Next steps for dementia mate wareware diagnosis and workforce development

Recommendations from the Dementia Mate Wareware Network / Te Tūhononga mō te Mate Wareware



Contents

This report was created for the Dementia Mate Wareware Leadership and Advisory Group / Te Whakaruruhau mō te Mate Wareware (the Leadership Group).

It provides a summary of the opinions and recommendations gathered from the Dementia Mate Wareware Network / Te Tūhononga mō te Mate Wareware (the Network) during two meetings held in March and April 2023.

This report covers the following topics:

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The Dementia Mate Wareware Network is supported by:

Te Whatu Ora Health New Zealand

Te Aka Whai Ora Māori Health Authority

The opinions expressed in this booklet are the Network's own and do not necessarily reflect the views of Te Whatu Ora or Te Aka Whai Ora.

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Introduction

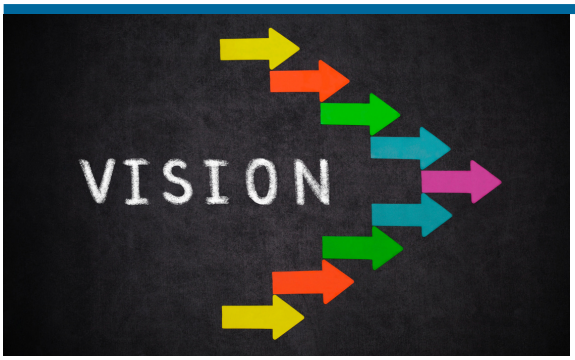
Ko tō hoe, ko taku hoe, ka tere te waka e -
With your paddle and my paddle, the waka will travel quickly



The Dementia Mate Wareware Action Plan is the vision for this mahi (work).



At the first meeting of the Dementia Mate Wareware Network / Te Tūhononga mō te Mate Wareware, we laid out our manifesto of what we want to see.



We have our vision.
Now we move to the practical steps of how to get there.

How we got here

Setting priorities

The Leadership Group met on March 2 2023. The Leadership Group started planning areas of focus for the next steps for making progress on putting the Dementia Mate Wareware Action Plan in place.

Brainstorming

The Network met on April 13. Over 80 people attended the meeting. The Network was told about the three priority areas identified by the Leadership Group for the next steps. The three areas were:

- brain health promotion,
- diagnosis, and
- workforce development.

The Network meeting broke up into smaller communities of interest groups for discussion. Each group discussed the priority area or areas they felt most relevant to them. The groups brainstormed ideas about important next steps.

Making a work plan

The Network met again on May 25. The meeting was attended by over 75 people. The Network broke into our smaller groups again. Each group reviewed their ideas from the previous meeting. The task was to narrow down the pool of ideas. Each group worked together to select one or more concrete steps that would be achievable and have the most impact.

Summarising

A spokesperson from each of the discussion groups talked about their group's 'big idea'. After the meeting, the New Zealand Dementia Foundation pulled together the main ideas to make this summary.

The areas covered

This report summarises the Network's key recommendations about achievable next steps to make progress on diagnosis and workforce development.

This report is divided into three sections: timely diagnosis, workforce development for whānau carers; and workforce development for professionals. The Network discussion emphasised that training and education should prioritise community family supporters, not just paid workers. Similar feedback was heard in consultation about the draft Action Plan. The Network groups chose not to discuss brain health promotion.

Focus	What the Action Plan says	What the Network says
Timely diagnosis	Options to improve timely and accurate diagnosis	Helping professionals to be confident, timely, and positive when making a diagnosis is a big priority
Workforce development for whānau carers	Support for whānau care partners including information, education, support, and flexible, available, and accessible respite services	We want people to be supported and to know what they are entitled to and the options that are available to them.
Professional workforce development	Strategies to improve capacity (enough skilled and qualified people) and capability (training support)	We want well-trained, person-centred professionals throughout the dementia journey

The following sections summarise the recommendations from the Network.

