

CONSIDERING

DEMENTIA MATE WAREWARE IN THE FUTURE OF AGEING WELL

A SUBMISSION TO THE FUTURE OF AGEING WELL FUNDING AND SERVICE MODELS REVIEW

Prepared by the New Zealand Dementia Foundation
as secretariat to the Dementia Mate Wareware
Leadership and Advisory Group June 2024

THE DEMENTIA MATE WAREWARE LEADERSHIP AND ADVISORY GROUP
TE WHAKARURUHAU MŌ TE MATE WAREWARE

Tē tōia, tē haumatia
Nothing can be achieved without a plan and way of doing things

There's a metaphor in co-design of building a house. It's tempting to start the design process by picking the colours of the curtains, but we need to start with by thinking about what we want from our house:

-What are our goals and the experience we want to create?
-What principles will deliver that experience?

We appreciate the opportunity to work with Health New Zealand to consider these important questions for the future of ageing well services and funding.

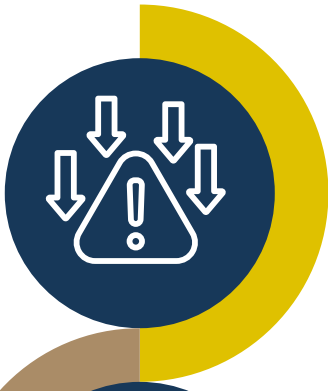
We have a simple message.
Dementia mate wareware is not normal ageing.
If dementia awareness isn't "baked in" to the core goals and principles of the Future of Ageing Well Funding and Service Models, then services will be poorly aligned with the needs of people living with dementia mate wareware. We are not going to be able to retrofit the model by changing the colour of the curtains. On the other hand, if the model is fit for purpose for people living with dementia mate wareware, it is more likely to work for everybody.

Summary: Rationale

for a dementia mate wareware aware health system in a future of ageing well

PREVENTION, HEALTHY AGEING AND RESILIENCE

It is never too early and never too late in the life course for dementia mate wareware prevention. Modifiable risk factors account for 40% of cases [1].





LIVING WELL WITH LONG-TERM HEALTH CONDITIONS

Dementia mate wareware is the largest single contributor to disability and need for care among older adults out of any chronic disease [2].

IMPROVING REHABILITATION AND RECOVERY FROM ACUTE EPISODES

Dementia mate wareware is associated with more frequent hospital admissions, prolonged hospital stays, and increased risk of emergency department visits [3].





BETTER SUPPORT FOR OLDER PEOPLE WITH HIGH AND COMPLEX NEEDS

The combination of dementia mate wareware with a physical health condition worsens health status and increases health service use and costs [4].

RESPECTFUL END-OF-LIFE CARE

One in four New Zealanders die with dementia mate wareware



Healthy Ageing Strategy's key strategic themes [5]

Dementia mate wareware is an umbrella term for a range of progressive disorders affecting the brain. Dementia mate wareware awareness is about preparing the Future of Ageing Well Funding and Service Models to be fit for purpose not just for physical but also cognitive needs.

Summary: Principles

for a dementia mate wareware aware health system in a future of ageing well

Enabling

We recognise the strengths and potential of people living with dementia mate wareware.

We support people living with dementia mate wareware to maintain and develop their own strengths and abilities to enable them to live well.

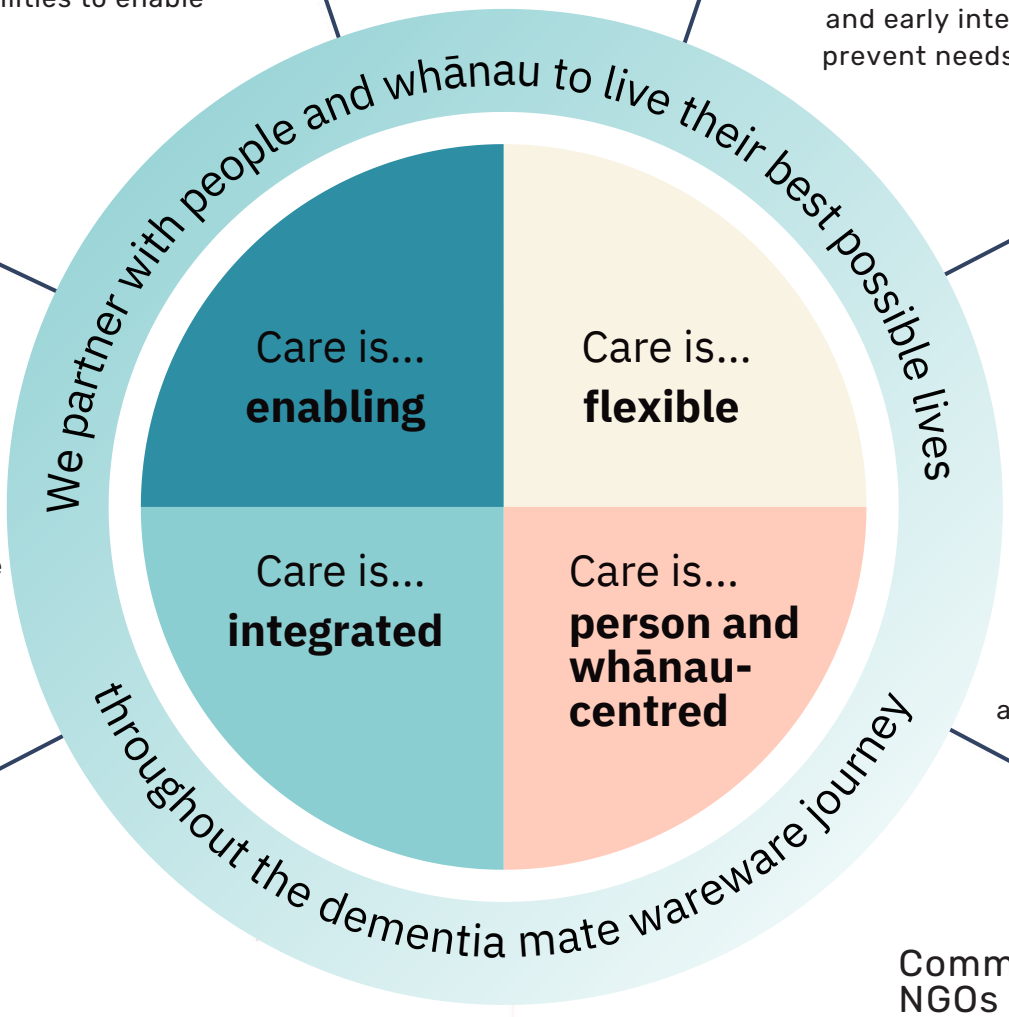
A shared goal

We partner wit people living with dementia mate wareware and their whānau to live their best possible lives.

A journey

We provide support and comprehensive management throughout the whole journey of dementia mate wareware.

We start early. We have a focus on prevention, timely diagnosis, and early intervention. We help prevent needs from developing or increasing.



Flexible

We have the capacity to meet diverse needs and priorities for people and whānau affected by dementia mate wareware in support and respite.

Person& whānau-centred

We are a dementia-capable workforce.

We understand, respect, and are responsive to the whole unique person and whānau affected by dementia mate wareware.

Primary care

Community-led, NGOs

Integrated partnership

We offer navigation support. We have integrated data and work together.

