Community-based dementia mate wareware services in Aotearoa New Zealand

Service model jointly developed by Alzheimers NZ and Dementia NZ

December 2023

Cover Image: Alzheimers Taranaki

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Ko ngā pae tawhiti, whāia kia tata; ko ngā pae tata, whakamaua kia tina.

Make the far horizons accessible; make the near ones secure.

Introduction

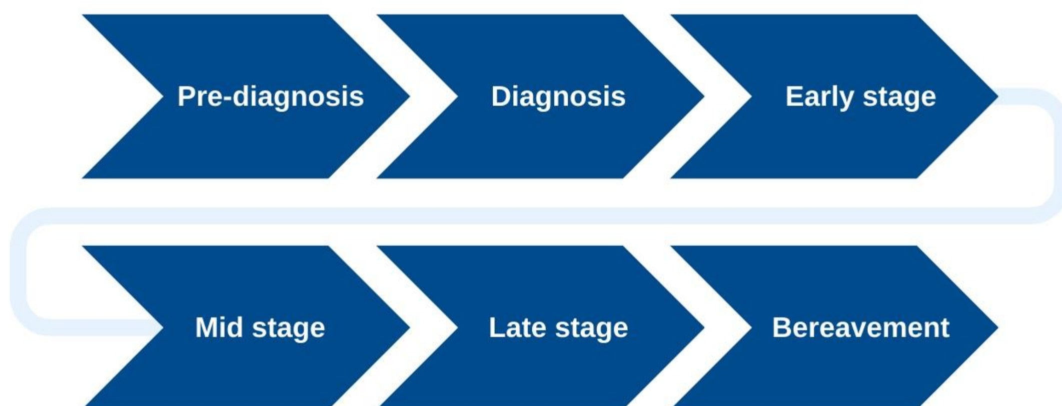
This service delivery model establishes best practice, self/whānau directed Aotearoa New Zealand relevant integrated multimodal community-based dementia mate wareware services. It was developed with input from people with lived experience of dementia mate wareware. This model is based on our shared future vision and has drawn on a number of key documents and current research both within Aotearoa and internationally. Amongst these documents have been the Improving Dementia Mate Wareware Services in Aotearoa New Zealand Action Plan (2021); the Post-Diagnostic Community Services for People Living with Dementia Mate Wareware in Aotearoa NZ Literature Review (2022); the World Alzheimer Report - Life after diagnosis: Navigating treatment, care and support (2022); Dementia Prevention, Intervention and Care: 2020 Report of the Lancet Commission; Alzheimers NZ Dementia Declaration (2019).

The model is aligned to the Pae Ora (Healthy Futures) Act 2022 and Te Pae Tata Interim Health Plan (2022).

Current funding arrangements with Te Whatu Ora do not enable Alzheimers and Dementia organisations to deliver this model of service delivery. The model has been costed and a business case developed seeking the funding necessary for this future focussed model to be implemented by Alzheimers and Dementia organisations across Aotearoa.

Scope

We support the people living with dementia mate wareware (people with dementia mate wareware and their care partner and whānau) through their dementia mate wareware journey. This journey is from pre-diagnosis, through the diagnosis period, and post diagnosis to living with dementia. It then progresses to changed behaviours and to decision points pertaining to advanced dementia and end of life care needs. This is at the core of what we do:



Services may be delivered in people's homes, in community venues, and in community-based support organisation venues.

The model encompasses the range of different diagnoses within the dementia mate wareware group of conditions along with the associated mix of acuity and complexity across our client population. Alzheimers and Dementia organisations will deliver a mix and range of services relevant to their client population and to their local network of providers. This means not all Alzheimers and Dementia organisations will deliver an active brain day programme. Neither organisation delivers kaupapa Māori services however we seek to partner with/support kaupapa Māori providers so kuia and kaumātua with dementia mate wareware can access those services as needed.

We deliver comprehensive, multimodal pre and post diagnostic support for people living with dementia mate wareware, and work in our communities to raise awareness of dementia mate wareware and its impacts, promote brain health and help build knowledge, acceptance and understanding.