Make diagnosis simpler

Timely diagnosis is vital for the person with dementia mate wareware and their family. You can't plan your dementia journey without a diagnosis. Without a diagnosis of dementia, you risk having avoidable complications if you have other health problems or if you're in secondary or tertiary care. You currently can't access many services without a diagnosis. For all of those reasons, access to timely diagnosis is really important.

1

We support extending the focus to cognitive loss. This will help provide navigation and support as early as possible.

We should focus on recognising cognitive loss to trigger earlier support and encourage earlier diagnosis. For example, the InterRAI gives a cognitive loss score that could be used as a trigger for a pathway. Shifting the focus earlier to cognitive loss may help

- facilitate earlier access to support, rather than relying on the formal diagnosis
- identify people to receive navigation support to help with early diagnosis
- provide an intermediate step between suspected and confirmed younger onset diagnosis
- help GPs ease into diagnosis
- take some of the burdens off GPs by involving other disciplines

2

We should simplify processes for primary care clinicians.

One of the barriers to timely diagnosis may be the time required for health professionals. This can be a cost to the person as well.

We should explore ways to make things simpler and reduce the administration time involved. This could include improved data sharing and data capture capabilities.

3

We should support a review of delivery models for primary care.

The 15-minute GP appointment doesn't work well for people living with dementia. The funding model that underpins the standard model of care for primary healthcare is set up for episodic care rather than long-term planned care.

We need new funding models that better fit the complex and ongoing needs of people living with dementia and their families.

Next Steps

What might this look like as a workplan?

01 Encourage a shift of focus to cognitive loss

Identify the steps needed to implement a paradigm shift to recognise cognitive loss and to agree on revisions for national pathways.

02 Simplify processes for primary care

Set up a workstream to look at simplifying processes.

03 Support a review of funding models for primary care

Contribute to national conversations about primary care funding models as they arise.

Support the whānau 'workforce'

We believe that training and education should be a priority not only for paid workers and professionals but also for family supporters in the community. This echoes past feedback from consultation about the draft Action Plan.

Whānau to whānau support was the key priority for the Māori community of interest. The success of whānau to whānau support can depend on how well we resource the whānau supporters and how much knowledge we share about accessing those resources.

4

We should make it easier for whānau supporters to access what they need to help prevent burnout, for example, respite.

We want needs assessment teams and other relevant health care and support service workers to be aware of the need to help prevent carer burnout.

We want the teams to be able to identify people at risk.

We want the teams to be aware of what is available to help whānau carers, including the respite and funding options that are available.

5

We should make it easier for whānau supporters to know what resources are available.

We need to ensure that carers have access to resources so that they know what's accessible in their community.

There are some good services out there. We need to pull them all together to make navigation easier.

We would also like to see discussion across agencies, for example between MSD and health teams, to help make sure that people get access to all the support that is available.

6

We should make it easier for whānau supporters to access education and information about supporting someone living with dementia, including kaupapa Māori and qualification options.

Whānau carers need access to sufficient information to care for their whānau member with dementia mate wareware. That information needs to be accessible and given in a way that is suitable.

Within Te Ao Māori this might include tautoko (support) from whānau ora navigators (a culturally-based and whānau-centred approach) with educational support by Māori, with Māori, for Māori.

If the whānau supporter is going to take on the support role for an extended amount of time, then it would be smart to encourage them to engage in any kind of training possible, including formal qualifications such as certificates. We need to ask: has the whānau supporter left that area with a knowledge kete of what they have learned so that they can go on to develop personally and professionally?

Next Steps

What might this look like as a workplan?

04 Help prevent carer burnout

Set up a workstream to look at how to enable a culture shift to recognise the needs of whānau and ensure simple access to what people need, for example, respite.

05 Make it easier for whanau supporters to know what resources are available

Recommend a one-stop-shop information hub for whānau about available local and national resources. Look at collaboration between government agencies to ensure coordinated and appropriate financial support for carers.

06 Make it easier for whānau supporters to access education and information

In addition to the information hub, identify how kaupapa Māori and qualification options can be implemented nationally. Some initiatives are already in place within some Māori health providers regionally.