Home and community support services

Aged residential care

Family & Whānau
are at the centre of the partnership

Dementia isn't normal ageing. If dementia awareness isn't "baked in" to the core goals and principles of the Future of Ageing Well Funding and Service Models, then services will be poorly aligned with the needs of people living with dementia mate wareware.

About us

The Dementia Mate Wareware Governance Ecosystem has been designed to help navigate a clear course towards a shared vision set out in the Dementia Action Plan [6]. That vision is

"An Aotearoa New Zealand in which dementia mate wareware is prevented as much as possible; and where people living with dementia mate wareware, their family and whānau, and care partners receive the support they need to live their best possible lives, with autonomy, meaning and dignity."

The Governance Ecosystem was established by Health New Zealand in partnership with the Māori Health Authority. It consists of the Dementia Mate Wareware Leadership and Advisory Group and the Dementia Mate Wareware Network. The Leadership Group provides strategic advice to the central agencies and the government, while the Network shares the views of those involved with dementia to inform and strengthen the Leadership Group's effectiveness. The New Zealand Dementia Foundation supports this process by facilitating communication between the groups as secretariat.

About this submission

The process of developing this submission brought together all these elements: the Dementia Action Plan, the Leadership Group, the Network, and the New Zealand Dementia Foundation. We particularly note the contribution of an online Network hui co-hosted by the Health New Zealand Future of Ageing Well Services and Funding Models review team. Over 100 people attended and discussed 12 aspirational statements for aged care services provided by Te Whatu Ora to stimulate debate.



PART
1

Dementia mate wareware matters

Key messages from the Dementia Mate Wareware Action plan

Our models aren't working. Dementia mate wareware needs a different approach.

"Implementing the Dementia Mate Wareware Action Plan is a commitment under Te Pae Tata Interim New Zealand Health Plan 2022.

With no treatment or cure on the horizon, dementia mate wareware is one of the 21st century's greatest global challenges for health and social care. It represents a major challenge for Aotearoa New Zealand, creating significant human, social, economic, health, workforce and economic costs. People living with dementia mate wareware are amongst the most vulnerable in Aotearoa New Zealand and services are not currently capable of meeting their needs...

[The] goal is to improve the wellbeing of people living with dementia mate wareware while decreasing the impact of dementia mate wareware on them, as well as on Aotearoa New Zealand, family and whānau, communities, the health system, and the economy."

- Health New Zealand Te Whata Ora [7]

Dementia mate wareware matters



Dementia matters because the lives of people and whānau living with dementia mate wareware in Aotearoa New Zealand matter.

Dementia matters because dementia is a major player in the health and care system.

It is essential that the Future of Ageing Well Funding and Service Models re-design is dementia-aware.

Dementia is ... the leading cause of dependency (i.e. need for care) and disability among older persons....
It is obvious that dementia, its consequences and responses can no longer be neglected
-World Health Organisation [8]

Dementia matewareware is a major player in our health and care system.

HOME & COMMUNITY

Two-thirds of people living with dementia live in the community [9]. Cognitive impairment is the most common condition in community-dwelling older adults who have an interRAI assessment (62% of Māori and Pacific older adults and 57% of other ethnicities) [10]. InterRAI data also shows that over a quarter of all people receiving home care have some form of dementia [28%, 11].

It has been estimated that over 52.7 million hours of unpaid care were provided to people living with dementia mate wareware in Aotearoa in 2020 [9].

NGOs are the primary providers of the dementia mate wareware post-diagnostic support services recommended by the Dementia Mate Wareware Action Plan. However, they are not funded to meet current, let alone future demand.

PRIMARY AND SECONDARY CARE

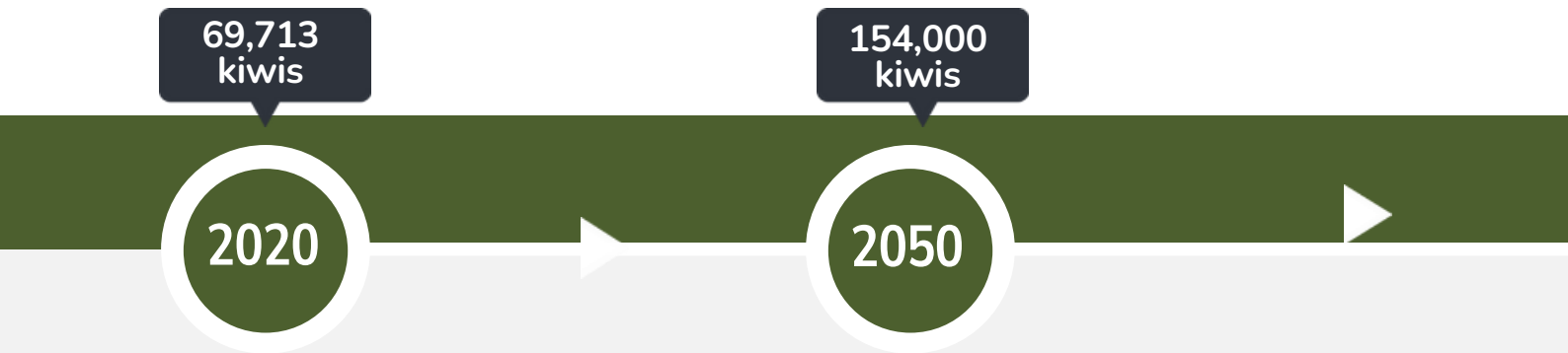
People living with dementia see their primary care team more often [12]. Dementia is a long-term condition, and its diagnosis and management are time-consuming for primary care.

People living with dementia are admitted more often and for longer to acute hospitals (with an estimated 25,827 hospitalisations per year [9] and have high rates of complications such as falls and delirium. Clinical staff report that people living with dementia are more likely to have delayed and "failed" discharges from hospital.

RESIDENTIAL AGED-CARE

Based on interRAI NZ data, nearly half of all those living in aged residential care have some form of dementia irrepsective of level of care [49%, 11].

Dementia mate wareware is a significant driver of entry into residential care as well as transitioning to higher levels of care. InterRAI data suggest that people living with dementia mate wareware are almost twice as likely to enter residential care as people without dementia [13]. The age and proportion of residents who have dementia and multiple co-morbidities when they enter residential care is increasing [12].



Planning for an ageing population means planning for dementia mate wareware. The incidence of dementia mate wareware rises sharply after age 75. The estimated number of New Zealanders living with dementia mate wareware is expected to more than double between 2020 and 2050 [9]. Dementia mate wareware is likely to be increasing more rapidly for Māori, Pacific, and Asian peoples [9].

The gaps are large



We welcome this essential review of aged care funding and services because we need meaningful change.

The consistent message from the Network hui on 2nd May 2024 was that we are far from the aspirations set out in the 12 statements by Te Whatu Ora.

There are gaps across the whole of the dementia journey that make service improvement urgent.

New Zealanders living with dementia / mate wareware are still being let down by inadequate services of variable quality, and the current services are not capable of meeting the growing demand, therefore the system is under increasing pressure.

