

Repositioning Dementia: A new start

Abbe Anderson
National Director, Commissioning




A bit about me...

- Grew up in Colorado mountains
- Volunteered with medical aid org, Mercy Ships, based in Tauranga 1992-1994
- Worked as a Medical Assistant in US general practices
- MBA at Otago Uni late 1990's
- Worked with Southland DHB until 2002
- CEO of Brisbane North Division of General Practice, Medicare Local and Primary Health Network until 2020
- PhD in Public Health and Community Medicine from University of New South Wales
- Institute for Urban Indigenous Health
- Sunshine Coast Hospital and Health Service
- Beyond Blue



  Nola Anderson, Erin Stevens McKay and 13 others 3 Comments

 Like

 Comment

 Share



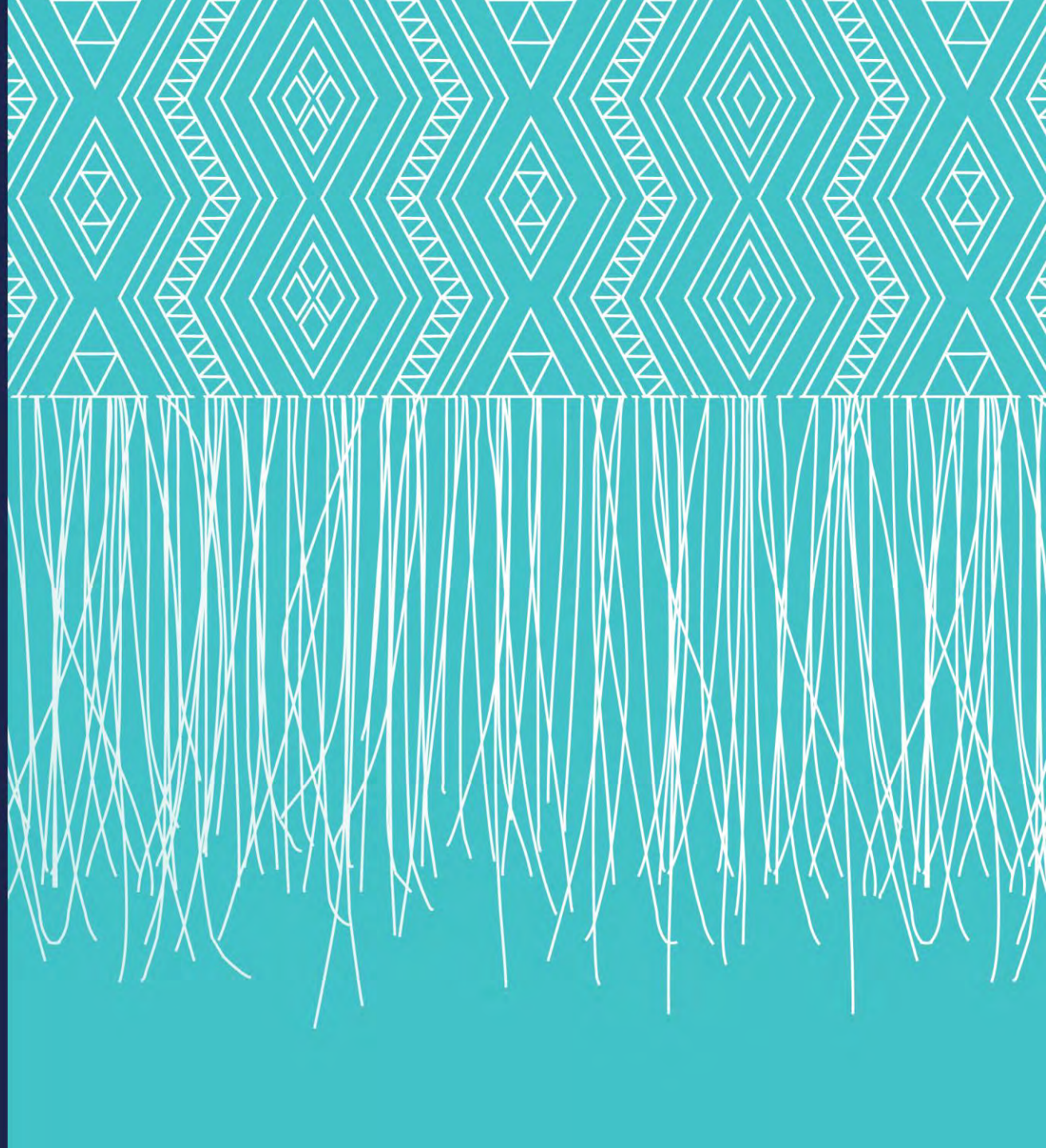
Nola Anderson
But have you climbed Mt. Garfield ? Your Mom has. ...

Love · Reply · 1d



Abbe Anderson
No, Mom. Alas, I am no competition for your greatness. Your legend will outlive us all! 🥰❤️ ...

Like · Reply · 16h



Equity.

Single, unified system.

“The most significant reforms I’ve witnessed in my lifetime.”



Our new health system

The reforms that came into effect on 1 July 2022:

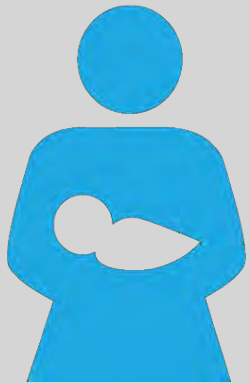
- strengthened Manatū Hauora's role as chief steward of the health system
- established the Public Health Agency within the Ministry, responsible for public health policy, strategy, monitoring and intelligence
- established Te Whatu Ora – Health New Zealand, which plans, commissions and delivers health services through a nationally coordinated health system
- established Te Aka Whai Ora – the Māori Health Authority, which prioritises the voice of whānau Māori, and ensures health services deliver equitable outcomes to Māori

Te Pae Tata - Interim New Zealand Health Plan

- Six priority actions:
 - whānau at the heart of the system to improve equity and outcomes
 - embed Te Tiriti o Waitangi principles and obligations across the health sector
 - develop an inclusive health workforce
 - keep people well in their communities
 - develop greater use of digital services to provide more care in homes and communities
 - establish Te Whatu Ora and Te Aka Whai Ora to support a financially sustainable system

National Commissioning Teams

- System Architects
 - Design national health systems
 - Content experts from the sector together with lived experience, care partners and whānau



Starting
Well



Living
Well



Ageing
Well



Mentally
Well

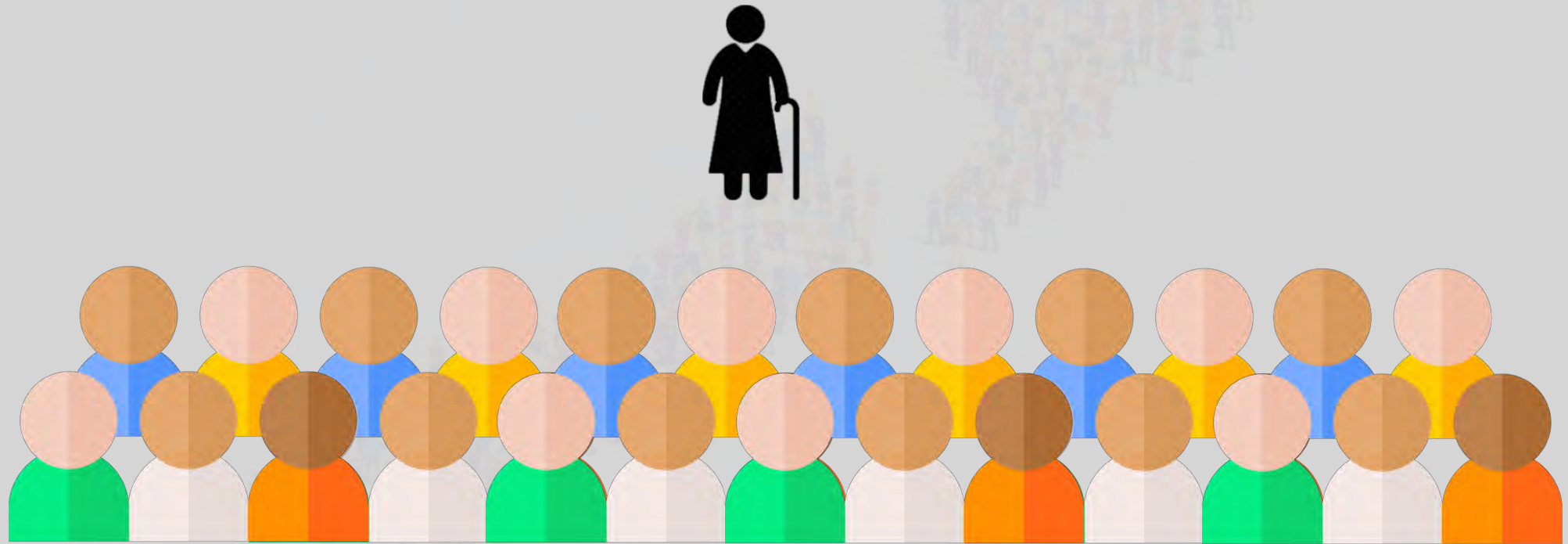
Reimagining Aged Care



Ageing
Well

Reimagining Aged Care

- Nationwide community conversation
- Developing long-term national blueprints



Te Pae Tata - Interim New Zealand Health Plan

- Dementia Mate Wareware will continue to grow in Aotearoa New Zealand
- 70,000 people are living with Dementia Mate Wareware in Aotearoa New Zealand. This is expected to double by 2050
- Implementing Budget 2022 and Government Priorities through support of the Dementia Mate Wareware Action Plan

Improving Dementia Mate Wareware Services in Aotearoa New Zealand - Action Plan

Vision

- 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.