Ee also play an active role within the local health network providing education and advice about dementia mate wareware and contributing to the multidisciplinary team.

This model does not include national services.

Service kaupapa

People living with dementia mate wareware are in control of their lives, are active and engaged with their community, and are able to live their best possible lives with confidence and autonomy.

Our contribution is delivery of accessible, equitable, quality assured and human rights based community support to people living in our communities. This includes raising awareness of dementia mate wareware, promoting brain health, and supporting people and their whānau to live their best possible lives with the condition.

We do this by:

- Partnering with people living with dementia mate wareware so they receive flexible, tailored and self/whānau directed services.
- Being responsive to Te Tiriti o Waitangi which informs and shapes our services and our support for kaupapa Māori services/ providers.
- Working collaboratively and strategically as part of our local networks of health and social services.
- Being knowledgeable and informed about our communities to deliver nationally consistent and locally relevant evidence-based services
- Supporting communities to be dementia mate wareware friendly and inclusive by challenging the stigma and discrimination associated with dementia mate wareware.

Principles

Our services are underpinned by eight interlinked principles:

- **Rangatiratanga and human rights** – people living with dementia mate wareware are self-determining citizens whose lives matter and who have the same human rights as everyone else.
- **Manaakitanga, wellbeing and person-directed** – people with dementia mate wareware and their care partners and whānau are at the forefront of decision-making about their care and support. They are supported to thrive through community-based services founded in aroha, empathy, respect and dignity.
- **Whanaungatanga** – recognises and respects the rights and reciprocal relationships and obligations consistent with being part of a professional network.
- **Wairuatanga**– recognition that Te Ao Māori and all other world views have ever-present spiritual dimensions and that every person will choose how they wish to express their spirituality in their own unique way.
- **Kaitiakitanga** – guidance, protection and the provision of compassionate support in a way that upholds the mana of people living with dementia mate wareware.
- **Kotahitanga** – working collaboratively and with unity of purpose to support people living with dementia mate wareware through integrated networks.
- **Comprehensive and integrated** – services are respectful of the whole life-course of dementia mate wareware, from onset to the end of life. There is a focus on the community-based phase of the journey.
- **Evidence-based and consistent** – services are grounded in evidence and best practice with flexibility to incorporate person-directed goals and to delivering solutions that are nationally consistent, effective, and sustainable.

Our clients

We deliver services to three client groups:

a) People living with dementia mate wareware including tailored and culturally appropriate services for priority populations – Māori, Pacific, young onset, rural and others.

b) The health and social service networks we are part of.

c) The communities within which we operate.

<table>
<tr><th colspan="2">Who</th><th>Description</th></tr>
<tr><td rowspan="3">People living with dementia mate wareware</td><td>Person with dementia mate wareware</td><td>Identified individuals whether diagnosed or not, and whether accepting or not, and living and supported in the community.</td></tr>
<tr><td>Care partners and supporters</td><td>Identified primary care partners of people with diagnosed or suspected dementia mate wareware whether living in the community or in residential care. Also includes secondary/others supporting the person with dementia mate wareware directly</td></tr>
<tr><td>Whare whānau</td><td>Includes any or all of the person living with dementia mate wareware, care partner, whānau, family, significant others. Considered as one group needing navigation through the support journey. Navigation can mean different things for different households</td></tr>
<tr><td colspan="2">Health and social service network</td><td>The local continuum of support that forms the health and social care network. Includes community, primary and secondary care.</td></tr>
<tr><td colspan="2">Community</td><td>The local community of which the organisation is part.</td></tr>
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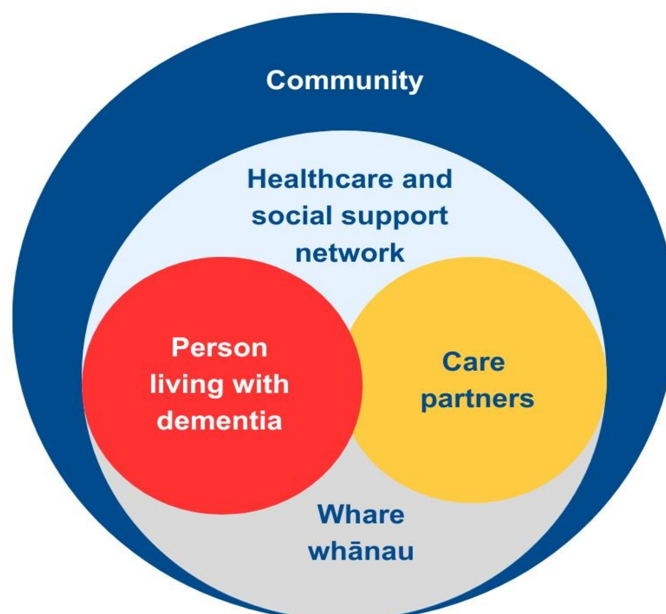
We and our clients are part of an integrated network:



Kaupapa Māori Cultural Services

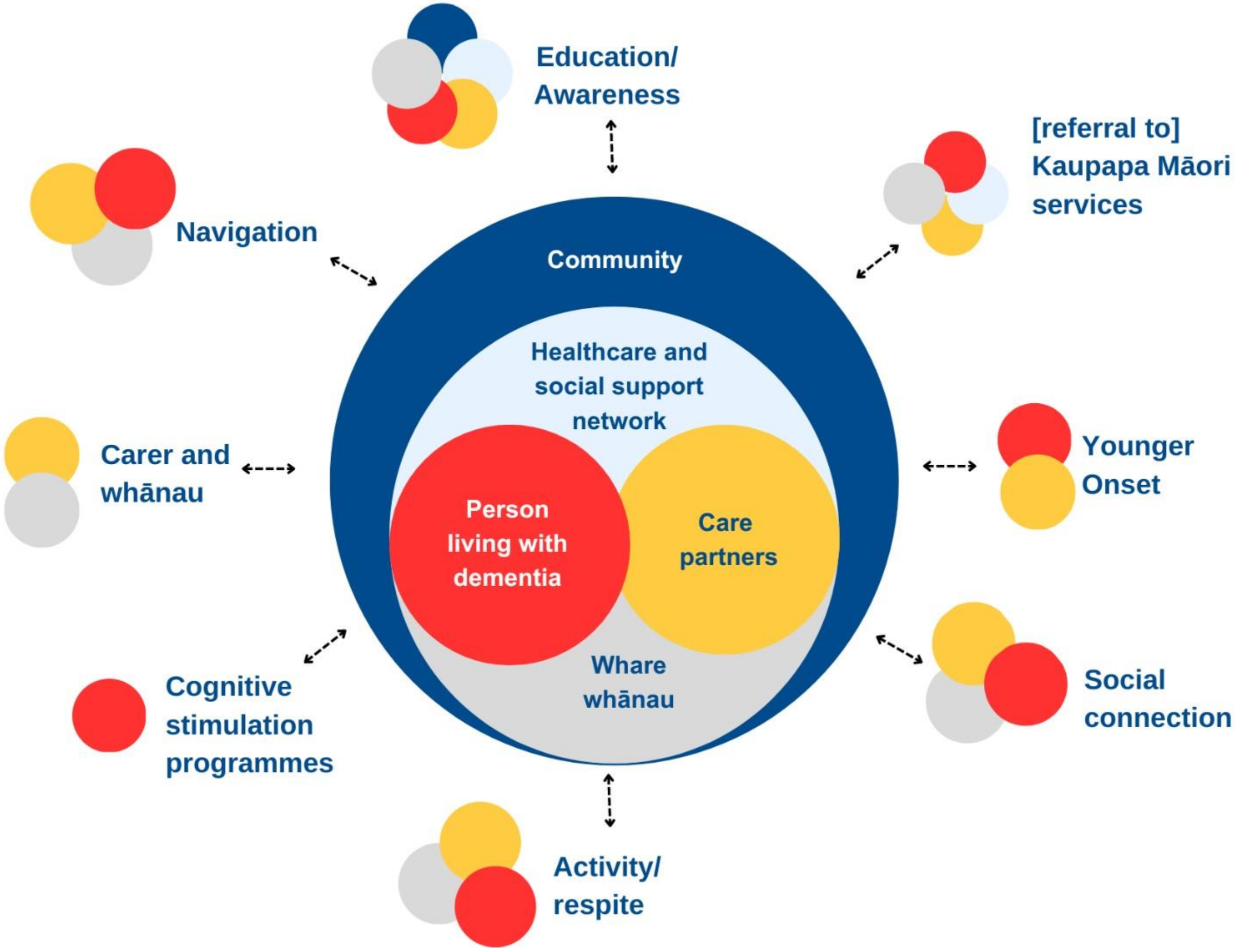
In the following service delivery model kaupapa Māori services are included in the mix of integrated services as an essential service delivery approach based on the commitment made in the Dementia Mate Wareware Action Plan (Page 6). That is to "aligning with Te Tiriti o Waitangi obligations: tino rangatiratanga, equity, active protection, options and partnership". We acknowledge that kaupapa Māori services are delivered by kaupapa Māori providers with "an approach grounded in Te Ao Māori underpinning design, development and delivery of solutions and programmes that work for Māori whānau". Through the commitment made in this service model we will support kuia and kaumātua to access kaupapa Māori services as needed through partnerships that reflect the right of Māori to receive culturally appropriate services in the manner best suited to their needs. It also reflects our commitment to the ongoing development of our own staff cultural competency.