-Dementia Mate Wareware Action Plan [6]

Human rights are often overlooked

- Stigma and discrimination create barrriers to accessing services and support
- Decision-making authority is often denied, the statutory model provides for substituted and not supported decision making

Significant inequities exist for Māori

- The ongoing impact of colonisation manifests in poorer outcomes
- Māori are more likely to be exposed to the development of risk factors because of their living circumstances
- Availability of culturally appropriate / kaupapa Māori services is limited which is a barrier to access

Quality of service is variable

- Shortages in dementia-capable workforce
- Services are often task-centred rather than person-centred
- Services often limited to medical solutions and/or to disability support services
- Opportunities for meaningful connection, activity and stimulation can be limited
- Psychotropic drugs continue to be used inappropriately



There are gaps across the dementia journey

- Pre-diagnosis: stigma, poor health literacy, no dementia prevention focus
- Timely diagnosis: poor workforce capability to deliver accurate diagnoses and poor initial management planning
- Living independently: limited and inflexible respite care, under-funded NGO-led supports
- Minimising symptoms: services limited to medical solutions and to disability support
- Dying with dementia: low synergy between palliative and dementia sectors

Access to and availability of services is inequitable

- Inequities across urban-rural divide and between regions
- Few age-appropriate services for people living with young onset dementia
- Limited services for specific groups such as Pacific and Asian peoples, the Deaf community and people who have become hearing impaired, refugees & migrants, people living alone, LGBTQIA+ people, people with dual diagnoses such as intellectual disability, neurological or psychiatric conditions, and addictions, homeless older people and people housed in corrections facilities, and the digitally excluded



PART
2

Guiding principles
for a dementia mate wareware aware future of ageing well

1

living well with dementia mate wareware

Living well with dementia mate wareware means finding ways to promote well-being and quality of life to help people be and do the things they have reason to value. The World Health Organisation provides an inclusive framework for this concept.

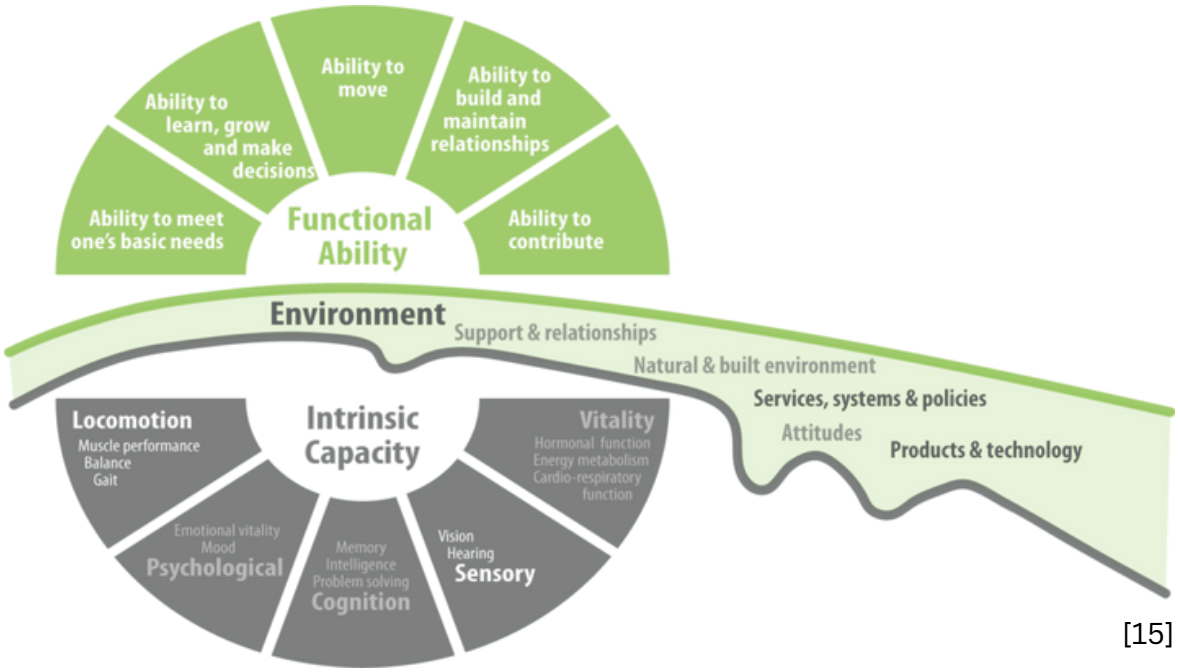
A focus on living well will encourage a more positive, empowering, and inclusive approach across the Future of Ageing Well Funding and Service Models.

We support people living with dementia mate wareware and their whānau to live their best possible lives.

We support people living with dementia mate wareware and their whānau to live their best possible lives.

In 2016, the World Health Organisation endorsed the goal of healthy ageing. This included a framework for a shared understanding of what healthy ageing or ageing well is [14]. For example this framework is the basis of the NZ Healthy Ageing Strategy [5].

Functional ability is about being able to be and do the things that the person has reason to value. As can be seen in the examples in the diagram below, functional ability in the framework is a much broader concept than just the ability to perform activities of daily living. Functional ability depends not just on the mental and physical abilities of the individual (intrinsic capacity) but also on how the person is scaffolded with support from the people, services, and other environmental factors (environment) to help them reach further.



[15]

In WHO terminology, a goal of our future ageing well services and funding models must be to optimise the functional ability of people with reduced intrinsic capacity while maintaining their dignity and human rights.

In simpler terms, our goal is to enable people living with dementia mate wareware and their whānau to live their best possible lives.

This framework has important implications for the revised funding and service models to combat the stigma around dementia mate wareware in aged care and health services:

- Everybody has the potential for enablement. Enablement doesn't mean that an individual has to be able to return to full functioning.
- Optimising functional ability is not simply about independent living or activities of daily living (although that may be important to many people). For example, care may still enable functional abilities such as the ability to engage the senses even very late in the dementia journey care [16].

2

throughout the journey of living with dementia

“Ngā hiahia ai ki te tīmatanga ā ka kite ai tātou i te mutunga.” You must understand the beginning if you wish to see the end.

At a fundamental level, the Future of Ageing Well Funding and Service re-design must be underpinned by an aim to proactively partner with people and their whānau / families to live well (optimise functional abilities) throughout the entire journey of dementia mate wareware, including prevention, not just at the later stages.

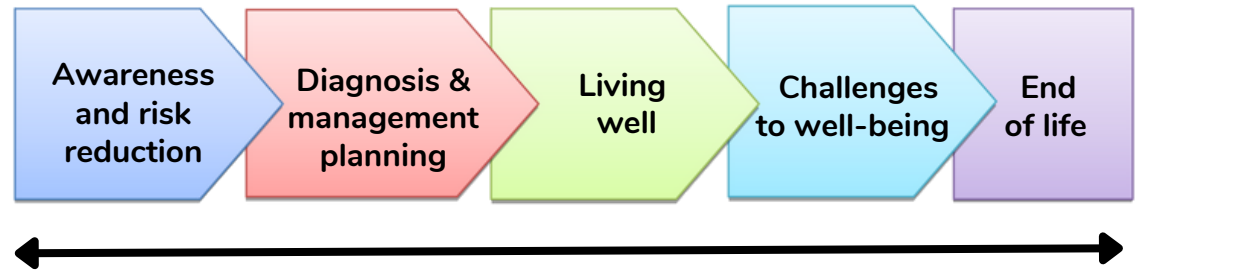
We provide support and comprehensive management throughout the journey of dementia mate wareware.
We start early. We have a focus on prevention, timely diagnosis, and early intervention. We help prevent needs from developing or increasing

> *Quote from Network Consultation Hui: we talked about the importance of primary and secondary prevention. We talked a lot about the importance of diagnosis...[we] need to be looking upstream quite significantly.*

The dementia journey

The WHO framework Ageing Well Framewok's **lifespan approach** emphasises that we can maximise current and future functional ability (help people to live their best possible lives) throughout the lifespan.