Objectives

- Reduce the incidence of Dementia Mate Wareware
- Support people living with Dementia Mate Wareware and their family and whānau, and care partners/supporters to live their best possible lives*
- Build accepting and understanding communities
- Strength leadership and capability across the sector (Initial priority for Budget 2022)

National Dementia Mate Wareware Governance Ecosystem

Dementia Mate Wareware Leadership and Advisory Group

- Provides advice to Government on implementation of the Action Plan
- Comprises seven sector, two Whānau voice + four central agency representatives

Dementia Mate Wareware Network

- Represents the Dementia Mate Wareware sector and stakeholders
- Provides advice to the Leadership Group
- Ecosystem website
- <https://www.nzdementia.org/Dementia-Ecosystem>

National Dementia Mate Wareware Budget 2022 initiative

Initial priority areas

- Four post-diagnostic support trials
- Sixteen Dementia Navigators
- Innovative respite care options

Initial priority population groups

- Māori
- Pacific peoples
- People with Dementia Mate Wareware living in rural areas
- People with younger onset Dementia Mate Wareware

Indicative timeline for commissioning Dementia Mate Wareware services

	Timeframe
• Registration of Interest (ROI) launched	Tuesday 7 March 2023
• ROI Closing Date	Monday 27 March 2023
• Respondents notified outcome of ROI evaluation	Friday 21 April 2023
• Shortlisted ROI - Request for Proposals (RFP) launched	Thursday 27 April 2023
• RFP closing date	Tuesday 16 May 20123
• Respondents notified outcome of RFP evaluation	Friday 9 June 2023
• Contracts negotiated, agreed and signed	Friday 30 June 2023

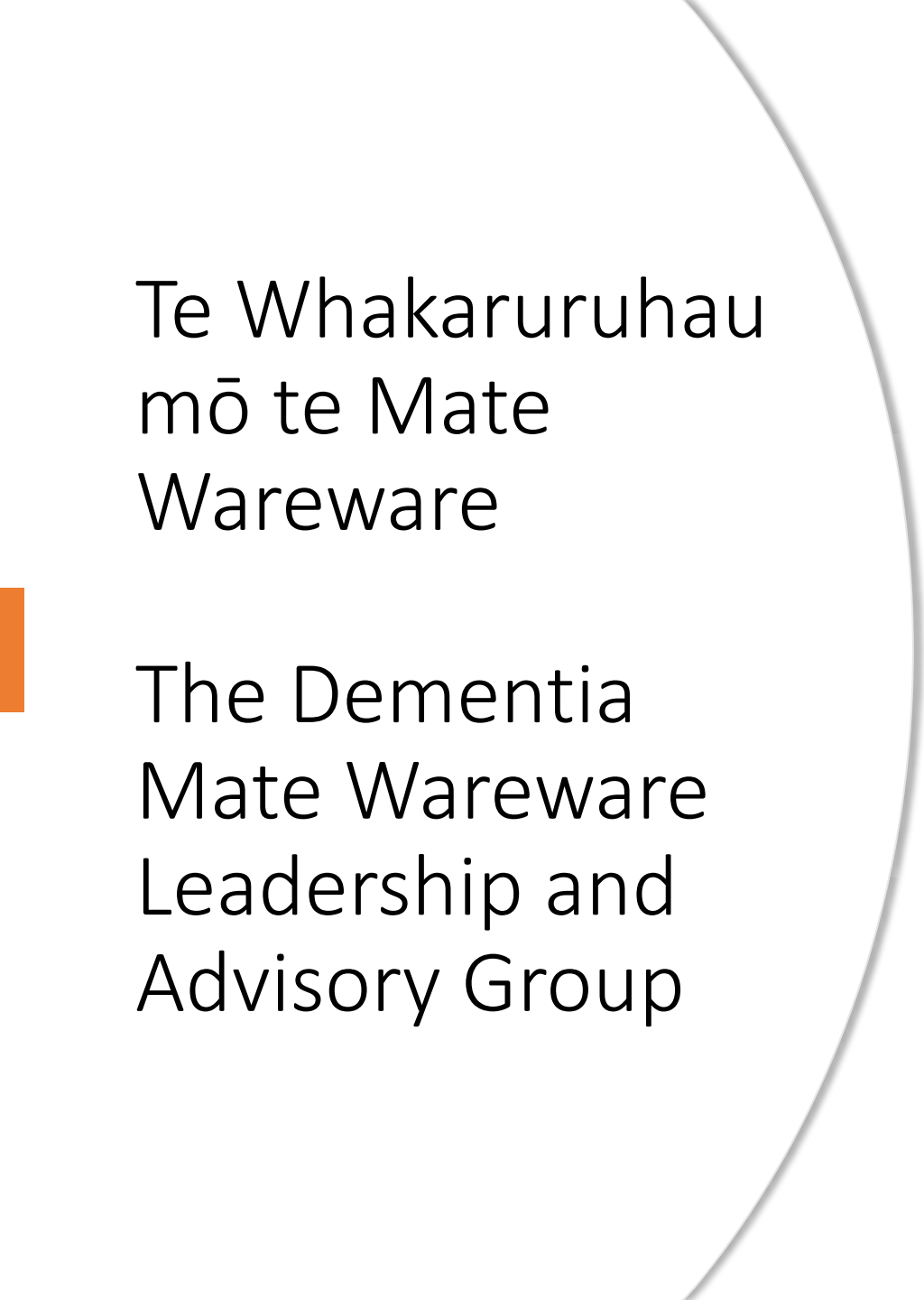
Ngā mihi nui ki a koe



Te Whakaruruhau mō te Mate
Wareware
Dementia Mate Wareware
Leadership and Advisory Group

Repositioning Dementia





Te Whakaruruhau
mō te Mate
Wareware

The Dementia
Mate Wareware
Leadership and
Advisory Group

- *is the kaiarataki – the leaders and guides – of the Dementia Mate Wareware Governance ecosystem - Te Puna Mana Whakahaere mō te Mate Wareware*
- *the Group currently includes six dementia mate wareware sector leaders along with four representatives from Central Government.*
- *Two people representing the whānau voice will be appointed to the Group soon*



Dr Makarena Dudley – Co Chair



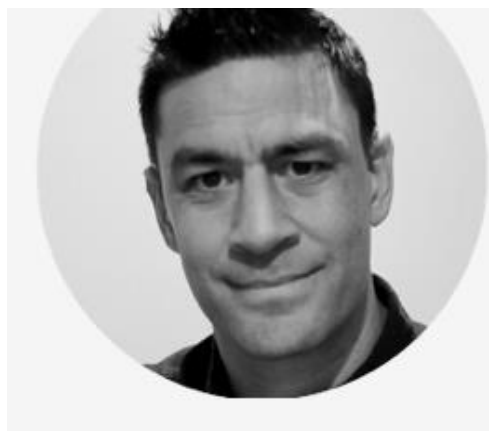
Teresa Wall – Co Chair



Dr Matthew Croucher – Deputy Chair



Anne Schumacher



Dr Etuini Ma'u



Alistair Robertson

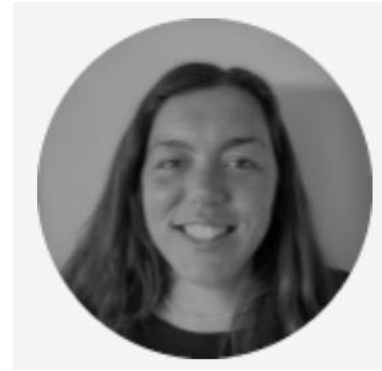
Central Agency Leaders



Harriet Pauga



Dr Kate Scott

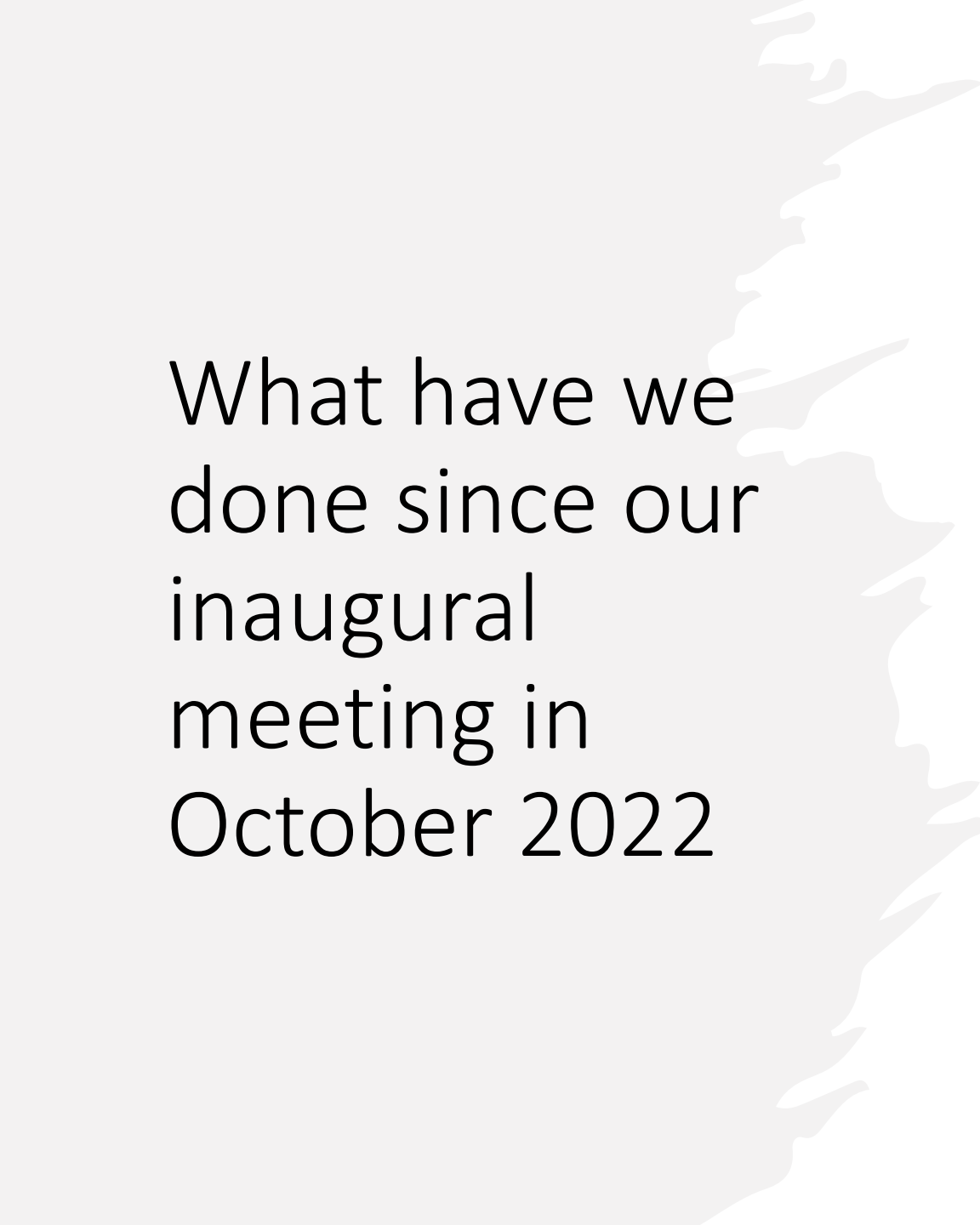


Abby Johnson

**The purpose of the Dementia Mate
Wareware Leadership and Advisory**

Group is to provide national leadership and advice across the dementia sector and advice to the Government.

This will be done through advice to Te Whatu Ora (Health New Zealand), Te Aka Whai Ora (Māori Health Authority), and Manatū Hauora (Ministry of Health) on the implementation of the Dementia Action Plan and future improvements to dementia supports for people with dementia and their whānau and carers.



What have we done since our inaugural meeting in October 2022

- in consultation with Te Tūhononga mō te Mate Wareware we provided advice to the commissioners of the Budget 2022 dementia mate wareware projects. Te Whatu Ora has written to us thanking us for our timely advice which they have accepted.
- You can find the advice on the NZ Dementia Foundation website.
- at the February 2023 Te Tūhononga mo te Mate Wareware meeting (the second meeting) initial discussions about forming groups with a special interest in topic areas like rural, dementia friendly communities, Māori and Pasifika - this is not an exhaustive list
- started planning our priorities for 2023/34 based on the actions in the Dementia Mate Wareware Action Plan. We will seek agreement from Te Tūhononga mō te Mate Wareware on these priorities.



Please be a part of
this exciting
opportunity to
design a health and
social system that
provides the best
care and support for
people with
dementia and their
whānau

- Information about Te Tūhononga mō te Mate Wareware meetings are posted on the New Zealand Dementia Foundation website
- along with regular newsletters to keep the community updated on Te Whakaruruhau mō te Mate Wareware news and initiatives.



HAUMANU WHAKAOHOOHO WHAKĀRO – MĀORI

COGNITIVE STIMULATION THERAPY – MĀORI

He puka Aratohu mā ngā Kaiwhakahaere
The manual for Group Facilitators

Makarena Dudley, Tai Kake, Gary Cheung, Kathy Peri.