Service Delivery Framework - See Appendix 1 for the logic that underpins this framework

Client Person/organisation receiving the service	Impact The difference we are looking to make	Services How we make that difference
People living with dementia mate wareware: • Person with dementia mate wareware • Care partner • Whare whānau	**People with dementia mate wareware** – maximising function, independence and autonomy for as long as possible **Care partners** – maximising support networks, resilience and capability and reducing stress so they can continue to act as primary carer for as long as is right for them **Whare whānau** – strengthening whānau to support the person with dementia mate wareware	• Pre and post diagnostic support
Health and social sector network (including Kaupapa Māori providers)	Building capability and networks	Education and advice Knowledgeable input and data as part of the multidisciplinary team referrals and integration of service

Client Person/organisation receiving the service	Impact The difference we are looking to make	Services How we make that difference
Community	Building understanding, acceptance and inclusion of people living with dementia mate wareware	Campaigns and awareness Brain health/prevention Dementia mate wareware friendly activities

The services we deliver



Navigation

- Getting a diagnosis
- Social assessment/goals/ support plan
- Advocacy/liaison /referral community /health/support providers
- Crisis/complex case management/transition/end of life National 0800 number for support

Education/Awareness

- Person living with dementia mate wareware/Whānau dementia education/Living well
- Brain health
- Dementia mate wareware Friendly
- Community/health providers/staff Public facing organisations/groups

Kaupapa Māori

- Referral to kaupapa Māori providers
- Referral for cultural assessment
- Advice and support to kaupapa Māori providers

Carer and whānau

- Carer support groups
- Specific ongoing education to support changes throughout dementia mate wareware journey
- Focused support/adjustment pre/post placement

Activity respite

- Variety of delivery methods
- Early to mild journey focus Cognitive
- programmes and purposeful activity
- (based on principles of CST)