The Dementia Mate Wareware Action Plan [6] and earlier New Zealand Framework for Dementia Care [17] provide a dementia context to the lifespan approach of the WHO model. This is represented below. It sets out a vision where people living with dementia mate wareware, their family and whānau "are valued partners in an integrated health and social support system. They are supported throughout their journey with dementia to maintain and maximise their abilities, optimise their sense of wellbeing and have control over their circumstances" [17].



We start early. We have a focus on prevention, timely diagnosis and early intevention.

Failing to consider and integrate prevention and diagnosis / initial management planning of dementia mate wareware will lead to continued major upstream impacts on service demands and whānau well-being.

Awareness and risk reduction

If COVID has taught this country anything, it is the value of "**flattening the curve**", that is, using preventative strategies to reduce overall numbers. Yet, so far, the discussion of revised models does not appear to integrate primary or secondary prevention into its structure, or the factors that support this, such as health literacy. There is a wealth of evidence summarised in a landmark Lancet report about the role of potentially modifiable risk factors for dementia mate wareware [1]. Local research has estimated that 47% of dementia cases in New Zealand Europeans would be potentially preventable if all risk factors were eliminated entirely, and the prevention potential is over 50% in Māori and Pacific peoples [17]. This could include encouraging lifestyle changes for at-risk people through health improvement practitioners alongside subsidised hearing aids [18].

Diagnosis and management

A timely diagnosis of dementia allows people to plan for their future care while they are able. It opens access to early interventions and supports the aim to preserve people's functional capability and well-being for as long as possible. However, primary care has inadequate **workforce capability and capacity** to support timely and accurate diagnosis and comprehensive initial management planning, and this must be covered in the revised models. "**Tertiary prevention"** of avoidable complications must be a strong part of the re-design process.

We help prevent needs from developing or increasing.

What emerges from the Dementia Mate Wareware Ecosystem's discussions is a sense of frustration about being trapped organising "ambulances at the bottom of the cliff" when they can see the missed opportunities "at the top of the cliff". A system's duty to meet eligible needs differs from its duty to prevent needs from developing or increasing [19].

> *If the goal of a re-designed aged care system is the creation and maintenance of a healthy, happy cohort of older people, then the system would assume an entirely different focus and function. Given what is known about how the absence of access to timely support hastens function loss, why would a re-designed system wait and demand proof of loss (via functional assessments) then start offering incremental access as the antidote. It is acknowledged that primary prevention services and aged care aren't one and the same, however the wisdom of one must surely inform the other. [20]*

In essence, the lifespan approach to living well across the dementia journey is a broad preventative model. We want our re-designed aged care and support system to **proactively promote wellbeing and functional ability**.



REDUCING RISK / STRENGTHENING

For example:

- Brain health promotion to help prevent dementia
- Community stigma reduction and awareness raising to help prevent social disability
- Community pharmacy medication reviews, medication management support, and appropriate antipsychotic prescribing to reduce harm from medicines
- Strengthening the dementia-capability of the formal workforce through training
- Education, support, and flexible respite options for whānau carers to help prevent burnout
- Advanced care planning and shared goals of care
- Whānau ora approaches



TIMELY INTERVENTION

For example:

- Timely diagnosis of dementia / cognitive decline in primary care.
- Restorative interventions including
  - Intensive restorative interventions, for example, to support successful discharge from the hospital.
  - Community post-diagnostic support programmes that proactively address broader social and psychological needs.
  - Cognitive stimulation therapy and "living well" meaningful activity programmes
- Elder abuse services
- Easy access to information and education
- Service navigation case management
- Timely InterRAI assessments
- Recognition and support of dying in line with the Te Ara Whakapiri guidelines



ON-GOING ENABLING SUPPORT

For example:

- Consistent care teams that follow person-centred, enabling and recovery approaches
- A holistic approach to assessing needs and proactively addressing the factors that impact on well-being across services
- Accessible primary care support for dementia mate wareware management

Care is... **enabling**

3

Dementia is progressive. Most forms of dementia can't be cured or reversed. This can lead to fatalism and stigma from health and care workers and systems and the exclusion of people living with dementia from support that could enable them to lead their possible lives.

The right enabling support can improve the experience of living with dementia mate wareware [21]. This can take the form of specific interventions and more generally, an enabling approach to day-to-day care interactions to minimise secondary losses of ability and maximise potential [22].

The Future of Ageing Well Funding and Service re-design must be underpinned by explicit inclusion of people living with dementia mate wareware in restorative / enablement goals.

We recognise the potential of people living with dementia mate wareware.

We support people to maintain and develop their own strengths and abilities to enable them to live well.

We recognise the strengths and potential of people living with dementia mate wareware.

People living with dementia mate wareware can benefit enormously from services that maximise functional abilities / living well in the context of progressive dementia mate wareware, but the outcomes may not fit neatly into independence or restoration to full intrinsic capacity. A focus on restorative interventions as time-limited effective rehabilitation, recovery and restoration after acute events [23] to enable 'independent living' to 'step down care' [24] may over-emphasise the goal as the service-defined outcome of reducing the need for care. Goals must focus on outcomes for older people instead not just providers /services.

Goals define eligibility or exclusion. Early adopters of restorative home and community support services in Canterbury struck unintended complications when people with dementia and other chronic, incurable, progressive conditions were sometimes disadvantaged by having their access to services restricted because of the interpretation that they could not have 'truly' restorative care plans to return to lower levels of care.

This is not a criticism of the programmes themselves. We welcome the inclusion and expansion of intensive time-limited restorative/reablement care programmes such as START and CREST to future models of aged care. We know that these are an effective and enabling approach for helping support the return to home from hospital. They are an important part of the continuum of enabling service (see the following page).

The Future of Ageing Well Funding and Service Models must allow a broader, flexible, **enabling good lives** approach to enable people living with dementia mate wareware to do what is important to them and maximise well-being. Outcomes may include supporting everyday living activities, supporting mobility and physical function, supporting cognition and communication, and supporting social engagement and participation in communities. The guiding principle that care is enabling, including for people living with dementia mate wareware, must be **consistent** across the integrated care and support system

- in the goals of specific rehabilitation and restorative programmes
- in consistent, ongoing funded support for restorative post-diagnostic support
- in the goals for home and community services and aged residential care, and reflected in the approach taken in care interactions in these settings
- in the access to allied health professionals.

> Quote from Network Consultation Hui: *When it comes to dementia we need to go beyond restorative, to progressive, living with, ageing well.*

We support people living with dementia to maintain and develop their own strengths and abilities

Rehabilitation, reablement/restorative care, and enabling approaches to services all focus on helping people maximise their functional ability, working with people to identify and achieve goals that are meaningful to them, and having a collaborative approach to care. They can be seen as being part of a continuum [25]. **People living with dementia mate wareware should have access to the full continuum:**

REHABILITATION

Rehabilitation is the most intensive level. It is time-limited and requires partnership with secondary care. Rehabilitation aims to restore recently lost function, for example after a fall. Rehabilitation must be **available in ARC** (permanent and respite) and it must be available to people living with dementia mate wareware with rehabilitation needs.