Māori and Mate Wareware

Evidence suggests Māori are more likely to have mate wareware than non-Māori

Māori are more likely to suffer from mate wareware at an earlier age

Māori are less likely to access medical services for mate wareware

Māori are more likely to care for their family member with mate wareware at home however with inadequate funding





Protective Factors

- Being on the marae
- Kaumātua rōpū
- Speaking te reo maori
- Listening to te reo Māori
- Waiata
- Karakia
- Māori kai
- Rongoa Māori
- Physical activity –walking, fishing, gardening, rārangi, tai chi, chair yoga
- Being with whānau/mokopuna

Cognitive Stimulation Therapy (CST)

- A structured group treatment for people with mild to moderate dementia
- Theoretical concepts of reality orientation, validation, reminiscence, and cognitive stimulation
- World Alzheimer Report 2011,
Cochrane Review 2023, NICE Guidelines

The Aotearoa Experience



Feasibility Study



Formulate Competencies



Training Workshops

Adaptation Process

- a) Consulted with Eastern BoP Alzheimers NZ
- b) Consulted with Kaumātua ō Whakatane
- c) Changed principles
- d) Made modifications/designed activities for Maori
- e) Held Pilot in Whakatane/Opotiki
- f) Consulted with several Māori NGOs/Health organisations/Kaumātua Rōpū
- g) Rewrote Manual





Back L-R: Val Baker ~ Chris Carrè ~ Frank Hunt ~ Brian Cribb ~ Ben Rickard ~ Pāora Brown ~ Lynda Rangitauira (Kaiako)

Front L-R: Elayne Tangitu (Kaiāwhina) ~ Vicky Toa (Kaiāwhina) ~ Lucy Hona ~ Betty Richter ~ Rita Marx









	Pre-CST N=15	Post-CST N=15	p-value (Wilcoxon Signed Rank Test)
RUDAS, mean (SD)	17.7 (2.3)	19.4 (2.6)	*0.003
WHOQOL-Physical, mean (SD)	75.9 (17.1)	88.5 (8.5)	*0.003
WHOQOL-Psychological, mean (SD)	72.7 (14.8)	81.3 (8.8)	*0.024
WHOQOL-Social, mean (SD)	69.2 (15.6)	69.6 (13.3)	0.789
WHOQOL-Environment, mean (SD)	80.6 (13.3)	88.0 (9.6)	*0.006

RUDAS = Rowland Universal Dementia Assesment Scale
WHOQOL = World Health Organisation Quality of Life

Ngā

Tikang

a



Mana Tangata (person-centred)

Whakaute respect

Whakatupu / Whakakahatia Te Hononga – Whakawhānaungatanga Building relationships

Whakakahatia Te Āheitanga – Tino Rangatiratanga- Maximising potential

Wakamanawa – Te Hihiritanga – Mental stimulation

Whakāro Hōu, Me Ngā Tōpūtanga – Ngā Whakāro Hōu New ideas, thoughts/associations

Ahunga Using orientation sensitively and implicitly

Whakaaro Opinions rather than facts

Te Maumāhara Hei Hono Ki Nāianeī – Hokinga Mahara **Using reminiscence as a link to the here and now**

Taputapu Ārahi Maumahara - Provide Triggers To Aid Recall

Kōrero Tahi Stimulating language

Whakamanawa Stimulating executive functioning)

Ngā Huarahi/Akoranga Takaāwhio Implicit rather than explicit learning

Ngā Whakaritenga Continuity and consistency between hui

Mahi Tahi Me Whakawhānaungatanga Involvement And Inclusion

Kowhiri Choice)

Whakangahau (Fun)

Tinana Kori Physical Movement

Haumanu Whakaohoho Whakāro (Māori)/CST (Māori)

- We included an extra initial session of whanaungatanga as this process and the concept of whanau is central to the wellbeing of Māori.
- All activities are now embedded in a Māori context that is relevant/familiar and of interest to kaumātua/pākeke.
- The lead facilitator must be Māori and have good ability to speak te reo Māori.
- Second Facilitator should be Māori and have some working knowledge of te reo Māori.
- Participants must whakapapa to Māori

Dudley, M., Cheung, G., Kake, T., Peri, K. (2023). *Adapting Cognitive Stimulation Therapy for Māori with matawareware (dementia)* (Unpublished). The University of Auckland.

Improving Dementia Mate Wareware Services in Aotearoa New Zealand **Action Plan** 2020/2021

Support people living with dementia/mate wareware and their family /whānau supporters/care partners to live their best possible lives :

- ❖ **Cognitive Stimulation Therapy and other proven interventions to maximise function**



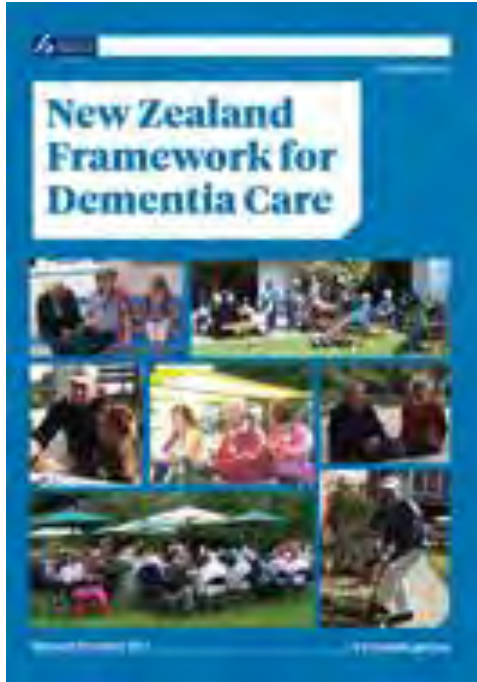






Post-Diagnostic Community Services

Anne Schumacher
Chief Executive
Dementia Wellington
23 March 2023



POST-DIAGNOSTIC COMMUNITY SERVICES

FOR PEOPLE LIVING WITH DEMENTIA IN AOTEAROA NEW ZEALAND

Croucher M, Chamberlain M, & Gee S.
Report prepared by the New Zealand Dementia Foundation
for Dementia New Zealand
October 2022





Post-Diagnostic Community Services

- Psycho-education
- Emotional & personal support
- Dementia Services navigation
- Modifying Dementia progression
- Other therapies
- Multi-modal interventions
- Special topics for Aotearoa/NZ

Psychoeducation

A programme that provides knowledge alongside emotional and motivational components to enable people living with dementia and their care partners to live well with dementia.





Dementia services navigation

A service to help facilitate access, continuity of care, and effective use of the health care system and to identify and removing barriers to care.

Mum's journey

In mid 2019 māmā was made redundant from her job at 60 years old this, coupled with the changes we'd noticed at home, made us seek medical advice.

After tests, the GP diagnosed mild cognitive impairment.

As the months went on we noticed changes in māmā's memory and went back for several visits to the GP until the probable diagnosis of vascular dementia was given.

To get this diagnosis took around 2.5 years from loss of work and clear deterioration of symptoms.

We wish it had come sooner



Mum's journey

When māmā was given the diagnosis the GP referred us to Dementia Wellington. We liaised regularly with the dementia advisor who helped us navigate the mist of uncertainty.

They have assisted with a range of resources, advice and support and most notably arranging a needs assessment.

We pushed for this assessment with our GP but they didn't grant this due to the fact that Māmā was under 65 coupled with the perception symptoms were not significant enough to validate.



Mum's journey

Now, having the needs assessment complete has helped open up opportunities for further support such as YODAT [Young Onset Dementia day programme]

What our dementia advisor Debbie has taught us is that although no one can change the outcome of dementia with the right support you can change the journey.

Multi-modal interventions

Services that deliberately combine two or more management strategies.

“It is impossible to imagine any stand-alone dementia service programme that does not include mixed elements to some extent. For example, the process of cognitive remediation will always meet some social contact goals, and the process of providing psychoeducation in a group will always meet some emotional support and service navigation goals” pg. 66

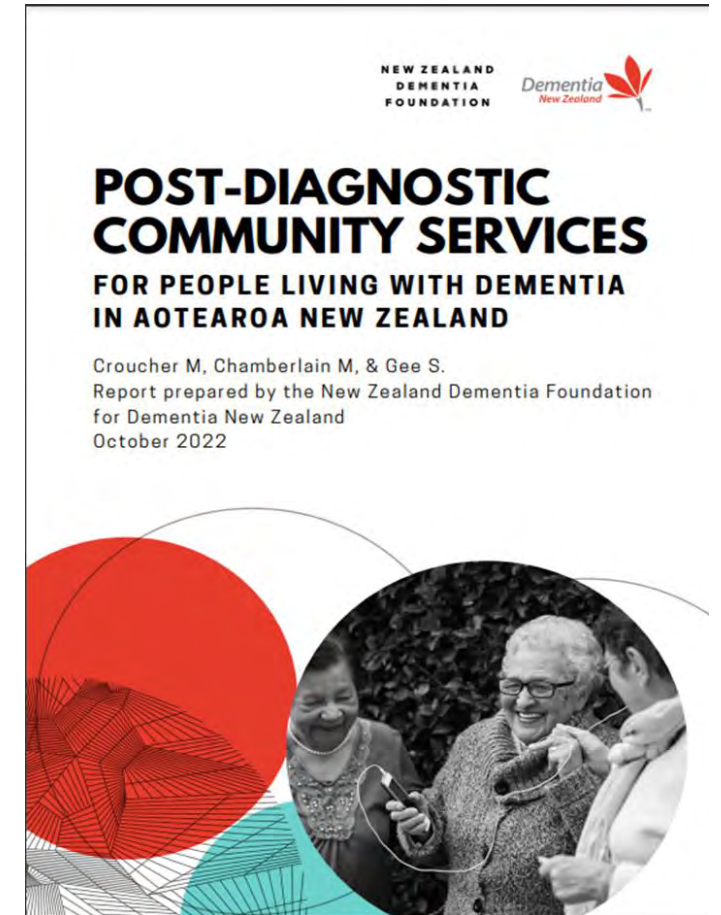


Modifying Dementia Progression

- **On this reading of the literature, a formal CST offering is the most supported disease modifying treatment modality indicated for inclusion in community post-diagnostic services in Aotearoa New Zealand.**

