementia mate wareware and poorer access to care.

Pacific peoples and Asian communities face barriers to accessing services while their populations are growing rapidly.

People with young onset dementia mate wareware lack age-appropriate services.

Rural communities have less access due to distance and workforce shortages.

### Health system is under pressure

Dementia mate wareware contributes to the pressure on the health system by increasing emergency presentations, lengths of stay and health system harms (such as falls, medication, and repeat admissions).

Acute hospitals often struggle to treat people living with dementia mate wareware, who often get worse during their stay and are more likely to develop delirium.

### **Demand is rising**

The number of people living with dementia mate wareware is increasing rapidly. Workforce issues in the dementia mate wareware sector also continue to worsen.

We know more about risk reduction than ever, but Aotearoa New Zealand's health system is not geared to respond.

Decades of research are starting to show promise, with disease modifying treatments and more accessible diagnostic tests closer than ever.

# The plan

### **Vision**

Dementia mate wareware is prevented as much as possible and people living with dementia mate wareware and their families and whānau get the help and support they need.

### Goal

Improve the wellbeing of people living with dementia mate wareware and their families and whānau, and decrease the impact of dementia mate wareware.

# **Purpose**

The purpose of this Action Plan is to:

- Provide a roadmap for action for government and the health system over the next five years
- Highlight the barriers to access
- Focus health system action and investment on specific evidence-based priorities that will have a material impact on the lives of people living with dementia mate wareware and their families and whānau, and the health system
- Provide a context within which primary, community, specialist, and hospital services can work together toward the same goals
- Hold decision-makers accountable for making progress on these priorities.

### **Foundations**

The refreshed Action Plan relies on these foundations being embedded across the whole health system:

- People living with dementia mate wareware have the same rights as every other person. They must be valued and treated with dignity and respect.
- People living with dementia mate wareware and their families and whānau will have access to services, no matter who they are, where they live, or what age they are.
- Services for people living with dementia mate wareware and their families and whānau will be seamless and integrated throughout their journey.
- Services for people living with dementia mate wareware, their families and whānau will model being inclusive and supportive of people living with dementia mate wareware, and challenge the stigma and discrimination associated with it.

# **Special groups**

This refreshed Action Plan continues to prioritise support for:

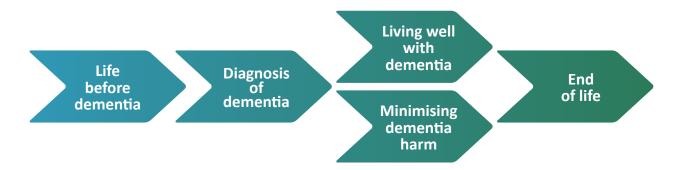
- Māori
- Pacific peoples
- people with young-onset dementia mate wareware
- those in remote and rural areas.

Other groups that also need special attention include:

- people of all cultures, including refugees and migrants
- the Rainbow community
- people with intellectual and developmental disabilities, people with severe hearing impairment, and people living with other disabilities
- people with long-term severe mental health, addictions, and neurological conditions
- people living alone
- people living in corrections facilities
- homeless people

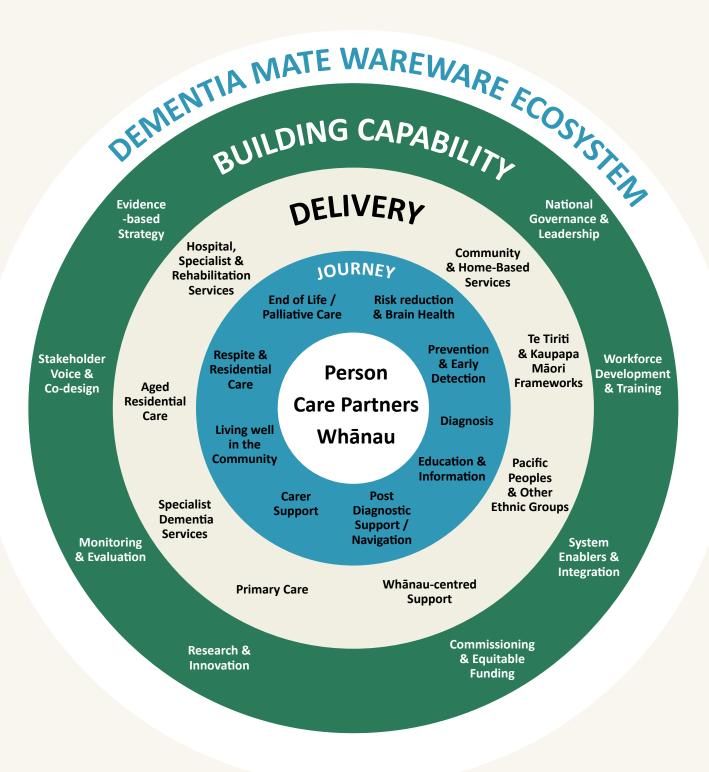
# Scope

This Action Plan covers the whole of the dementia mate wareware journey:



### **Dementia Mate Wareware Ecosystem**

The Action Plan encompasses a wide and complex environment, with each part making a valuable contribution to creating a person-, care partner-, and whānau-centred system. This plan also covers the whole of the dementia mate wareware sector including people with dementia mate wareware and their care partners, family and whānau, as well as people working in health promotion, primary care, community support, home support, aged residential care, health professionals, secondary care and specialist services, palliative care and end of life, education, research, policy-making, and government. This is shown in the following diagram.



# **Priority actions**

This Action Plan focuses on five areas where urgent and practical action is needed to respond to the dementia mate wareware challenge in Aotearoa New Zealand.





### Taking action to promote brain health

- A. Local and central governments will make decisions that help shape healthier environments by:
  - reducing the key social drivers of poor brain health, making it easier for people, families and whānau to make healthier choices.
  - supporting initiatives that build understanding of brain health.
- B. Health service and community capacity for informing and motivating individuals and whānau to make brainhealthy choices will be enhanced:
  - for people across the whole lifespan with an emphasis on modifiable risk factors.
  - with tailored solutions that meet the needs of different populations.





# Timely and accurate diagnosis and comprehensive management planning

Primary care and community services are supported by government and health agencies:

- A. Implementing the recommendations of the Dementia Mate Wareware Primary Care Working Group.
   Diagnosis and management of dementia mate wareware is part of routine practice in primary care.
- B. Facilitating consistent use of the national Cognitive Impairment Community Health Pathways.
- C. Providing equitable access to a viable primary care and community sector including aged residential care.



# Improved community dementia mate wareware support

- A. Families, whānau and care partners supporting people living with dementia mate wareware will have their contribution recognised and supported, access to respite options, and their financial status better protected.
- B. Accessible, reliable, culturally appropriate information will be available, including an emphasis on equipping care partners for their roles.
- C. People living with dementia mate wareware, their families and whānau will have access to culturally appropriate, enabling community dementia mate wareware services wherever they live. These will help people adjust, maintain function for as long as possible, and live well, with ongoing support that changes with their needs.
- D. Evidence-based, person- and whānau-centred community dementia mate wareware services that are multimodal (using multiple types of support) will be a minimum standard<sup>3</sup>.





### Formal and informal workforces are supported

- A. Accessible, best-practice information and training will be available for all health workers who work with people affected by dementia mate wareware.
- B. A Dementia Mate Wareware Workforce Plan will be developed and implemented.
- C. Pathways for accredited learning will be designed and implemented to benefit families, whānau, and care partners who want their experience to be formally recognised.
- 3 An example of an evidence-based, multimodal, person- and whānau-centred community dementia mate wareware services model that has been made available across Aotearoa New Zealand is 'Community-based dementia mate wareware services in Aotearoa New Zealand'. See reference on p15.



### **Effective governance**

- A. The national Dementia Mate Wareware Leadership and Advisory Group and Network will be structured and resourced to support the achievement of goals of the Action Plan in a nationally consistent way. This will include expert multidisciplinary governance, effective whānau and community voices, and input from people living with dementia mate wareware.
- B. Outcome measures will be designed, tested, and adopted to assess progress towards achieving the goals of the Action Plan.
- C. A national plan for collecting and sharing dementia mate wareware data in the same way across the country will be developed to measure progress, identify inequities, and plan better services.

# Plan at a glance

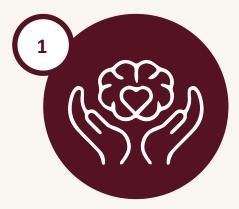
### **Vision**

Dementia mate wareware is prevented as much as possible and people living with dementia mate wareware and their families and whānau get the help and support they need.

### Goal

Improve the wellbeing of people living with dementia mate wareware and their families and whānau, and decrease the impact of dementia mate wareware.

### **Priority actions**



Taking action to promote brain health



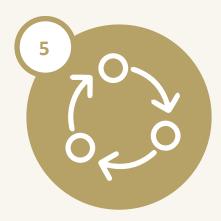
Timely and accurate diagnosis and comprehensive management planning



Improved community dementia mate wareware support



Formal and informal workforces are supported



**Effective governance** 









# What's behind this Plan?

# The history of this Action Plan

The first Dementia Mate Wareware Action Plan (2020–2025) was ambitious because dementia mate wareware poses a big challenge to Aotearoa New Zealand. It provided a roadmap for government and health system action to drive the changes needed across the dementia mate wareware sector. It was structured around four overarching objectives and 26 evidence-based practice actions. The Action Plan was informed by input from over 300 individuals and organisations.