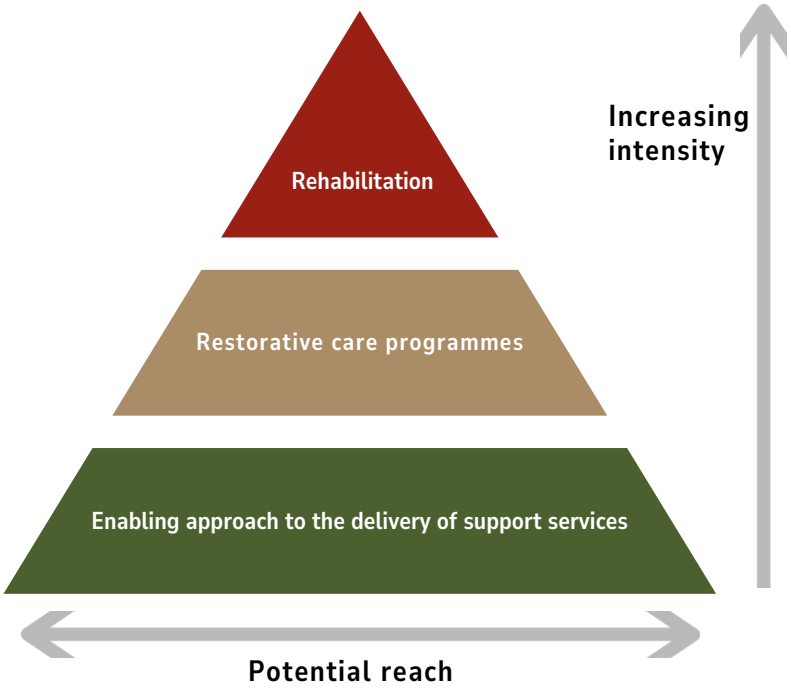
RESTORATIVE CARE PROGRAMMES

This is the next step down in intensity and aims to restore or maintain people's abilities and roles. This includes time-limited interventions helping people living with dementia mate wareware maintain functional ability within the person's specific goals, for example, when discharged from hospital. **People living with dementia mate wareware must not be excluded.**

This also includes post-diagnostic support programmes that address broader social and psychological needs, such as education, group-based programs and opportunities to reconnect with the community for people living with dementia and their whānau [25]. **NGOs are key providers.**

ENABLEMENT APPROACH TO HCSS & ARC SERVICES

This is the lowest tier in terms of intensity. It is an "always there" ethos as part of person-centred care rather than a specific programme. It aims to maintain and enhance people's abilities and participation by working with people rather than doing for them and thinking about what they can do instead of what they can't. This requires **consistent person-centred dementia care training.**



Note: Restorative care programmes are also sometime called reablement programmes. We use the term enabling for clarity as it separates the general concept from time-limited approaches [26,27], is easily understood by older people [28], and encompasses the progressive nature of dementia mate wareware [29].

Care is... **flexible**

4

The goals of clinical and support services should be meaningful and important to the person with dementia mate wareware and their family / whānau. What is important to people varies widely so there must be flexibility to respond to this.

When services are not flexible enough to provide a good fit, people may decline them despite having unmet needs.

We need dementia matewareware aware Ageing Well Funding and Service Models that achieve equity for all population groups in Aotearoa New Zealand.

We have the capacity to meet diverse needs and priorities for people and whānau affected by dementia mate wareware in support and respite.

We offer options

Service options need to be diverse to reflect the diversity of people, families and whānau living with dementia. **Choice is an equity issue**. In particular, people require:

- Culturally appropriate service options.
- Age-appropriate service options for people living with younger-onset dementia.
- A broader range of service options, for example, for respite.
- Options that prevent disadvantage for those on the 'wrong side' of the digital divide.

These revised models must align with **Te Tiriti o Waitangi obligations**: tino rangatiratanga, equity, active protection, options, and partnership. They must be based on the principle that an approach grounded in Te Ao Māori underpins the design, development and delivery of solutions and programmes that work for Māori whānau.[6] The re-designed Future of Ageing Well Funding and Service Models must address the need to **pluralise trusted models for varying demographics**, including Māori models [30] and models co-designed with specific Pacific communities. The re-designed Ageing Well Funding and Service Models will need to encourage the co-design of accessible, appropriate, and effective dementia mate wareware services within tangata whenua and other identity groups. To be effective at addressing equity concerns, these services are unlikely to be 'business-as-usual' modified to look more appropriate. Instead, it will require service providers to meet directly with the communities involved to understand what they need and to add the dementia mate wareware sector's knowledge and experience to the strengths of those communities so that something new can be developed [31].

We have the capacity to be flexible

Home and community support services

Home and community support services need flexibility to be able to:

- value social goals as well as health goals.
- respond to the person in the moment.
- ask, "What helps to make more good days for you?" or "What can I help you with today?" rather than coming into the interaction with an agenda or list of tasks.
- be able to "do what it takes" to achieve a big-picture goal.
- provide care that is culturally appropriate for each person living with dementia mate wareware
- be comfortable taking a Whānau Ora approach when working with Māori.

This requires funding and models to ensure:

- **Dementia-friendly provider organisations** not just expectations for individual staff.
- Consistent and clear valuing of **social goals** for support services
- **Time**. Care is provided at the pace of the person living with dementia. It is difficult to be flexible and person-centred in time-pressured home visits.
- Flexibility in **funding** to allow choice and creativity.

Respite care

We appreciate the inclusion of flexible respite care in the aspirations for the Future of Ageing Well Funding and Service Models provided for discussions. The revised Funding and Service Models have the potential ability to make a significant contribution to this component of the Dementia Mate Wareware Action Plan. Respite can be a fraught issue when change and poor person-environment fit cause reluctance and distress, and lack of options exacerbates carer stress. Respite should include funded **options** for:

- In-home respite: usually, a paid care worker comes to the home and stays or takes the person out of the house for a few hours
- Centre-based day respite (daycare): This type of respite usually takes place at a day centre. It offers personalised structured activities or group activities.
- Community access respite: Community access respite provides meaningful social connections and activities to people with dementia mate wareware, usually in a group setting. This includes community-based activity programmes offered by NGOs and kaupapa Maori groups.
- Overnight or weekend respite: Overnight care might be provided in a variety of settings including at home, in a respite house ('cottage-style' respite) or the home of a host family. The Dementia Network hui identified overnight support as particularly important for carers of people living with dementia mate wareware given disrupted sleep patterns.
- Respite in a residential aged care facility: People who need help every day can arrange to stay in an aged care facility, either on a planned or emergency basis

Flexibility must also extend to **rural areas, people living with young onset dementia mate wareware, and Māori and Pacific peoples** respite care models co-designed with the communities. Flexibility in choice may be facilitated by initiatives to

- to promote partnerships with iwi, hapū, and kaupapa Māori organisations, and with other population-specific services
- support the national rollout of successful local projects, such as the Budget 2022 Dementia Mate Wareware initiatives and Dementia Canterbury's comprehensive younger-onset dementia programme.

Aged residential care

In many areas of the country, there is a crisis in the availability of any **specialist dementia mate wareware (psychogeriatric) care**, let alone a choice. As the Aged Care Commissioner notes, the aged residential care sector has decreased its provision of hospital-level care, especially much-needed psychogeriatric care. From January 2022 to June 2023, the Aged Care Association reported that around 66 specialist dementia mate wareware or psychogeriatric care beds had closed [15]. The environment of third-party provision of psychogeriatric care does not currently meet equity requirements for provision across the country [32]. We support the conclusion of the Sapere report that market conditions alone will not ensure beds are sufficient and equitable across areas and rurality, particularly for dementia and psychogeriatric beds and short-term stays / respite care. It will be an essential component of the Future of Ageing Well Funding and Service Models to idenitify strategies for nationally equitable and culturally safe coverage for dementia and psychogeriatric care levels of aged residential care.