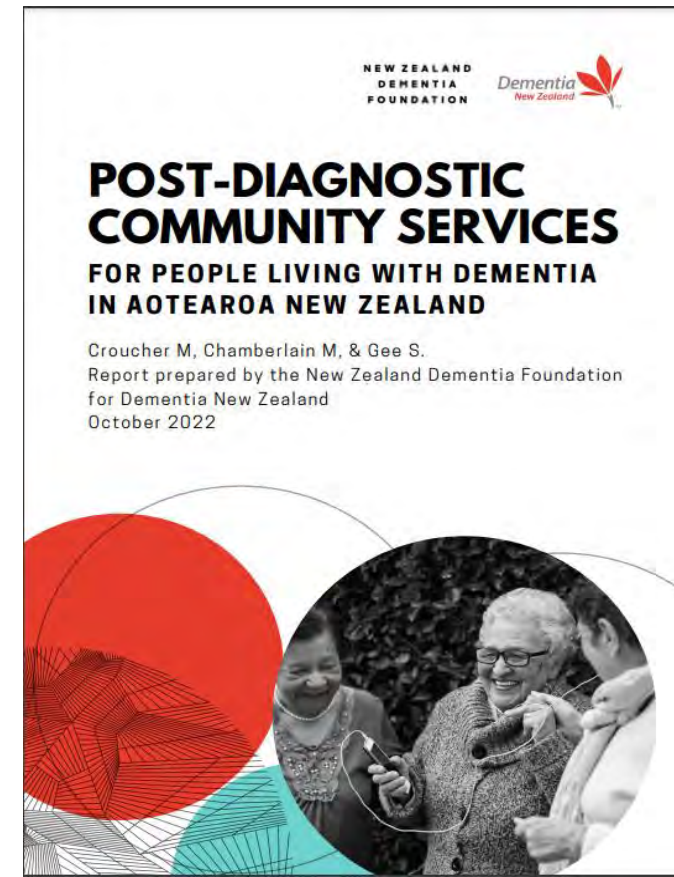
Post-Diagnostic Community Services

- Psycho-education
- Emotional & personal support
- Dementia Services navigation
- Modifying Dementia progression
- Other therapies
- Multi-modal interventions
- Special topics for Aotearoa/NZ





<https://dementia.nz/wp-content/uploads/2022/11/Post-diagnostic-Community-Services-PDS.pdf>





My Life's Journey

Tōku Haerenga

Empowering people to record their life's story, using a guided, user-friendly platform to preserve a sense of, and value of self

WHO is My Life's Journey

Yvette Bibby – Occupational Therapist

Julie Cummins – Project Manager

Taylor Hamling – App Developer

Alice Lee – Branding & Digital Designer

Zoe Barnes – Marketing

WHY My Life's Journey

Primarily, this app is built for people living with dementia mate wareware, or for anyone who would benefit from having an easily accessible, digital life story available.

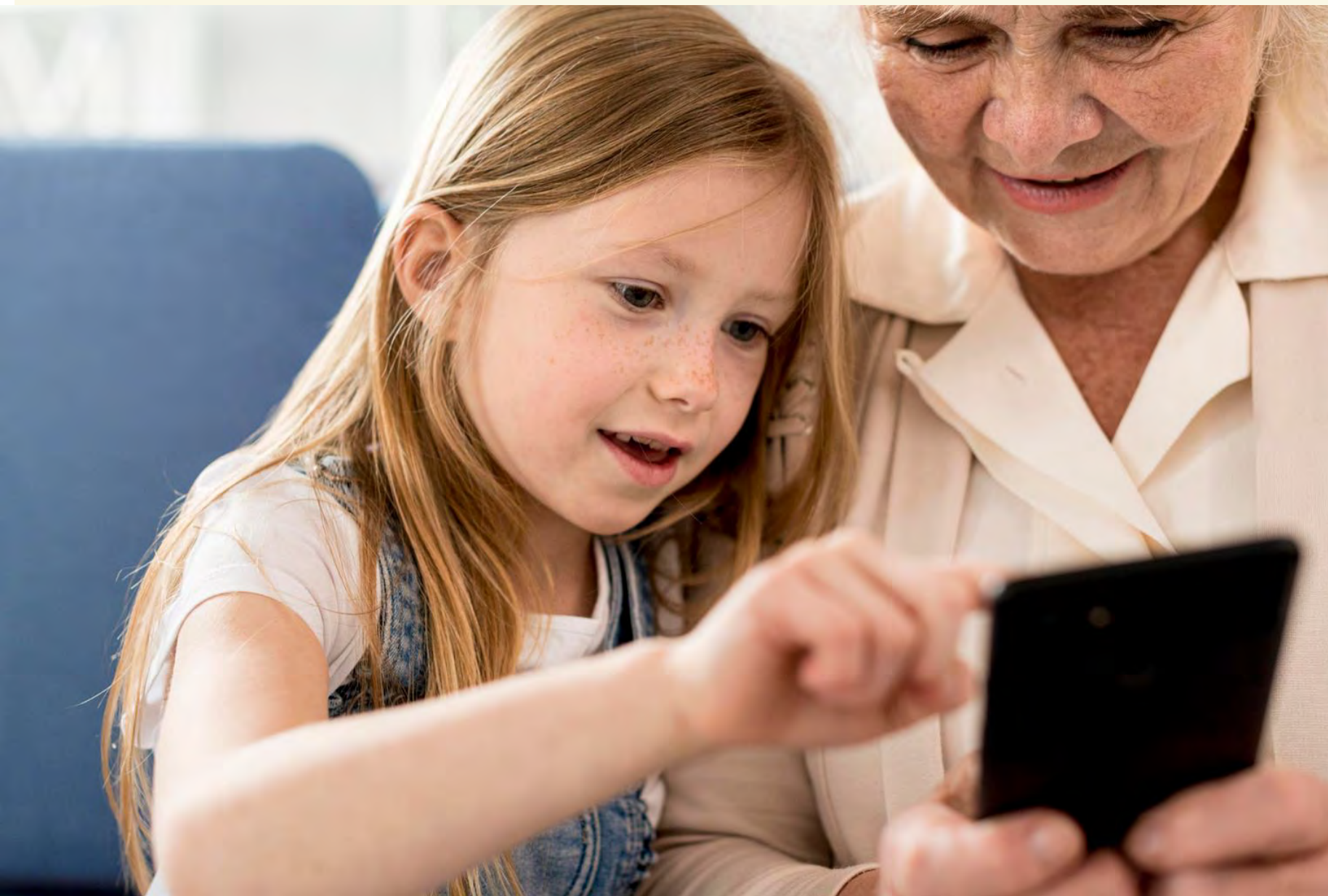
- Reflect and reminisce on moments that are important to you
- **Your** story, **your** words, **your** history

HOW does My Life's Journey work

- Tapping into reminiscence therapy
- Using guided prompts and open questions
- Involving family and friends to enrich the memories

WHAT is My Life's Journey

- Life story book in a digital format
- Utilising text, photos, audio, video and music



WHERE is My Life's Journey

Eventually, in every care
facility in New Zealand



Everyone has a life story

- Learn about someone
- Generates conversation
- Encompasses so many experiences

Additional benefits

- **Improve quality of life**
- **Draw out long term memories**
- **Tool for carers and health practitioners**
- **Authentic sense of identity**
- **Record your bucket list, goals...**
- **Provide inspiration and motivation**

Recording tips

- Text and words are your own, they are the right ones
- Your story can start from anywhere you like
- Think about what is important to you
- Just start - and see where it takes you

Telling the stories

Reflect on the defining moments in your life

- What stood out
- What did you sense and feel
- Did this moment change you...

Leaving a legacy

- How do you want to be remembered by your future generations?
- What lessons, traditions, skills do you want passed on?

www.mylifesjourney.co.nz



Alzheimer's Conference

March 2023

Carolyn Cooper

Aged Care Commissioner



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**New Zealanders are living longer.
By 2034, just over a fifth of our total population
– around 1.2 million people will be 65 and over**



Dementia/Mate Wareware

- 70,000 people living with dementia/mate wareware today
- 170,000 people living with dementia/mate wareware by 2050
- Care partners provide over 1 million of unpaid care per week

Stats from Alzheimers NZ website



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Role of the Aged Care Commissioner

- Advocate for quality health and disability services on behalf of older people and their whānau
- Support the government's commitment to Te Tiriti o Waitangi
- Provide strategic oversight and leadership to drive quality improvement
- Analyse emerging issues and report on improvements in the aged care sector



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Responsibilities

Ensure quality of care and access to health and disability services for older people, wherever and whenever needed

- in their home, primary care, community care, care home or public/private hospitals



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Statutory decision-maker on complaints and formal investigations about older people's health and disability services to protect their rights under the Code of Health and Disability Services Consumers' Rights.

- Will not have responsibility for issues such as family violence (e.g. elder abuse), housing, or retirement income
- Will work closely with wider agencies and commissions
- Will monitor responsiveness of health and disability system to the needs of older people



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10

Consumers'
rights

1 ➤ Whakamana | **Respect**

2 ➤ Manaakitanga | **Fair treatment**

3 ➤ Tu rangatira motuhake | **Dignity and independence**

4 ➤ Tautikanga | **Appropriate standard of care**

5 ➤ Whakawhiwhitinga whakaaro | **Effective communication**

6 ➤ Whakamōhio | **Full information**

7 ➤ Whakaritenga mōu ake | **Informed choice and consent**

8 ➤ Tautoko | **Support**

9 ➤ Ako me te rangahau | **Teaching and research**

10 ➤ Mana to amuamu | **Right to complain**



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Challenges for Older People





Vulnerable groups of older people are at risk

- Living longer can be challenging for some
 - particularly those with requirements for secure care
- Future models of care that inform home support services and facility design need to take this into account
- Technology use is increasing but the workforce is critical



Aged care workforce – our biggest challenge





Workforce shortages

Aged care workforce under significant pressure, especially Home & Community Support Services (HCSS), and Aged Residential Care (ARC)

- Older people are high users of the health system
- Limited access to HCSS and ARC means longer stays in public hospitals
- Priority on retention and recruitment of nurses and support staff in HCSS and ARC facilities



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Workforce sustainability

Sustainable workforce = sustainable health and disability sector

- Need a well-qualified workforce with numbers to provide care wherever and whenever it is required
- Fair remuneration for those working in the health sector
- Pay parity for nurses working in the aged care sector and community sector



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Home and community support services - a critical enabler of government's 'ageing in place' policy





Home and Community Support Services

- Older people are living healthier longer lives, but demand for services will increase, and with greater complexity of need
- Pressure on community based support if access to ARC facilities is limited
- Ensure quality delivery of these services to enable older people to live safe, independent lives



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Opportunities





Equity

HDC must contribute to improvement of health inequities

- Commitment to embedding Te Tiriti principles
- Ensure our processes are culturally appropriate and accessible
- Enhance our data collection and monitoring



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Critical partners

- Primary care, home and community support services and aged care, are critical partners in the delivery of quality services
- Delivery of services that enable older people to live safely and independently will ease the pressure on the entire health system
- We need to unblock the health system to enable older people to age in their place of choice, and in supported care environments



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The value of complaints





What are complaints telling us?

- Equity
- Access to planned/specialist care
- Pressure on emergency care
- Capacity constraints in aged care
- Electronic systems
- Women's health – maternity care
- Mental health – complex care provision



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Review of the Act and Code

- HDC is required to conduct regular reviews of the HDC Act and the Code, and make recommendations to Minister of Health
- Important opportunity to ensure Act and Code remain effective in promoting and protecting people's rights
- We are currently scoping the next review – expect to begin public consultation at end of 2023
- Significant alignment between this review and other legislative reviews currently underway



Priorities

- Advocate for delivery of great quality of care and quality of life
- Improve processes for complaints and support
- Processes are culturally appropriate
- Processes are equitable and accessible
- Develop a monitoring framework to drive system improvements
- Early resolution underpins all the work we do



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New ways of working at HDC

- New roles
- Improve processes for complaints and support
- Additional Nurse Advisors
- Maori and Pasifika Advisors
- Principals Advisors (Clinical/Policy)
- Navigators



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Monitoring and Reporting

- Connect and collaborate with older people/whanau/agencies/providers
- Underpinned by:
 - Te Tiriti
 - HDC Code of Consumer Rights
 - Human Rights



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Monitoring and Reporting cont

Each year focus on some key areas

- - Maori hauora and wellbeing
- - Dementia/mate wareware
- - ARC, HCSS, respite services and carer relief



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Vision for older people



Older people need/want to....