Cognitive stimulation therapy

- Community CST
- Day programmes CST
- Māori CST

Younger onset

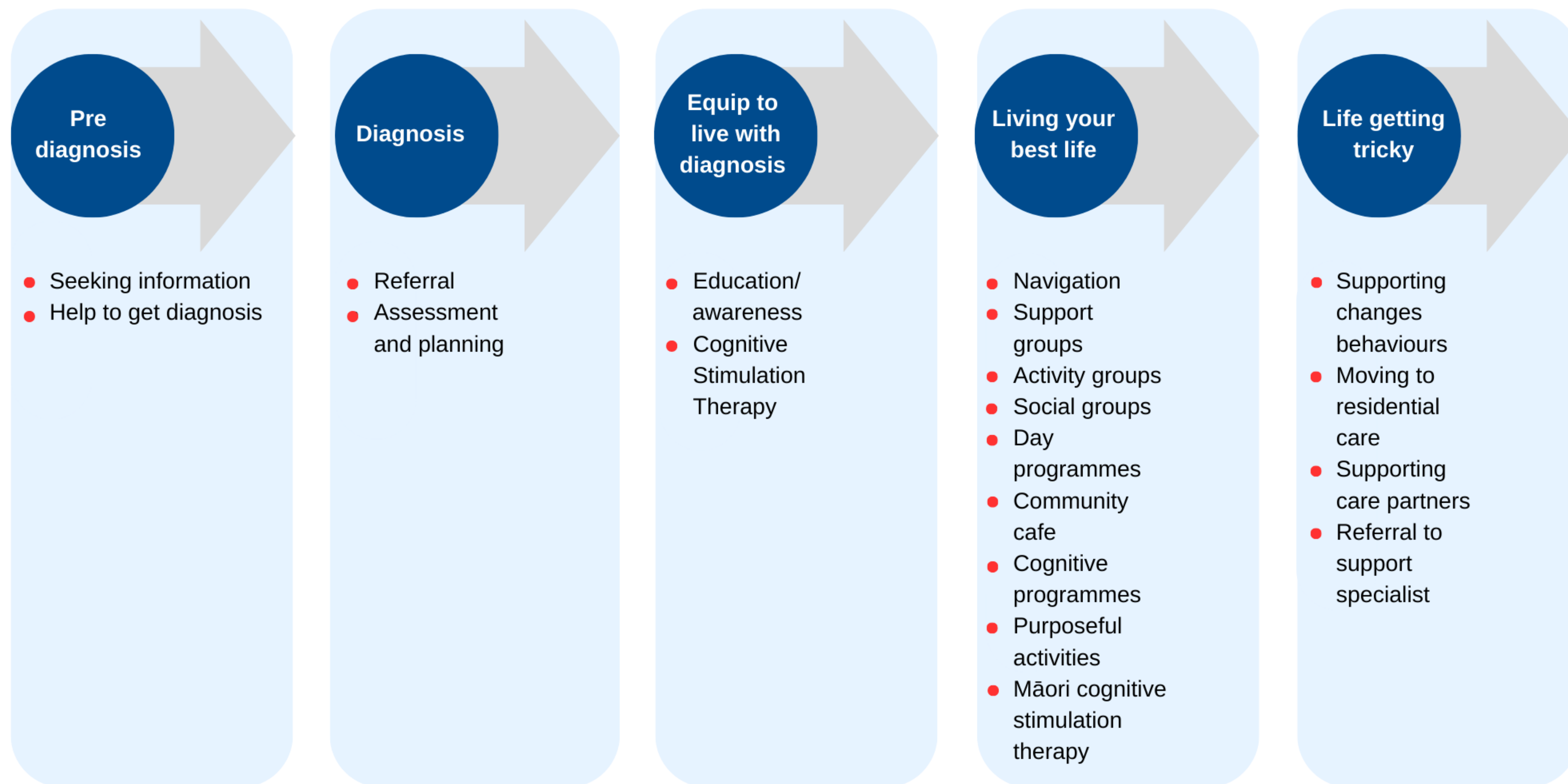
- Range of programmes specifically age appropriate, providing connection, stimulation and support/people with dementia/whānau (Ref Angila Report)

Social connection

- Community cafes and social events designed to bring person living with dementia mate wareware and whānau together for social support/to avoid isolation/provide normalised opportunities for connection

Pathways

Services are provided across the whole journey with dementia as demonstrated in the diagram below. The diagram looks linear but people living with dementia mate wareware will move into and out of our services depending on need and on their individual situations. For example, people may enter at the beginning of this pathway and move through each stage, or they may dip in and out of services as is right for them at that time.