We echo the Aged Care Commissioner's call to address the significant gap in the availability of **kaupapa Māori** aged-care services for people with dementia mate wareware, particularly psychogeriatric care needs [15]. We note the conclusions of a report commissioned by the New Zealand Health Quality & Safety Commission that current aged residential care contracting can be a barrier or enabler to innovative Māori-led models [33]. The report suggests several ways forward:

- Develop policies that promote equity and prioritise the monitoring of aged residential care access and quality outcomes for Māori.
- Establish an aged residential care workforce that is capable of providing culturally safe care and that is valued and compensated for both clinical and cultural skills.
- Support and adequately resource the development of kaumātua-led and Māori-led aged residential care
- Integrate tikanga Māori, te reo Māori, and Māori cultural values into care models authentically, involving and resourcing appropriate expertise.
- Allow flexibility in the contracting for aged residential care services to enable care delivery that can accommodate more than just the resident's clinical needs.
- Acknowledge the diversity of Māori and recognize that appropriate models of care will vary for different regions, different whānau, individuals, and age groups.
- Socialise the idea of increased care in later years as normal and encourage whānau discussions about wishes and realities throughout the life course.

Primary care

Primary care is central to the diagnosis and medical management of dementia mate wareware. People living with dementia mate wareware are therefore particularly vulnerable to the crisis in GP availability.

We support the emergent multi-disciplinary **Comprehensive Primary Care Team** models of care [34]. Strengthening comprehensive primary care teams may reduce an exclusive focus on individual doctor consultations and help to improve supply and accessibility, to help more people access timely and accurate diagnoses of dementia mate wareware in primary care.

Older people generally value enduring relationships with their care team and having **consistency** with the care team members with whom they interact [15]. This is even more important for people living with dementia mate wareware. Familiarity fosters competence and confidence for the person living with dementia mate wareware and, by knowing the person, fosters person-centred care and timely identification of changes. General practice models based on people seeing the next available health professional are a poor fit for people living with dementia mate wareware. There must be flexibility to allow a consistent relationship with key health professional/s for people living with dementia mate wareware.

We support a review of delivery models for primary care. The **15-minute GP appointment** system doesn't work well for people living with dementia mate wareware. 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 for chronic conditions. We need new funding models that better fit the complex and ongoing needs of people living with dementia mate wareware and their families. The baseline capitation model has to change to recognise complexity - including dementia mate wareware explicitly - as well as comorbidity and deprivation.

Community led / NGOs

Our consultation strongly emphasised how **essential** the services and support provided by community led NGOS are. These organisations are a taonga for people living with dementia mate wateware and the whānau who support them.

The Dementia Mate Wareware Action plan includes as a first priority for improved services the commissioning of at least 12 months' **post-diagnosis support** to equip people to live their best possible lives, including but not limited to:

- information on what to expect,
- services available and their rights;
- tools and support to plan and prepare for the future; support services to strengthen resilience and wellbeing;
- Cognitive Stimulation Therapy and other proven interventions to maximise function;
- a long-term plan including referrals to ongoing services and support.

We also note the call for all people who identify as Māori and their whānau should have access to a specific post-diagnostic service co-designed with local iwi or a delegated authority [31].

Post-diagnostic support provision relies on Alzheimers New Zealand and Dementia New Zealand organisations, along with other community-led and non-government organisations. Health New Zealand **funding contracts** are outdated, grossly inadequate, and inequitable across regions. We note that Dementia New Zealand and Alzheimers New Zealand have submitted a shared model of care proposal for funding, including workforce costings. We are aware that Alzheimers New Zealand and Dementia New Zealand have indicated to Te Whatu Ora that some of their member and affiliate organisations are already facing existential funding crises. These organisations are providing most of the evidence-based post-diagnostic supports and havete the community credibility or experience to do so. The re-designed Ageing Well Funding and Service Models must value this essential pillar of the dementia mate wareware ecosystem.

Care is... **person and whānau-centred**

5

We welcome the aspiration for a person- and whānau-centred aged care sector.

Person-centered care can positively improve the psychosocial experience of care for service users and for care team members, and help improve safety, quality and cost-effectiveness of care. It is internationally recognised as the gold standard for dementia care. In a uniquely Aotearoa New Zealand context, whānau-centred approaches are a powerful catalyst for creating positive change [35].

A dementia-capable workforce is well-trained and addresses the complex and highly variable needs of people living with dementia mate wareware and their caregivers withing these approaches [35,36]. The dementia matewareware aware Ageing Well Funding and Service Models must have dementia capability of the workforce as a prioirty.

We are a dementia-capable workforce.

We understand, respect, and are responsive to the whole unique person and whānau affected by dementia mate wareware.

The principles

In the context of dementia care, a person-centred approach [37] has four components:



VALUING PEOPLE

Valuing people living with dementia and those who care for them: promoting human rights and citizenship entitlements enables people to continue to participate in their communities.



INDIVIDUAL LIVES

Recognising that all people are different: everyone has a unique combination of history and personality, physical and psychological strengths and needs, preferences and values, social and economic resources, and cultural identities. Support must therefore be strength-based and flexibly tailored to a person's unique situation.



PERSONAL PERSPECTIVES

Looking at the world from the perspective of the person living with dementia: recognising that each person acts from this perspective. Support is based on empathy and sees so-called 'challenging behaviour' as a communication of unmet needs.



SOCIAL ENVIRONMENT

Providing a social environment that accounts for our psychological needs: support that enables social inclusion in relationships and communities, and helps people to be as active and involved in their own care as possible, treated as an equal partner with their caregivers.

For Māori families, there must also be capability and commitment to work in a whānau-centred approach.



WHĀNAU-CENTRED / WHĀNAU ORA

The Whānau Ora / whānau-centred approach is culturally grounded, holistic, and focused on addressing individual needs within a whānau context and improving the well-being of the whole whānau. This is a challenge to mainstream services used to working with individuals and single-issue problems. There are five essential themes for implementing a whānau-centred approach, anchored in te ao Māori (the Māori world) and shaped by whānaungatanga (relationship, kinship) [35]:

- Establishing relationships that benefit whānau
- Building whānau capability to support whānau self-management, independence, and autonomy
- Growing a culturally competent and technically skilled workforce able to adopt a holistic approach to supporting whānau aspirations
- Placing whānau needs and aspirations at the centre of integrated and accessible services
- Supportive funding, contracting, and policy arrangements, and leadership.

Pacific peoples

Pacific families have their own unique needs that vary between cultures and communities. However, service providers would be able to offer much better assistance to Pacific families if whānau-centred approaches were assumed to be a good base from which to begin listening to what they need from services. A whānau-centred approach informed by te ao Māori is not a substitute for engaging directly with Pacific communities to co-design their own services, but it is likely to be more sympathetic to the cultural needs of Pacific families than mainstream pākehā / palagi models are.

Dementia-capability

People living with dementia mate wareware should receive high-quality, person-centred, evidence-based care in every setting and location [36,37]. They should receive dementia capable care whether the support is directly related to their dementia mate wareware or not.