- have their voice amplified;
- and for them and their whānau to be **placed at the centre of the system**
- have access to services to enable them to **live independently and safely** and remain connected to their communities; and
- have **confidence in the quality of these services**



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Any questions?





UNIVERSITY OF
AUCKLAND
Waipapa Taumata Rau
NEW ZEALAND

CENTRE FOR CO-CREATED AGEING RESEARCH CCREATE-AGE

Vanessa Burholt, Ngaire Kerse,
Jo Hikaka, Tia Reihana





GLOBAL AGEING: A GRAND OPPORTUNITY AND CHALLENGE

A close-up photograph of a hand dropping a small, brown seed into a pile of dark soil. To the right of the seed, a small green seedling with two leaves is growing out of the soil. The background is a soft, out-of-focus green. A large, semi-transparent white circle is overlaid on the right side of the image, containing the text.

VISION

By 2027 CCREATE-AGE will:

- be a world-leading **transdisciplinary research centre**
- be **underpinned by orietetanga**.
- have **a vibrant community of co-creators** bonded in a quadruple helix innovation ecosystem of mutual benefit
- have **stable funding** sources; and a financially resilient infrastructure to support collaborative spaces, a Living Laboratory and Aged Care Consortium.
- be a **safe and innovative place to learn**
- be a te Tiriti o Waitangi partner who has had **influential impact** on health, environment, society and science

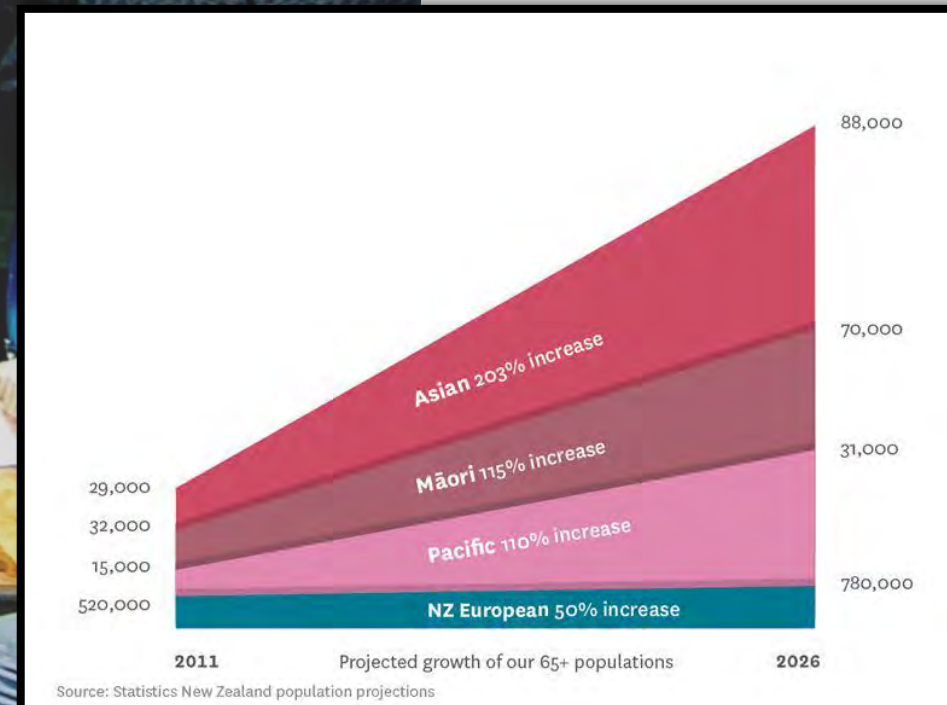
MISSION

To develop a transdisciplinary centre that will deliver creative and innovative solutions to realise opportunities, needs, and concerns identified by older people **to improve health, wellbeing and human flourishing**. To walk alongside Māori and Pacific communities as equitable partners **unlocking human potential** by giving older people, researchers and other stakeholders the opportunity to **co-create world-class ageing research**. To be guided by Kotahitanga fostering inclusivity that is respectful of the difference for diverse older people and the communities to which they belong.





DIVERSITY OF OLDER PEOPLE





INVOLVEMENT	When older people and other stakeholders are actively involved in research. Activities or projects are carried out 'with' or 'by' older people and other stakeholders rather than 'to', 'about' or 'for' them.
ENGAGEMENT	When researchers interact with older people and other stakeholders for the mutual beneficial transfer of information and knowledge, technologies, methods or resources.
PARTICIPATION	When older people are recruited to take part in a project (e.g. undergoing physical tests, completing a questions, participating in focus groups).

HEALTH & WELLBEING: Ensuring healthy ageing and promoting wellbeing in later life

Research changing health and long term care social systems to underpin equitable access to disease prevention, health promotion, treatment, rongoā Māori; maximising function, quality of life, wairuatanga, hinengaro, whenua and whanaungatanga and psychosocial outcomes for older people, their whānau, family and caregivers.

PLACE: Age friendly and dementia supportive places

Research contributing to the creation of inclusive, safe, resilient human settlements and accommodation; understanding the complexities of place for iwi, hapū and whānau and that safes spaces need to be designed by and delivered for Māori; respecting older people's decisions and lifestyle choices; protecting those who are most vulnerable; and promoting inclusion and contribution to community life.

WORK, INCOME & RETIREMENT: Age-Friendly Workplaces, Policies & Practice

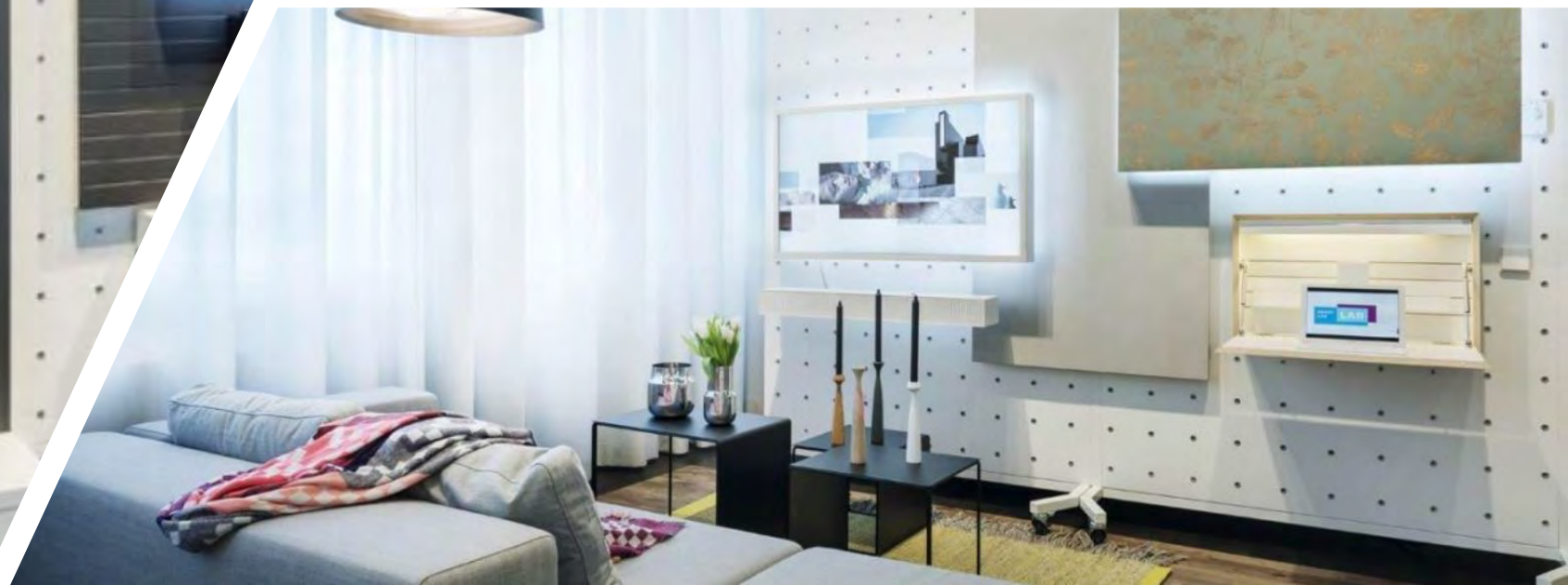
Research helping to prevent poverty by contributing to the development of equitable, flexible retirement and pension policies; promoting lifelong learning. Supporting older workers in acquiring or adapting skills and knowledge to continue to work or become olderpreneurs, if they wish to do so. Research will recognise inequities associated with extending working lives.

TECHNOLOGY, ENGINEERING & THE DIGITAL ECONOMY Research on medical devices, assistive technologies, monitored mobility to provide solutions to match social, psychological and service needs and aspirations of older people, their families and whānau. Understanding the potential and limitations of digital technologies, including digital equity.

ARCHITECTURE, CREATIVE ARTS & DESIGN Research on design improving products and environments that impact the health and well-being of older people. Using arts-based research methods to generate research, to challenge assumptions (e.g. ageism), and share knowledge with communities.

EQUITY, INCLUSION & FUTURE GENERATIONS Research informed by Māori rights under te Tiriti and Human Rights that acknowledges, values and responds to differences with regard to age, income, socio-economic class, health literacy, race, culture, ethnicity, gender, physical and mental abilities, sexual orientation and religion or spiritual practice; taking into account oppression, privilege, structural policies and institutions that perpetuate inequities. Intergenerational research and attitudes towards ageing of future generations.