Measurement and monitoring

We will use a results-based accountability (RBA) approach to measure and monitor our service delivery model including:

a) Counting how much we do
b) Monitoring how well we did it
c) Measuring the impact for those living with dementia mate wareware and their carers.

We hope Te Whatu Ora will work with us to develop these measures and include them in any new contracts.

A Results Based Accountability Framework example is provided in Appendix 2.

Appendix 1 – Logic Model

Definition: A comprehensive, responsive, and sustainable service that provides tailored support, advice and resources for people with dementia mate wareware, their care partners, whānau, other services and the wider community. The inputs and resources part of the model is contained in the costing model.

Activities/Outputs	Short term outcomes	Long term outcomes	Goals
Navigation - support to get a diagnosis and during the post-diagnostic period from a named person (e.g. dementia mate wareware advisor/key worker) allocated for the duration of their journey. **Support** – support for personal, social and emotional wellbeing **Education** - education for people with dementia mate wareware and carer **CST** – formal cognitive stimulation therapy **Kaupapa Māori** - people who identify as Māori and whānau have access to services grounded in Te Ao Māori and relevant to their needs **Socialisation** - opportunities suited to the needs of the individual	People living with mate wareware and their whānau are empowered to make decisions about their care and support People receive information that supports their planning now and for the future People are supported to have a smooth journey through the course of their mate wareware and get the services they need in a timely manner Organisations and the community are provided with education and support that builds their acceptance and understanding of mate wareware	**People with dementia mate wareware** – live well in their community by maximising function and independence for as long as possible **Care partners** – maximising their support networks, building their resilience and capability and reducing stress so they can continue to act as primary carer for as long as is right for them **Whare whānau** – are strengthened to support the person with dementia mate wareware and whānau **The Community** - understanding, acceptance and inclusion of people living with dementia mate wareware grows	**Population Goals:** Mauri Ora – better health and wellbeing Whānau Ora – including a sense of belonging and secure identity by confidently participating in society **Overarching Goals:** A comprehensive and sustainable service underpinned by the core principles of Te Tiriti o Waitangi An integrated whole of sector approach to dementia mate wareware support within our rohe

Activities/Outputs	Short term outcomes	Long term outcomes	Goals
Respite - support and micro respite options for care partners and whare whānau **Active brain day programme -** Physical, cognitive and social programmes to support the person’s abilities, interests and goals.	Activities that promote brain health and wellbeing in older age are available	**Brain Health** – prevention and wellness focus evident **Preventable presentations -** reduction in crisis presentations to emergency settings / primary care **Delayed admission** to long-term residential care	A tailored and responsive service that meets the needs of people and their care partners

Appendix 2 – Results Based Accountability Framework Example

Activity	How much?	How well?	Better off?
Notes	Split by ethnicity + location + age + gender	Split by ethnicity + location + age + gender	Mostly measured by client self-reporting
General overview	# service users # whānau # referrals/exits	% referrals seen with X time period % of referrals referred at type of stage e.g. mild, mod, severe (indicates over time earlier referrals may be working in earlier stages and earlier referrals)	# and % of whānau who feel better supported to continue management of person with dementia at home # and % service users admitted to residential care – (high level measure done by Te Whatu Ora)
Navigation services	# people supported to get a diagnosis # people with a living well plan developed + # living well plans developed # people with Advanced Care Plan (ACP) developed + # ACP developed # people with Enduring Power Of Attorney (EPOA) developed + # EPOA developed # liaison & linkages with other services	% people who have a living well plan % people with an ACP % people with an EPOA % of referral to other services	# and % of people of people who access range of services at optimum time