A dementia-capable workforce is an integrated workforce consisting of both the workforce resources (knowledge, skills, and competency) and the structural system resources that address the special needs of people living with dementia mate wareware and their whānau [36]. There must be planning for this capability in the revised Future of Ageing Well Funding and Service Models. We encourage the explicit inclusion of a tiered training needs framework across the health and social care spectrum for working with people living with dementia mate wareware and their whānau, following the example of England, Scotland and Australia:

- Awareness of dementia mate wareware, which everyone should have;
- Basic skills that are relevant to settings where staff regularly work directly with people living with dementia mate wareware, such as how to effectively communicate with people whose cognitive abilities are impaired;
- Enhanced practice skills including those required for progressing to become dementia mate wareware specialist practitioners; and
- High-level leadership and clinical expertise [38,39].

A human right

There is increasing commitment to a human and disability rights approach to achieve change for people living with dementia mate wareware [40]. Dementia is recognised under the United Nations Convention on the Rights of Persons with Disabilities. In Aotearoa New Zealand, there is a clear synergy with the Enabling Good Lives principles that are guiding Whaikaha to transform the disability support system [41].

Care is... **Integrated**

6

The negative consequences of fragmented and disjointed dementia mate wareware care are numerous, including unnecessary health and social care professional visits, emergency hospital admissions, remaining in hospital longer than necessary, and unreliable transitions through care pathways [42].

We welcome the emphasis on integration in the discussion of the Ageing Well Funding and Service Models that achieve equity for all population groups in Aotearoa New Zealand. We note that dementia mate wareware awareness will be needed in planning for navigation support, ensuring flexible access to integrated data, and developing ways of working.

We offer navigation support. We have integrated data and work together.

Hokonui Rūnanga Kaiārahi/Navigation Support

People and whānau affected by dementia often have complex needs in a complex system. Dementia Mate Wareware Navigators can assist them in accessing appropriate care and support.

Face-to-face

The Dementia Mate Wareware Action Plan [6] sets out an expectation that whānau can access 'dementia/mate wareware navigation services'. This is a named contact person trained in dementia and person-centred care and has sound local knowledge of available dementia mate wareware services to help navigate and smooth access to appropriate services (with varying titles in use). Internationally and in Aotearoa, New Zealand, there are clear recommendations for everyone to have a named case manager for their journey through post-diagnostic dementia community services [6, 31]. The revised Future of Ageing Well Funding and Service Models needs to significantly expand **access to navigators** for whānau affected by dementia mate wareware.

Technology-based

Our Dementia Mate Wareware Network has emphasised the need for a **single online entry point** for whānau to help them easily find and assess general and dementia-specific education, information, support, and care options [43]. We note the Australian *My Aged Care* and *Carers Gateway* portals as examples of this type of approach.

Integrated data

We recognise a clear need for a **single national platform for health information** that enables information to be shared across the care team for the person broadly including Te Whatu Ora, primary care, aged residential care, and home and community providers, community-led and NGO providers, secondary care and emergency services:

- to share medication information
- to enable information to 'go with' the person on entry to new settings
- to cut down repetition of providing information and duplication of tests

We know that successful regional shared data systems such as HealthOne in the South Island have made a positive difference. We await the launch of the national HIRA searchable shared information platform and patient portal. We see giving people access to information about themselves and what's happening as empowering.

The COVID-19 pandemic helped to unmask an emerging form of **technology-related social inequalities**: the ability of digitally confident whānau to support a person living with dementia mate wareware to use health technology [44]. The availability of technological options such as using a patient portal or telehealth must not become an expectation that everyone can use them.

We emphasise the importance of the dementia mate wareware ecosystem being enabled to design its own **indicators** for continuous improvement, and the strong desire to see these implemented in integrated data collection.

We work together

Ways of working

We encourage consideration of ways to encourage **interprofessional communication and collaboration** within and across services for people living with dementia mate wareware [42]. This should include better

- discharge planning
- support for transitions of care
- use of multiservice multidisciplinary team meetings for complex cases in aged residential care
- integration of community-led and NGO providers through referrals, data sharing, and inclusion in multi-disciplinary communication.

Whānau / family as partners

Involving whānau / family carers as partners in decision-making and care of the person living with dementia mate wareware is recognised as an integral part of providing good quality integrated care for people living with dementia mate wareware [32,45]. Whānau are often not just direct providers of care but also facilitators of care [45]. They have an important role as experts in the person living with dementia mate wareware when their verbal communication becomes more limited. The Dementia Mate Wareware Governance Ecosystem is committed to a **whānau / family approach** to all aspects of dementia mate wareware health and social support and to holding the voices of whānau / family in the heart of planning. Indeed the Network has clearly asserted that whānau carers should be integrated into planning as an essential backbone of the dementia mate wareware workforce [43].

Workforce planning

To achieve integrated workforce planning, we need to understand the needs of our communities and the contributions of different practitioners and sectors and work together to ensure that there is appropriate capacity [46]. We note that this dementia-capability planning must include

- planning for the **kaiawhina** (unregistered) workforce who provide the greatest amount of hands-on care for people living with dementia mate wareware,
- addressing **crises in staffing** in providers outside Health New Zealand. Ongoing integrated workforce planning and pay equity mechanisms could help prevent future exodus from other areas of the sector to Health New Zealand acute hospitals.
- dementia mate wareware **training** for comprehensive primary care teams

We reiterate the importance of **time and staffing levels**, recognising that people living with dementia mate wareware typically need more time. Lack of funding has been described as the greatest barrier to providing good quality integrated care for people living with dementia mate wareware [47].

References

[1] Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., ... & Mukadam, N. (2020). *Dementia prevention, intervention, and care: 2020 report of the Lancet Commission*. The Lancet, 396(10248), 413-446.

[2] Wimo, A., & Prince, M. J. (2010). *World Alzheimer Report 2010: the global economic impact of dementia*.

[3] Zafeiridi, E., McMichael, A., O'Hara, L., Passmore, P., & McGuinness, B. (2024). H*ospital admissions and emergency department visits for people with dementia*. QJM: An International Journal of Medicine, 117(2), 119-124.

[4] Kerse, N., Lapsley, H., Moyes, S., Zawaly, K., & Hayman, K. (2017). *Dementia: supplementary findings from LiLACS NZ for Section five, 'Service use and common health conditions*' in the report 'Health, independence and caregiving in advanced age'.

[5] Associate Minister of Health. 2016. *Healthy Ageing Strategy*. Wellington: Ministry of Health.

[6] Dementia Mate Wareware Rōpū, Alzheimers New Zealand, New Zealand Dementia Foundation, & Dementia New Zealand (2021). *Improving dementia mate wareware services in Aotearoa New Zealand Action Plan*.

[7] Health New Zealand te Whatu Ora (2024). *Dementia Mate Wareware* [webpage] https://www.tewhatuora.govt.nz/for-health-professionals/clinical-guidance/specific-life-stage-health-information/health-of-older-people/dementia-mate-wareware

[8] World Health Organization. (2012). *Dementia: a public health priority*. World Health Organization https://www.alzint.org/u/2020/08/Dementia-A-Public-Health-Priority.pdf

[9] Ma'u, E., Cullum, S., Yates, S., Te Ao, B., Cheung, G., Burholt, V., Dudley, M., Krishnamurthi, R., & Kerse, N. (2020) *Dementia Economic Impact Report 2020*. University of Auckland. https://cdn.alzheimers.org.nz/wp-content/uploads/2021/09/Dementia-Economic-Impact-Report-2020.pdf

[10] Abey-Nesbit, R., Jamieson, H. A., Bergler, H. U., Kerse, N., Pickering, J. W., & Teh, R. (2023). *Chronic health conditions and mortality among older adults with complex care needs in Aotearoa New Zealand*. BMC Geriatrics, 23(1), 318.