TAUMATA TEITEI: ENABLING ENVIRONMENT





**RIISING TO MEET THE
OPPORTUNITY**

CO-CREATION WITH PEOPLE LIVING WITH DEMENTIA

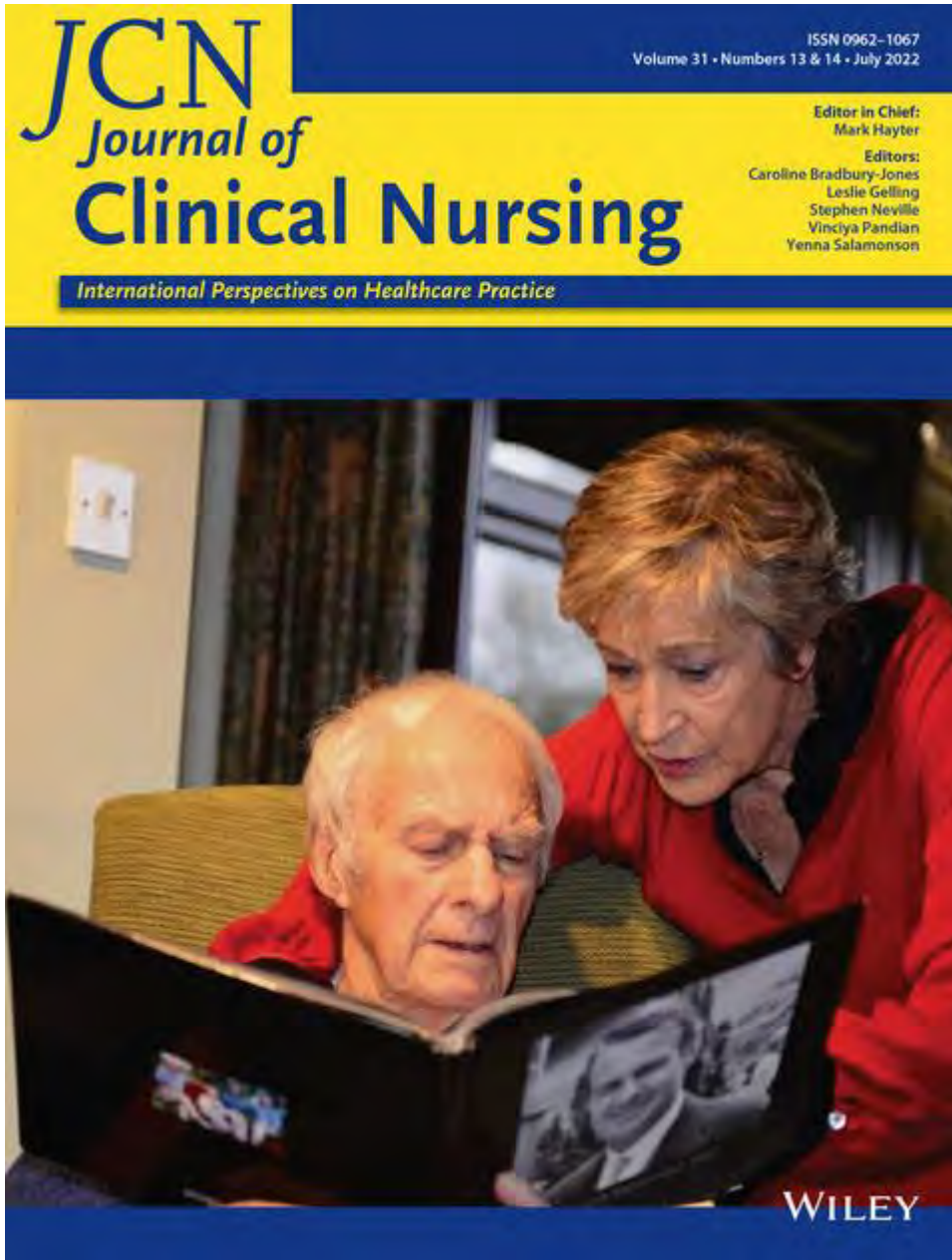
CURRENT RESEARCH

Improving continence management for people with dementia in the community



Co-creating a research proposal to explore the role of domestic soundscapes in dementia friendly housing

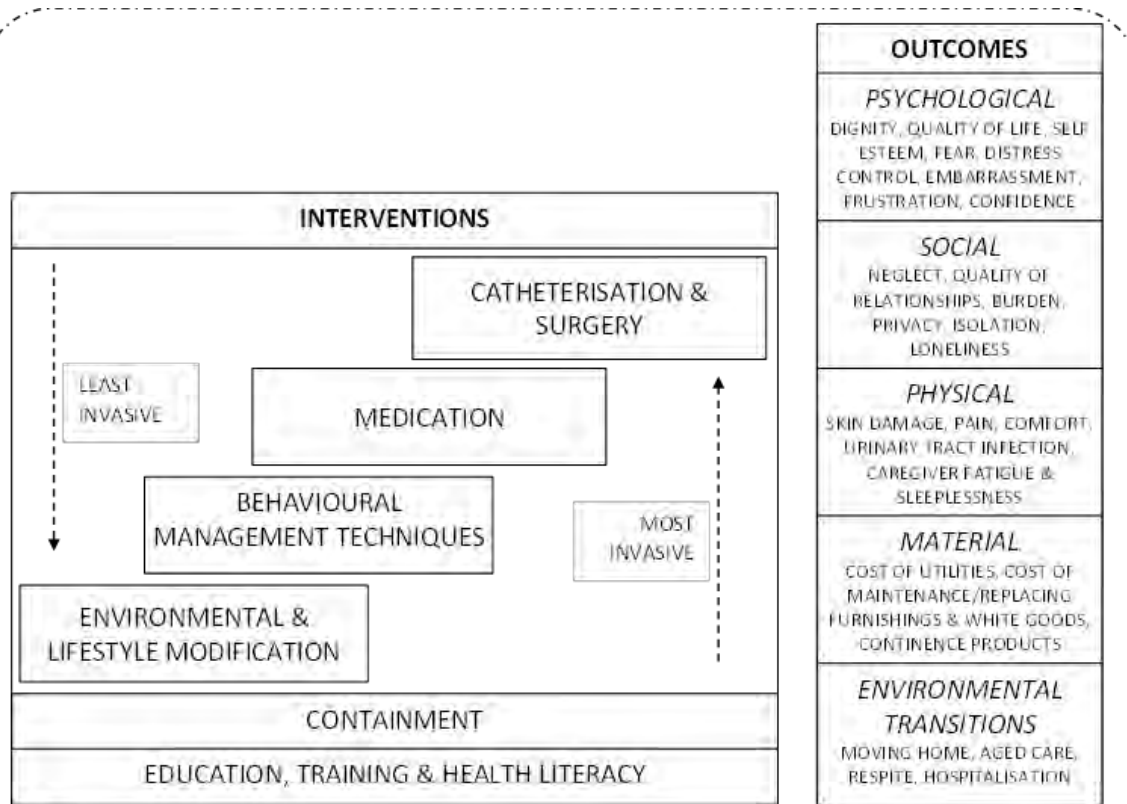




CO-CREATING A CRITICAL REVIEW WITH PEOPLE LIVING WITH DEMENTIA

The cover image is based on the Special Issue Review *A research agenda for promoting continence for people living with dementia in the community: Recommendations based on a critical review and expert-by-experience opinion* by Vanessa Burholt et al., <https://doi.org/10.1111/jocn.15537>. Image Credit: Silin Cyfyngedig. Photographer: Barry Davies.

IMPROVING CONTINENCE MANAGEMENT: WHAT MATTERS TO PEOPLE LIVING WITH DEMENTIA IN THE COMMUNITY?



Current environment
without a core outcome set

	Outcomes			
	A	B	C	D
Trial 1	✓	✓		
Trial 2			✓	
Trial 3		✓		
Trial N	✓			✓

But "D" is what
matters most
to me!



This Photo by Unknown Author is licensed under
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CAREGIVING, DEMENTIA AND INCONTINENCE: AN OPEN ONLINE COURSE

Many people living with dementia experience difficulties with bladder and/or bowel function and control. Continence issues significantly impact the quality of life for the person and their carer.

The free online course Caregiving, Dementia and Incontinence has been developed with the input of people living with dementia, carers and health professionals. It aims to provide family and professional carers with the knowledge, skills and resources to cope with the physical and psychosocial aspects of assisting with toileting, promoting continence, and managing incontinence.

In this five week course learners will cover the following topics:

Week 1 - Coping with the lived experience

Week 2 - Basics of bowel and bladder function

WHEN

Start: 30 January, 2023 at 12:00am

End: 31 December, 2023 at 12:00am

[ADD TO CALENDAR](#)

WHERE

Online

Personal Care

WHEN TOILETING BECOMES A CHALLENGE: TIPS AND STRATEGIES

Alzheimer Society

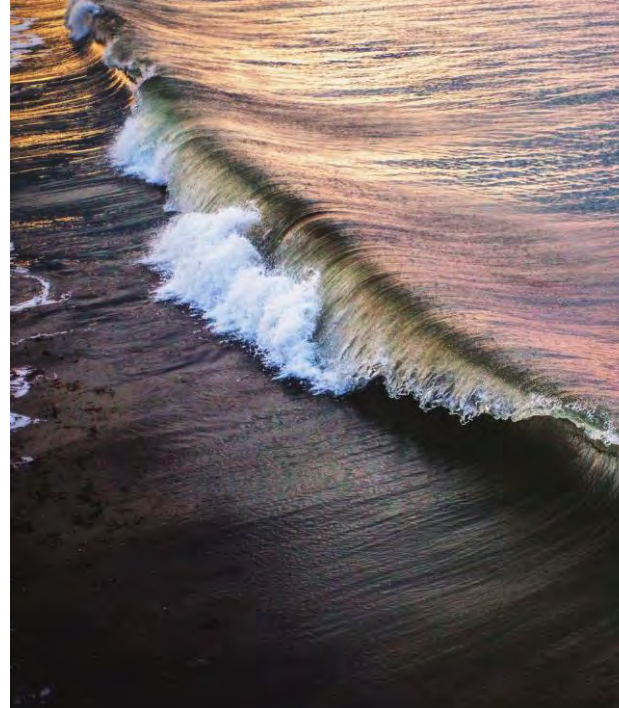
Day to Day Series

WHEN TOILETING BECOMES A CHALLENGE: TIPS AND STRATEGIES

Consider the person's overall health and abilities:

- ☒ Could there be other medical problems besides the dementia that should be treated, such as a bladder infection, constipation, loss of bladder tone, weakening of control muscles, decreased bladder capacity or prostate problems for men?
- ☒ Is the person taking medication or drinking a large amount of liquids which may be contrib to a frequent need to go to the bathroom? Drinking a large amount of tea or coffee may the person feel an urgency to go to the bathroom.
- ☒ Is urine being released with the pressure of a sneeze, cough or laugh?

IMPROVING CONTINENCE MANAGEMENT FOR PEOPLE LIVING WITH DEMENTIA IN THE COMMUNITY



EXPLORING THE ROLE OF DOMESTIC SOUNDSCAPES IN DEMENTIA FRIENDLY HOUSING



NURTURING AUTHENTIC INVOLVEMENT IN RESEARCH DEVELOPMENT





ACKNOWLEDGEMENTS

We would like to acknowledge the beautiful art work by Theresa Reihana, who has permitted us to use these images to support our presentation and the images of LiLACS NZ group celebrations also given with permission.



We would also like to acknowledge all of the external organisations and individuals who have supported our research and contributed to the mahi that has led to the development of the proposal for CCREATE-AGE.



Young Onset Dementia in Aotearoa New Zealand

Dr Brigid Ryan, PhD

Senior Lecturer

University of Auckland

Centre for Brain Research and
Department of Anatomy and Medical Imaging

b.ryan@auckland.ac.nz



**CENTRE FOR
BRAIN RESEARCH**



Mihimihi | Introduction

Kia ora tātou

Hi everybody

Nō Airangi, nō Koterangi hoki ōku tūpuna

My ancestors are from Ireland and Scotland,

engari i tupu ake au i Ōtepoti

but I grew up in Dunedin

kei Tāmaki Makaurau ahau e noho ana.

and I live in Auckland.

Ko Brigid Ryan ahau

I'm Brigid Ryan,

he kairangahau roro ahau i Waipapa Taumata Rau.

I'm a neuroscientist at the University of Auckland.

Nō reira tēnā koutou katoa!

So, hello to you all!