Help make the formal workforce stronger

The key area for the next steps in workforce development is education.

Education impacts timely diagnosis. Education can help the primary healthcare workforce actively support people living with dementia to navigate diagnosis.

7

We should consider the primary healthcare workforce broadly when planning education and upskilling around cognitive loss and dementia.

One aspect of education we discussed was around improving early diagnosis and support. Primary health care in the community is often the first point of contact. Primary care is where most consultations and referrals start. GPs are undoubtedly vital, but the primary care workforce also includes other important roles. We should improve the knowledge and skill base for dementia across the whole primary care workforce.

We need more practice nurses and other personnel taking up skills and training for dementia assessments.

There also needs to be a multidisciplinary approach to therapies.

8

Make it simpler to find education resources

Implementing simple workforce development education for the residential care and home and community care workforce is one of the main ideas that can be achieved now. There is a lot of good material that we can use now.

There are challenges with so much information on a lot of different websites. People may not know about some of the excellent educational material that's available, both within New Zealand and in Australia.

The first step is to identify what is already available to make it more accessible and easy to find, especially online education. If an aged care worker wants to learn about a common issue, for example, managing challenging behaviour, the ideal would be that they could go to a single website and be able to find relevant educational resources quickly and easily.

9

Develop an information sharing culture

We need to review what's working across the country and how to collaborate so that we can disseminate what best practices can look like.

We talked about the need to do a stocktake of what's working well across the motu, and to look at how we might share or enable what's working well to be spread and delivered across all of our regions. We want to share across the motu and get feedback from different perspectives.

The areas that we would like to share about include:

- young onset services,
- support groups for carers,
- what’s working in rural areas,
- community support models.

Next Steps

What might this look like as a workplan?

07 Consider primary healthcare broadly when planning education

Recommend national consultation about education and upskilling for the dementia ecosystem workforce, addressing what's needed and how it can be provided. When considering primary care, be sure to consider the needs of the broad primary care workforce.

08 Make it simpler to find education resources

Recommend/support the development of a one-stop shop information hub for workforce education around dementia.

09 Develop an information sharing culture

As an initial step, use some Network meetings as an avenue for sharing what is happening around the country.

Other messages

The Network's discussion concentrated on the priority areas that the Leadership Group asked us to consider. To help identify steps that would be achievable and have a large impact, the discussion emphasised steps that could proceed without having to release large amounts of new funding.

Lack of funding

Funding is a big issue. The discussion touched on many things that additional funding could enable, for example:

- a new funding model for general practice
- new models of community support services, particularly for people living alone
- better financial support for carers
- more access to initiatives for people with younger onset dementia
- a more multidisciplinary approach, integrating allied health professionals including recreational therapists
- access to ongoing 'maintenance' CST.

A few next steps

The areas we discussed do not cover everything that is important to us. It is only part of the vision laid out in the Dementia Action Plan and our Korero Mai manifesto.

For example, indicators were suggested as another potential priority area. It is important to identify the measures that we are going to use as a sector to track our progress and see whether we are making a positive difference in the lives of people living with dementia.

The communities of interest for our discussions were:

- Māori Perspectives
- Young Onset Dementia
- Respite Care
- Navigation
- Community Support
- Therapeutic Approaches, Including CST
- Primary care.

We did not have enough people for some important communities of interest perspectives the Network had suggested:

- Pasifika Perspectives
- Dual Diagnosis With Intellectual Disability
- Rural Perspectives.

Ensuring equity

We acknowledge the importance of gaining an understanding of how we address inequities across our populations and what it would cost, including Māori and Pasifika.

We want to highlight the difficulties in access for rural and smaller communities. We do not want any improvements in diagnosis and workforce development to continue the postcode lottery, with different opportunities depending on where you live. There are big questions about how we develop services across the country that:

- Are inclusive;
- Address the fact that not every area has a specialist;
- Share what is working well and enable it to be spread and delivered across the motu.