[11] InterRAI New Zealand (2024, accessed 20 March). *Data visualisation*. https://www.interrai.co.nz/data-research-and-reporting/data-visualisation-2

[12] Knopf, E. (2022). *Case study: Aged Residential Care*. New Zealand Productivity Commission.

[13] Jamieson, H., Abey-Nesbit, R., Nishtala, P. S., Allore, H., Han, L., Deely, J. M., & Pickering, J. W. (2020). *Predictors of residential care admission in community-dwelling older people with dementia.* Journal of the American Medical Directors Association, 21(11), 1665-1670.

[14] World Health Organization (2015). *World Report on Ageing and Health*. https://iris.who.int/bitstream/handle/10665/186463/9789240694811_eng.pdf?sequence=1

[15] Diagram from CareTech (2024). https://www.caretech.nl/

[16] Jecker, N. S. (2022). *Dignity in dementia care: a capability approach*. Journal of Medical Ethics, 48(12), 972-973.

[17] Ministry of Health (2013). *New Zealand Framework for Dementia Care*.

[18]. Ma'u, E., Cullum, S., Cheung, G., Livingston, G., & Mukadam, N. (2021). *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.

[19]. Social Care Institute for Excellence (2021). *Prevention in social care*. UK

[20] Older Persons Advocacy Network (2019). *Aged care program design*. Australia.

[21] Quinn, C., Pickett, J. A., Litherland, R., Morris, R. G., Martyr, A., & Clare, L. (2022). *Living well with dementia: What is possible and how to promote it*. International Journal of Geriatric Psychiatry, 37(1).

[22] Loveday, B. (2012). *Leadership for person-centred dementia care*. Jessica Kingsley Publishers.

[23]. Ministry of Health. 2020. National Framework for Home and Community Support Services (HCSS). Wellington: Ministry of Health.

[24]. Inder, A. (2024, 7 May). Ageing Well, Building the future of health - Stakeholder hui [online]. https://www.tewhatuora.govt.nz/for-health-professionals/health-sector-updates/stakeholder-hui/#7-may-2024

[25] Poulos, C. J., Bayer, A., Beaupre, L., Clare, L., Poulos, R. G., Wang, R. H., ... & McGilton, K. S. (2017). *A comprehensive approach to reablement in dementia*. Alzheimer's & Dementia: Translational Research & Clinical Interventions, 3(3), 450-458.

[26]. Poulos, C. J., & Poulos, R. G. (2019). *A function-focused approach in primary care for older people with functional decline*. Australian Journal of General Practice, 48(7), 434-439.

[27] Sims-Gould, J., Tong, C. E., Wallis-Mayer, L., & Ashe, M. C. (2017). *Reablement, reactivation, rehabilitation and restorative interventions with older adults in receipt of home care: a systematic review*. Journal of the American Medical Directors Association, 18(8), 653-663.

[28]. Hearn, R. (2023). *Reablement' – what does it mean?*. [online] Australia. https://www.resthaven.asn.au/reablement-what-does-it-mean/

[29]. Bødker, M. N., Christensen, U., & Langstrup, H. (2019). *Home care as reablement or enabling arrangements? An exploration of the precarious dependencies in living with functional decline.* Sociology of Health & Illness, 41(7), 1358-1372.

[30] Menzies, O., Garrett, N., & Dudley, M. (2024). *He Taonga Te Wareware: Connecting Older Māori Experiences of Wairuatanga with Mate Wareware (Dementia)*. Journal of Cross-Cultural Gerontology, 1-16.

[31]. Croucher M, Chamberlain M, & Gee S. (2022). *Post-diagnostic community services for people living with dementia in Aotearoa New Zealand*. Report prepared by the New Zealand Dementia Foundation for Dementia New Zealand.

[32] Copeland, B., Barak, Y., & Cheung, G. (2023). T*he 2023 New Zealand psychiatry of old age services and workforce survey*. Australasian Psychiatry, 31(4), 480-484.

[33] Hikaka, J., & Kerse, N. (2021). *Older Maori and aged residential care in Aotearoa*. Report commissioned by the Health Quality & Safety Commission New Zealand.

[34] General Practice NZ (2019). *Workforce and resources for future general practice: Discussion paper*.

[35] Te Puni Kōkiri. (2015). *Understanding whānau-centred approaches: Analysis of Phase One Whānau Ora research and monitoring results*.

[36]. Ty, D., & McDermott, M.(2021). *Building Workforce Capacity to Improve Detection and Diagnosis of Dementia*. Milken Institute.

[37]. Lin, S. Y., & Lewis, F. M. (2015). *Dementia friendly, dementia capable, and dementia positive: concepts to prepare for the future*. The Gerontologist, 55(2), 237-244.

[37]. Brooker D. (2004) *What is person-centred care in dementia*? Clinical Gerontology, 13, 215–222.

[38] Pit, S., Horstmanshof, L., Moehead, A., Hayes, O., Schache, V., & Parkinson L. (2022). *Workforce Education and Training Standards for Dementia: an Evidence Check rapid review*. Sax Institute for Dementia Training Australia, 2022.

[39]. Dementia Training Australia (2024). *National Dementia Education and Training Standards Framework*. [website] https://dta.com.au/dementia-education-standards-framework/

[40]. All-Party Parliamentary Group on Dementia (2019). *Hidden no more: Dementia and disability*. UK.

[41]. Enabling Good Lives (n.d). *Enabling Good Lives Toolbox*. [Note: Principles agreed in 2012.]

[42] Smith, R., Martin, A., Wright, T., Hulbert, S., & Hatzidimitriadou, E. (2021). *Integrated dementia care: A qualitative evidence synthesis of the experiences of people living with dementia, informal carers and healthcare professionals*. Archives of Gerontology and Geriatrics, 97, 104471.

[43]. The Dementia Mate Wareware Network / Te Tūhononga mō te Mate Wareware (2023, April). *Next steps for dementia mate wareware diagnosis and workforce development.* www.nzdementia.org/Dementia-Ecosystem/Dementia-Mate-Wareware-Network

[44] Arighi, A., Fumagalli, G. G., Carandini, T., Pietroboni, A. M., De Riz, M. A., Galimberti, D., & Scarpini, E. (2021). *Facing the digital divide into a dementia clinic during COVID-19 pandemic: caregiver age matters*. Neurological Sciences, 42, 1247-1251.

[45] Draper, B., Low, L. F., & Brodaty, H. (2018). I*ntegrated care for adults with dementia and other cognitive disorders*. International Review of Psychiatry, 30(6), 272-291.

[46]. Social Care Institute for Excellence (SCIE). (N.D.) *Integrated workforce for integrated care.*
https://www.scie.org.uk/integrated-care/research-practice/enablers/integrated-workforce/#whatis

[47] Gilster, S. D., Boltz, M., & Dalessandro, J. L. (2018). *Long-term care workforce issues: Practice principles for quality dementia care*. The Gerontologist, 58(suppl_1), S103-S113.