Young Onset Dementia in Aotearoa New Zealand

Dr Brigid Ryan, PhD

Senior Lecturer

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Centre for Brain Research and
Department of Anatomy and Medical Imaging

b.ryan@auckland.ac.nz



**CENTRE FOR
BRAIN RESEARCH**



Outline



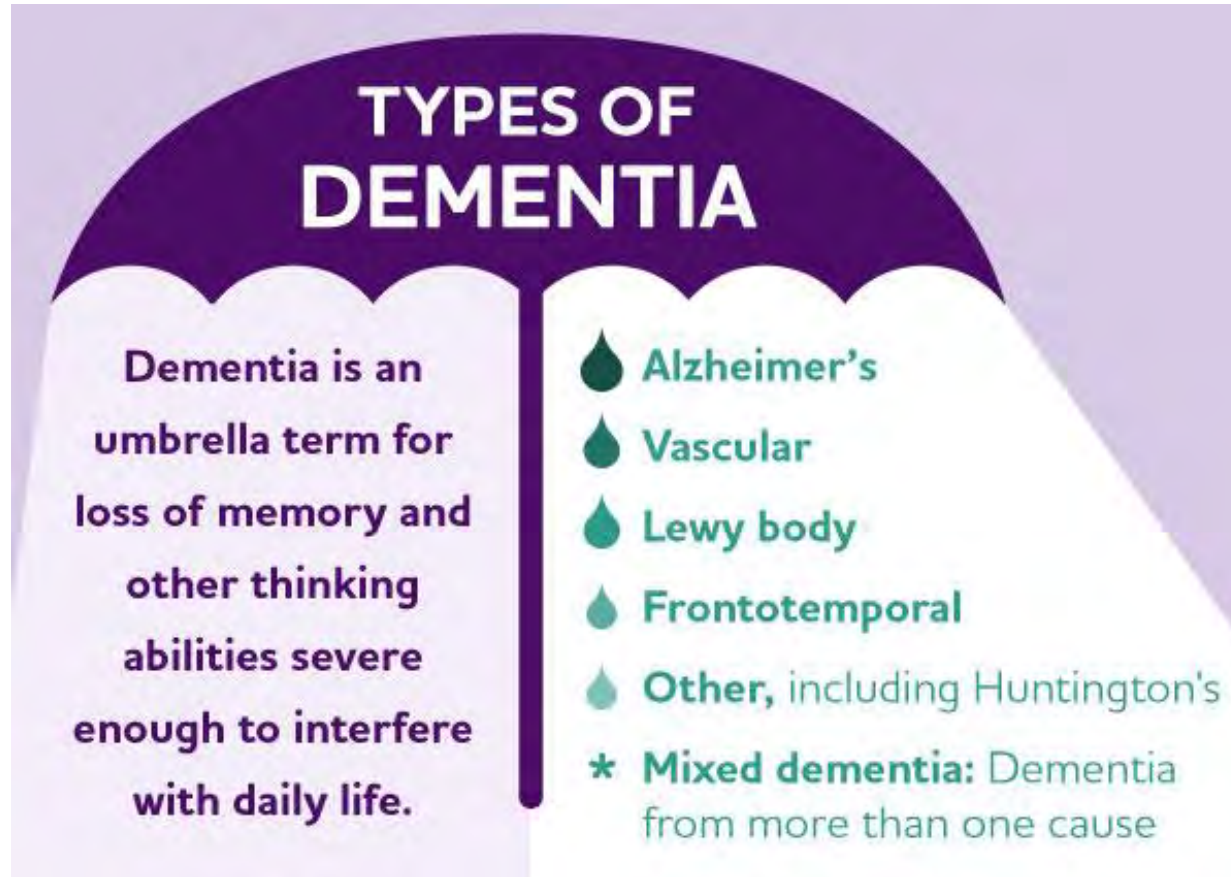
Unique challenges of young onset dementia



Latest **research** in Aotearoa

- **Who** is affected?
- **What** are the challenges?

Young onset dementia (YOD)



Young onset dementia: any type of dementia with **symptom onset** before the age of **65**

How young is young?



Nick, diagnosed with young-onset vascular dementia at 48 years of age, with his wife Helen.



Suz, diagnosed with young-onset dementia at the age of 59, with her husband David.



Campbell, developed symptoms of frontotemporal dementia aged 49.

Why does age matter?

- Life stage
- Diagnosis:
 - No-one suspects dementia
 - Clinical pathway is not clear
 - Rare; sub-types even rarer
 - Can take a long time
- Post-diagnostic support:
 - 'Fall between the cracks': disability support and aged care
 - Navigating the health system: support may be there, but hard to find
 - Age-appropriate services: day services, respite, support groups, residential care



Why does age matter?



Lived experience:

Rimkeit & McIntosh 2017¹

- 9 people with YOD using aged care

The activities weren't to his satisfaction...I would like to see somewhere for the people who are a little bit more active...he's still fit enough to have a life...why take it away from him?



Leanne Bolton MN

- 3 people with YOD

Alzheimers NZ qualitative report 2019²



- 11 people with YOD

Younger people with dementia want services tailored for their age group

Who is affected in Aotearoa?

Original research

Prevalence of young-onset dementia: nationwide analysis of routinely collected data

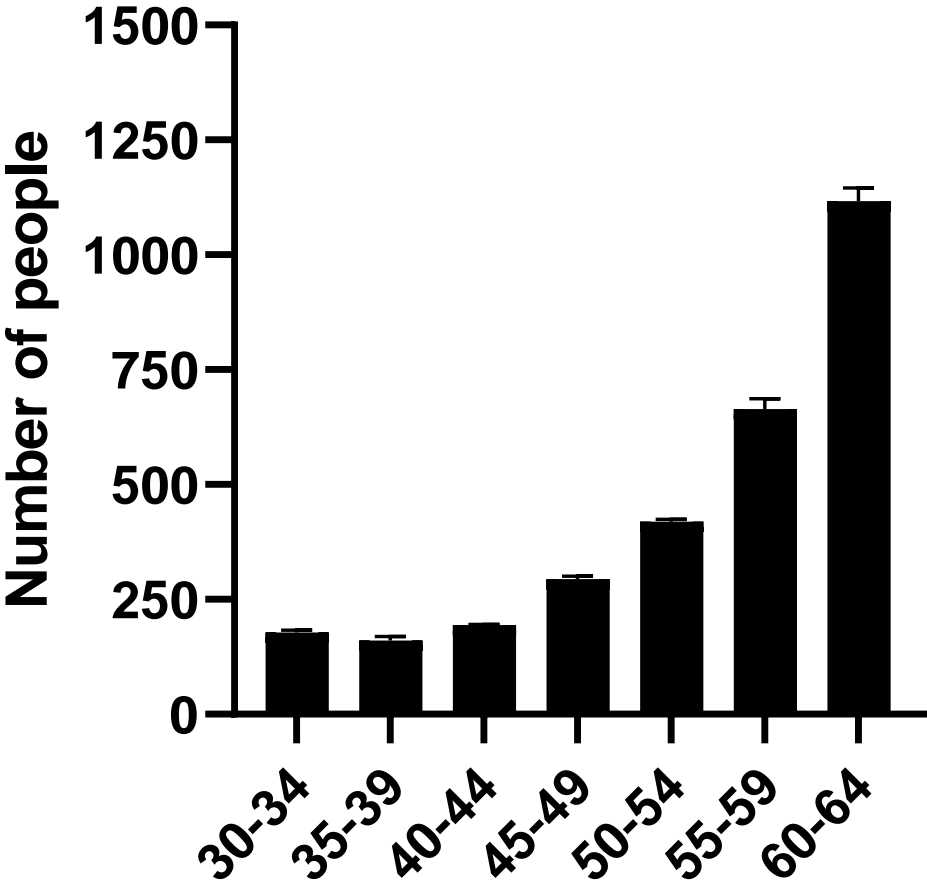
Brigid Ryan ¹, Edith To,² Etuini Ma'u,³ Amy Hai Yan Chan,⁴
Claudia Rivera-Rodriguez,² Maurice A Curtis,¹ Sarah Cullum ³, Gary Cheung³

Who is affected in Aotearoa?

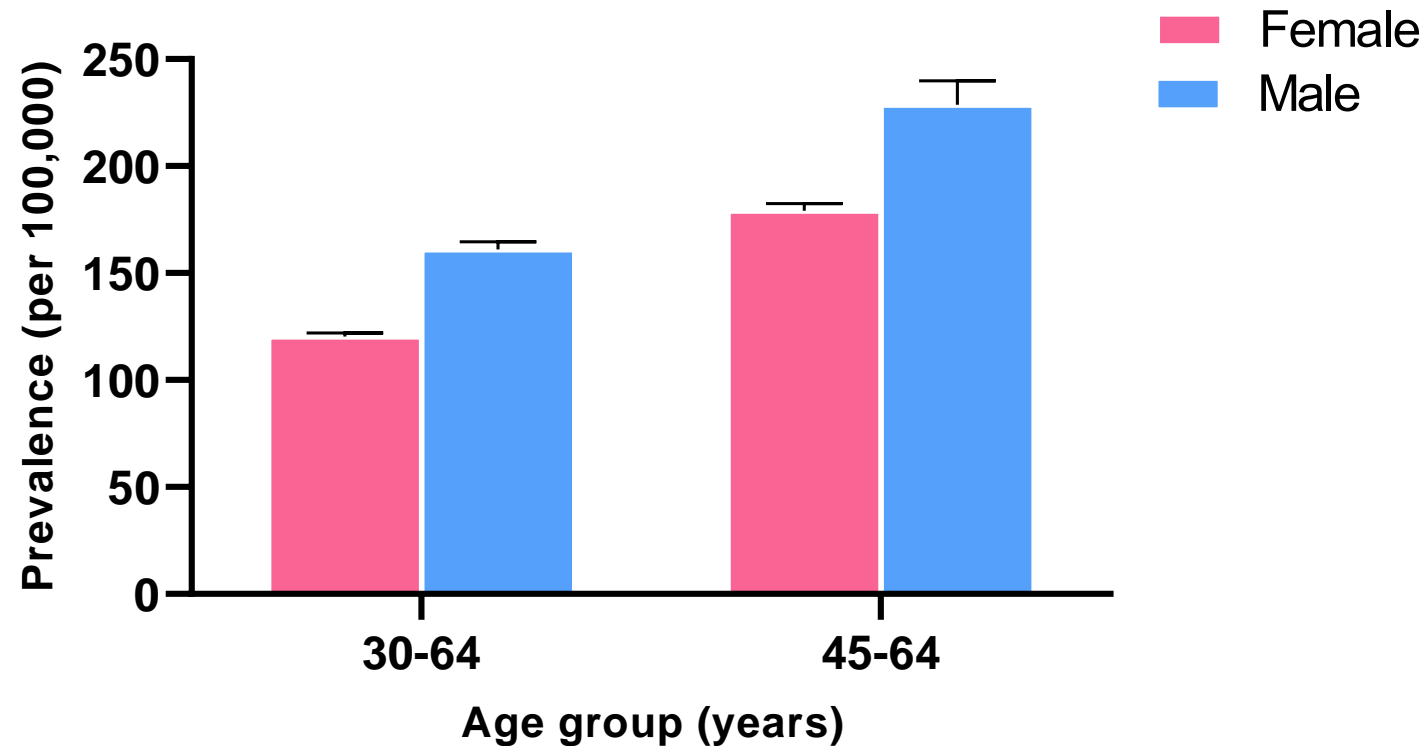
- 3400 people with a diagnosis of young onset dementia¹
- 140/100,000 30-64 (US: 115; Europe; 159²)
- 7% of all dementia