The first Action Plan was finalised and submitted to government in May 2020, then updated a year later to strengthen its kaupapa Māori and equity provisions. In Budget 2022 the government allocated \$12 million over four years:

- to develop the Dementia Mate Wareware Network and Leadership and Advisory Group (the "ecosystem") to oversee implementation of the Action Plan, and
- to establish pilot projects spanning navigation, support and respite services for people living with dementia mate wareware at home, as well as their families and whānau.

An evaluation of the ecosystem and the pilot initiatives commenced in 2025 and is expected to inform future developments.

### Why was the Action Plan refreshed?

Since it was launched in 2020, the Action Plan has gained wide recognition and acceptance. Knowledge about what works has continued to grow, and the sector has worked collaboratively in support of the directions set in the Action Plan. However, at the same time, it has become harder for people living with dementia mate wareware to get the help they need. The size and scale of the dementia mate wareware challenge in Aotearoa New Zealand continues to grow.

Aotearoa New Zealand needs to keep building momentum for implementing the Action Plan so that the support for people living with dementia mate wareware and their families and whānau is accessible and appropriate for the country's diverse populations. The ageing population and rapidly rising numbers of people living with dementia mate wareware make this an urgent problem for government and the health system. The more support New Zealanders living with dementia mate wareware and their families and whānau receive in their communities to maintain their strength and live well, the better it will be for all.

### The five priorities

The authors of this refreshed Action Plan support the four priority actions identified by the Dementia Mate Wareware Leadership and Advisory Group and Dementia Mate Wareware Network and have added a fifth to highlight the critical need for effective governance over this next period.

# **Continuing important work**

Important work aligned with the first Action Plan (2020-2025) needs to continue.

#### **National Reviews**

Health New Zealand is reviewing how care is funded and organised, including rest homes and home-based care services. Parliament's Health Select Committee is reviewing aged care for people with neurological conditions like dementia mate wareware. Interpreting and applying these recommendations will fall under this Action Plan.

### **Supported Decision-Making**

The NZ Law Commission is reviewing the law to better support people to make their own decisions, rather than having others decide for them. The Ministry of Social Development has developed resources to support this approach. Promoting and adopting this work will be ongoing work under this Action Plan.

#### **Budget 2022 Pilot Programmes**

The government funded seven pilot programmes to test new ways to support people living with dementia mate wareware, their families and whānau, focusing on Māori, Pacific peoples, and rural communities. These pilots finish in 2026. Using these findings to improve and expand successful programmes is ongoing work under this Action Plan.

#### Research

The Impact of Dementia and Equity in Aotearoa (IDEA) research programme is studying dementia mate wareware rates in different ethnic groups and how to provide better culturally appropriate services. Other research is looking at services to promote brain health and services for Māori and other communities. These findings will help improve dementia mate wareware care.

#### **End of Life Care**

New tools and training programmes have been developed to better support people living with dementia mate wareware in their final stages of life. These include the "Three Tools" approach and specialist training for healthcare workers. Expanding the use of these tools and improving training is ongoing work under this Action Plan.

### What is this Action Plan based on?

This Plan is based on the information, evidence and research outlined in these resources:

- Alzheimer's Disease International. World Alzheimer's Reports 2021 to 2024.
- Alzheimers NZ Advisory Group. <u>Dementia Declaration: Our Lives Matters</u> (2019).
- Alzheimers NZ and Dementia NZ. <u>Community-based dementia mate</u> wareware services in Aotearoa New Zealand (2023).
- Alzheimers NZ and Dementia NZ. <u>Fair funding for community-based</u> dementia mate wareware support services (2023).
- Cheung G, To E, Rivera-Rodriguez C, Ma'u E, Chan A et al. <u>Dementia</u>
   prevalence estimation amongst the main ethnic groups in New Zealand: A population-based descriptive study of routinely collected health data. BMJ Open (2022).
- Croucher M, Chamberlain M & Gee S. <u>Post-diagnostic community services</u> for people living with dementia in Aotearoa New Zealand (2023).
- Dudley, M., Menzies, O., Elder, H., Nathan, L., Garrett, &Wilson, D. <u>Mate</u>
   Wareware: Understanding 'dementia' from a Māori perspective (2019).
- Lancet Commission on Dementia. <u>Dementia prevention, intervention, and care</u>. (2020).
- Lancet Commission on Dementia. <u>Dementia Prevention, Intervention and</u>
   Care: 2024 report of the Lancet standing Commission. (2024).
- Litmus Research for Alzheimers NZ. <u>This is our Story: A qualitative research</u> report on living with dementia (2019).
- Ma'u E, Cullum S, Cheung G, Livingston G, & Mukadam N. <u>Differences in the potential for dementia prevention between major ethnic groups within one country: A cross-sectional analysis of population attributable fraction of potentially modifiable risk factors in New Zealand. The Lancet Regional Health Western Pacific 13(100191) (2021).
  </u>
- Ma'u E, Cullum S, Mukadam N, Davis D, Rivera-Rodriguez C & Cheung
  G. Estimating the prevalence of dementia in New Zealand using capture
  recapture analysis on routinely collected health data. J Geriat Psychiat 39
  (e6131) (2024).