Activity	How much?	How well?	Better off?
Education	# education sessions + # people attending education sessions	% of education sessions completed	# and % of people sessions with positive change for participants
Kaupapa Māori Services	# referrals to kaupapa Māori providers	TBC	TBC
Carer Support	# individual interventions + # people who were provided # group sessions + # people who were provided	% carers/whānau supported – timeliness and reach	# and % of carers (indicator of improvement in wellbeing/management)
Cognitive Stimulation Programme	# CSP programmes delivered + # people attended	% of people eligible/referred for CSP programme who accessed/started/completed a programme	As recorded in the CSP outcome measures
Activity respite	# people provided respite	Indicator of timeliness – regarding need for respite % of people accessing respite options	# and % of people who report an improvement in wellbeing
Young Onset	# activities and # people attending activities		
Social Connection	# activities	% of people accessed activities	# and % of people who report an improvement in wellbeing

Appendix 3 – Post Diagnostic Dementia Community Support Services Staffing Resource Requirements

Support Services	Description
1. **Navigation**	Dementia mate wareware specialist staff are skilled and knowledgeable in the delivery of community-based post diagnostic service interventions, inclusive of personal and emotional support for both the person with dementia mate wareware and their care partners. A named case manager (Advisor/Key Worker) should be available to provide navigation and support throughout their journey. They will understand the philosophy of care and its service provision implications. [In the Post-Diagnostic Community-Based Service for People Living with Dementia in Aotearoa New Zealand Recommendation number 4 states: 'All people should have a named case manager for the duration of their journey through post diagnostic dementia mate wareware community services']. With appropriate tailored support in place, most people with dementia mate wareware can continue living well in the community for some years. Dementia Community Support Organisations (DCSO's) can support all involved to plan, feel more confident about the future, and navigate their way through changes and challenges as they happen. https://www.nzdementia.org/
2. **Education**	DCSO's offer specialist psycho education programmes for people living with dementia mate wareware, care partners and whānau throughout their journey tailored to social and cultural needs of those with dementia mate wareware. Multi-modal programs which offer both the person with dementia mate wareware and their partner sessions to attend in tandem are recommended. Free specialist community seminars on a range of topics associated with Mate Wareware, Brain health, and taking care of general hauora-wellbeing are provided. Workshops and seminars may also be offered to health professionals, businesses, and community organisations.

Support Services	Description
3. **Whānau and Carer Support**	In order to take care of someone close with dementia mate wareware, care partners and whānau also need to take care of themselves. Support groups are available to share experiences with others on similar journeys, and people can awhi and learn from each other. The team also provide tailored education for whānau facing challenges and can tautoko-support whānau through the adjustment of their loved one entering specialised care and in the post placement period.
4. **Specialised Brain Health Programmes**	Formal Cognitive Stimulation Therapy programmes following standard protocols are available. These programmes are best suited to people who are in the early to mid-stages of their dementia mate wareware journey.
5. **Active Brain Day Programmes**	Physical, cognitive and social programmes are developed around attendees' abilities, interests and goals. Programmes can include community outings, exercising, active brain sessions, singing and a lot of laughter.
6. **Community Activity Groups**	DCSO's coordinate a range of engaging, cognitively stimulating and fun activity groups. Exercise programmes, Life story work and groups focusing on the arts are recommended. These can include gardening, walking, singing waiata, golf, and existing community group events. Opportunities to partner and deliver groups in normalised community settings are encouraged. [Tool Kit Resource: https://www.sialliance.health.nz/programmes/health-of-older-people/useful-resources/]
7. **Social Events**	These include café groups, movies, special local events, holiday celebrations, all intended for people [including care partners and whānau] to enjoy experiences together and to get to know other people living with the impact of dementia mate wareware on their lives fostering social connection and support

8. Younger Onset - (and underserved groups)	• Tailored programmes – targeting specific needs of those living with younger onset dementia mate wareware, their care partners and whānau, which include navigation and support, education and activities all of which are age appropriate, and where possible co designed.
Support Services	**Description**
	• Under-served groups, especially Pasifika, rural populations, but also people living with dementia mate wareware alongside enduring mental illness, homelessness, major central nervous system neurological illnesses, and intellectual disability; as well as people with dementia mate wareware in the deaf community, and in other ethnic / cultural communities including LGBTQIA+ people.
9. Kaupapa Māori Services	DCSO's respect and honour the importance of services being culturally appropriate for tangata whenua. Continue to partner with kaupapa Māori providers to support a Te Ao Māori approach and expand its depth and reach. Services for Māori are co-designed with local iwi or a delegated authority, as standalone kaupapa Māori service or, a co-designed adaption.