- Ma'u E, Cullum S, Cheung G. <u>Navigating ethnic diversity: Rethinking</u> dementia prevention in Aotearoa New Zealand. Aus NZ J Psychiat 58(5) (2024).
- New Zealand Ministry of Health. <u>New Zealand Framework for Dementia Care</u> (2013).
- New Zealand Ministry of Health. <u>HAUORA</u>: Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry (2019).
- New Zealand Ministry of Health. Whakamaua Māori Health Action plan 2020-2025 (2020).
- Organisation for Economic Co-operation and Development (OECD). <u>Care</u>
   Needed: Improving the Lives of People with Dementia (2018).
- Statistics NZ. Stats NZ official reports readily available online.
- United Nations. Convention on the Rights of Persons with a Disability (2008).
- University of Auckland for Alzheimers NZ. <u>Dementia Economic Impact Report</u> (2021).
- World Health Organization. <u>Global Action Plan on the Public Health</u> Response to Dementia (2017).

# What other strategies and plans does this Action Plan link to?

This Action Plan aligns with the <u>Pae Ora (Healthy Futures) Act 2022</u>, the <u>Government Policy Statement on Health 2024 to 2027</u>, and the <u>New Zealand Health Plan | Te Pae Waenga 2024–2027</u>. Its implementation will help Government achieve timely access to quality health care and improved quality of life for all New Zealanders.

This Action Plan also has links to, and supports, other strategies and plans, including:

- Better Later Life He Oranga Kaumātua 2019 to 2034
- The Carers' Strategy 2008 and the Carers' Strategy Action Plan (being refreshed in 2025).

Aotearoa New Zealand is not alone in facing the challenges posed by dementia mate wareware. Funding the implementation of this Action Plan would meet Aotearoa New Zealand's international obligations under the Global action plan on the public health response to dementia 2017–2025.<sup>4</sup>

<sup>4</sup> In May 2025, the World Health Assembly agreed to extend the Global Action Plan for a further six years.

# Explanation of some of the key terms used

### **Cognitive Impairment Community Health Pathways**

Standardised guidelines that help healthcare providers assess and diagnose dementia mate wareware consistently across New Zealand.

### **Community dementia mate wareware support**

Community-based services provided by organisations like Dementia NZ, Alzheimers NZ, community groups, and iwi providers. This includes information, emotional support, and activities but not hands-on home care services.

#### Dementia mate wareware

Mate wareware is a te reo Māori (Māori language) term for dementia. It recognises dementia as a health condition, not a normal part of ageing. This term was adopted following the recommendations of kaupapa Māori research by Dr Makarena Dudley and her colleagues.

# Dementia Mate Wareware Governance Ecosystem / Te Pūnaha Mana Whakahaere mō te Mate Wareware

This governance system includes the Network and the Leadership and Advisory Group that provides advice to government on implementing the Action Plan. It ensures people affected by dementia mate wareware have a voice in decision-making.

### Dementia Mate Wareware Network / Te Tühononga mõ te Mate Wareware

A large, open group that includes people living with dementia mate wareware, their families and whānau, health workers, service providers, researchers, and anyone interested in dementia mate wareware care. The Network meets regularly to share views and provide input to the Leadership and Advisory Group.

# The Dementia Mate Wareware Leadership and Advisory Group / Te Whakaruruhau mō te Mate Wareware

A smaller group of leaders from the dementia mate wareware sector and government agencies who work with the Network to provide strategic advice to government on achieving the Action Plan's priorities.

### **Home-based support services**

Services that help people living with dementia mate wareware stay in their own homes. These include personal care, help with daily tasks, medication support, and services like Meals on Wheels. They are usually funded by Health New Zealand but can also be paid for privately.

### **Primary Care Working Group**

A group of primary care leaders working with the Leadership and Advisory Group to make recommendations about supporting GPs and primary care teams in diagnosing dementia mate wareware and creating management plans.

#### Tangata whenua

Māori as the first people of Aotearoa New Zealand. The words mean 'people of the land'.

#### Whānau

A group of connected people that may include relatives and those considered family or community. Whānau are the essential building blocks of Māori society.

### **Young-onset dementia**

Dementia mate wareware that develops in people under 65 years of age, which requires different support approaches than dementia mate wareware in older adults.