Staffing Resource

Following are the staffing resources needed for our support services together with the rationale for staffing choices.

Tautoko – Support Services	Staffing Resource Required to Meet Needs
1. **Navigation**	Registered Health Professional (APC – Annual Practising Certificate)
2. **Education**	Registered Health Professional (APC or Qualifications in Teaching or Adult Education)
3. **Whānau and Carer Support**	Registered Health Professional (APC – Annual Practising Certificate) Supported by expanded service team to include Kaiāwhina roles (e.g. Level 4 Health and Wellbeing; Level 5 Whānau ora; Level 5 Dementia or L5 Health Coach)
4. **Specialised Brain Health Programmes**	Kaiāwhina trained in Cognitive Stimulation Therapy - Māori
5. **Active Brain Day Programmes**	Programme Facilitators – Level 3 Health & Wellbeing or equivalent Service Leaders – Level 4 Health & Wellbeing or equivalent
6. **Community Activity Groups**	Experience in working with groups in community context. Interest/experience in activity co-ordination. Kaiāwhina (e.g. Level 2 or above Health and Wellbeing or equivalent)
7. **Social Events**	Experience / interest in social and community group facilitation Kaiāwhina (e.g. Level 2 or above Health and Wellbeing or equivalent)
8. **Younger Onset - (and underserved groups)**	Registered Health Professional (APC – Annual Practising Certificate)
9. **Kaupapa Māori Support**	Recognised by Māori as cultural expert – regarded and recognised by Māori (Qualification in e.g. Level 5 – Health Coach, Community Facilitation; Whānau ora) Registered Health Professional (APC-Annual Practising Certificate)

Explanation and rationale provided for the staffing choices:

1. Roles requiring a Registered Health Professional (RHP) – Annual Practising Certificate (APC)
   - These roles require the knowledge, skills and behaviours commensurate with the profile of a RHP
   - Professional Registration with an APC ensures public protection and safety with indemnity cover, and practice competency is monitored and assured.
   - Visiting clients and whānau in the community requires – making a connection and building trust; therapeutic relationship skills with individuals and whānau groups taking into account the complexities of family dynamics; risk assessment; clinical assessment and reasoning; critical thinking and problem solving; initiative; care planning and review; enhancing health literacy; engaging in effective dialogue with a range of health and social service personnel; overseeing, a professional standard of documentation, supporting and managing kaiāwhina (un-registered) staff and volunteers
2. Group Coordinator Role – Experience in working with groups, facilitating therapeutic aspects of activities
3. Social Activity Coordinator Role – Experience and interest in facilitating social groups and activities
4. Kaupapa Māori support – as deemed culturally appropriate for this role, e.g. Kaiāwhina roles with Registered Health Professional input (as above)

Resources which have informed the staffing allocation:

- Improving Dementia Mate Wareware Services in Aotearoa New Zealand Action Plan (2021)
- Literature Review (2022): Post-Diagnostic Community Services for People Living with Dementia Mate Wareware (2022)
- South Island Alliance (2021) - Community Activity Groups for People Living with Dementia: A Guide to Getting Started
- Culturally appropriate assessment tool pp25-26 (2023) https://www.interrai.co.nz/interrai-service-design/caam/ Best Practice Information – national and international
- Dementia NZ Workforce – experience and expertise

Leadership and Management

Organisations require appropriate leadership – clinical and management – to delivery safe, quality services consistent with this model.

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.

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