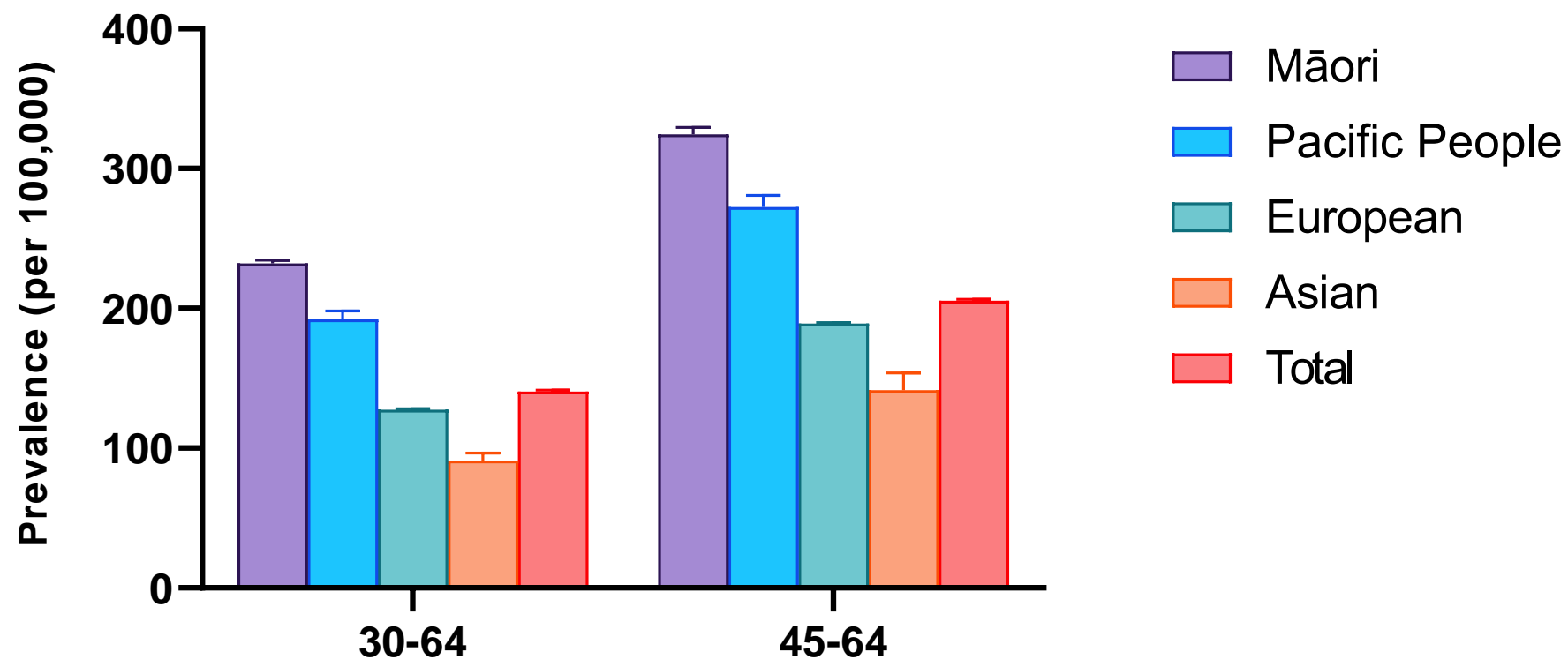
Who is affected in Aotearoa?



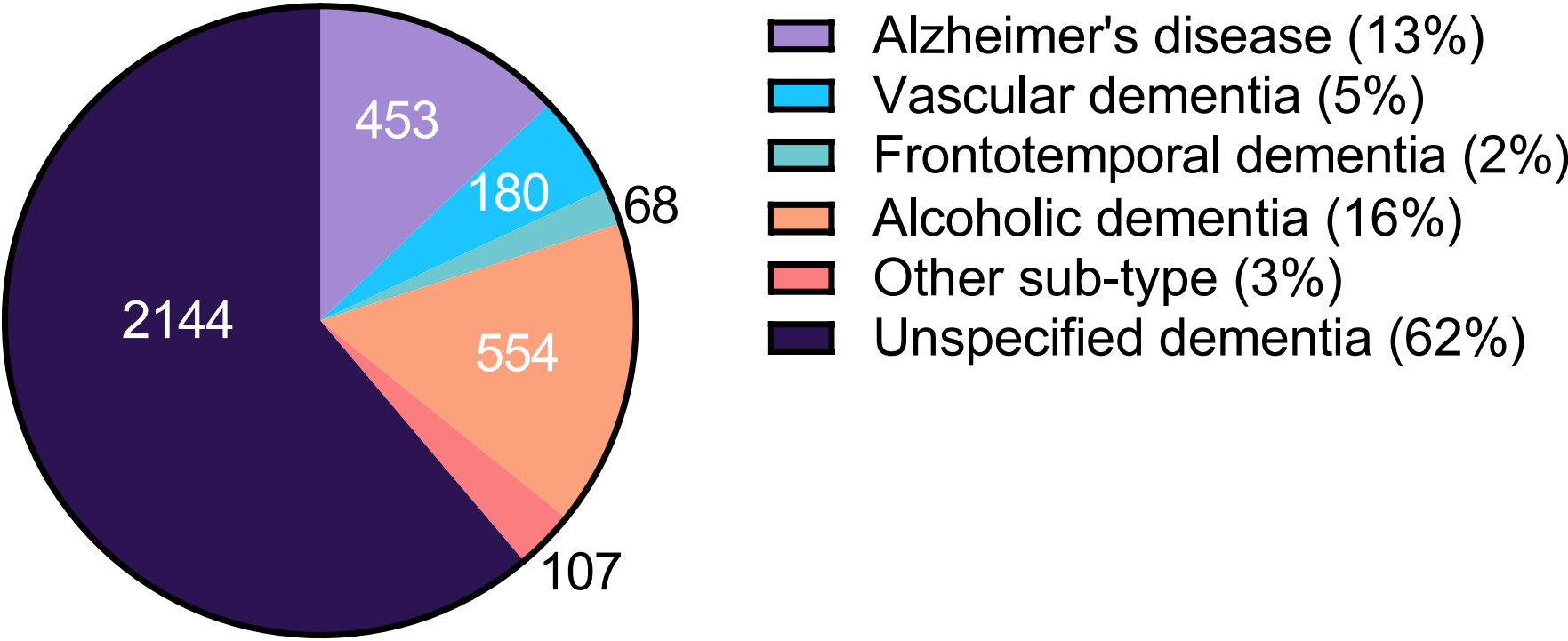
Who is affected in Aotearoa?



Who is affected in Aotearoa?



Who is affected in Aotearoa?



Who is affected in Aotearoa?

Journal of Alzheimer's Disease 90 (2022) 1321–1327
DOI 10.3233/JAD-220802
IOS Press

1321

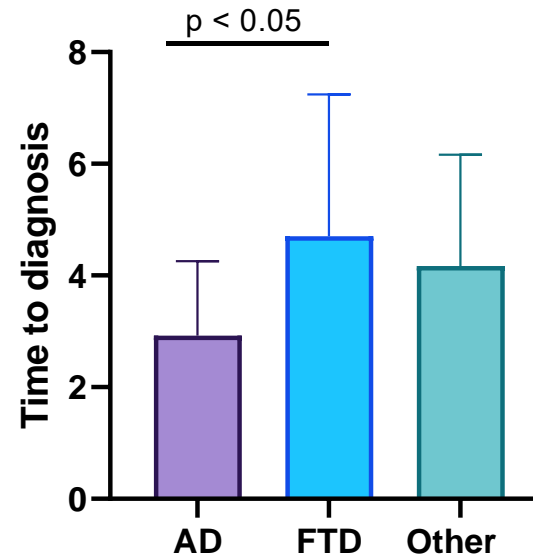
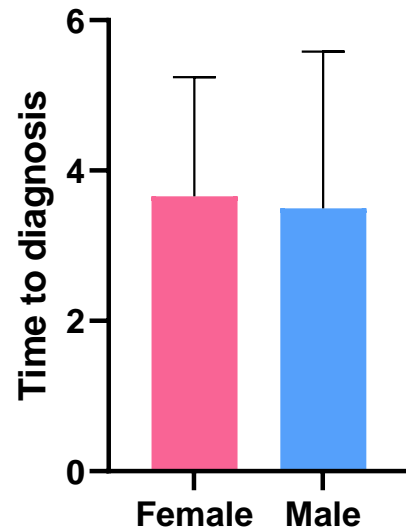
Incidence of Young Onset Dementia in Waikato, New Zealand: A Population-Based Study

Lochanie Fonseka^a, David Wang^b, Brigid Ryan^{c,d}, Gary Cheung^e and Etuini Ma'u^{e,*}

- Identified 64 new diagnoses in a 3-year period
- Suggests 220 new diagnoses in Aotearoa each year
- Higher incidence in Māori compared to non-Māori (1.7x)
- 22% Alzheimer's disease, 20% vascular dementia, 23% unspecified

What are the challenges?

- On average, it takes **3.7 years** to get a **diagnosis** in Aotearoa¹
 - Very similar to previous Australian studies (3.2, 3.4 years)^{2,3}
 - Netherlands, 2012⁴: 4.4 years vs 2.8 years for late onset dementia



What are the challenges?

ORIGINAL ARTICLE

Sociodemographic and Clinical Characteristics of 1350 Patients With Young Onset Dementia *A Comparison With Older Patients*

Brigid Ryan, PhD,† Adrian Martinez Ruiz, MD,†‡§
Claudia Rivera-Rodriguez, PhD,|| Maurice Curtis, PhD,*†
and Gary Cheung, PhD†‡*

- Higher prevalence of neuropsychiatric symptoms and problematic behaviours
- More likely to experience financial strain, carer distress, and loneliness

Take-home messages

- 3400 people with young onset dementia in NZ
- Estimated 220 new diagnoses each year in NZ
- Māori (1.8x) and Pacific (1.5x) are over-represented
- On average, it takes 3.7 years to be diagnosed in NZ
- People with young onset dementia have different needs

Thank you!

AP Gary Cheung

Edith To

Dr Etuini Ma'u

Dr Amy Hai Yan Chan

Dr Claudia Rivera-Rodriguez

Prof Maurice Curtis

AP Sarah Cullum

Dr Lochanie Fonseka

Dr David Wang

Dr Adrian Martinez Ruiz

Prof Lynette Tippet

Dr Kiri Brickell

Dr Campbell Le Heron

Dr Christina Ilse

Dr Keith Woods

Shruti Sharma

Ashleigh O'Mara Baker

Dr Waiora Port

Elayne Tangitu

Dr Nicole Edwards

Dr Maas Mollenhauer

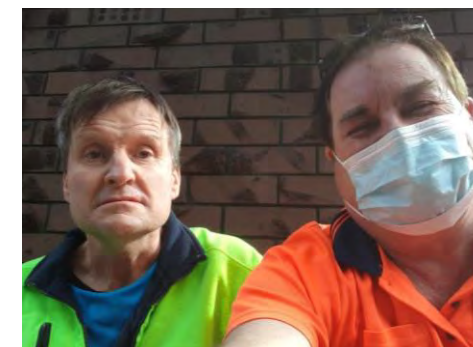
Dr Sally Rimkeit

Rhonda Preston-Jones & The Young Ones

Study participants



Suz continues to live at home with David and joins in the Dementia Auckland Living Well Programme. She loves the Singing & Walking groups. David belongs to the Young Ones Support Group.



Campbell, aged 60, is now in residential care. He is supported by his partner David, who belongs to the Young Ones Support Group.

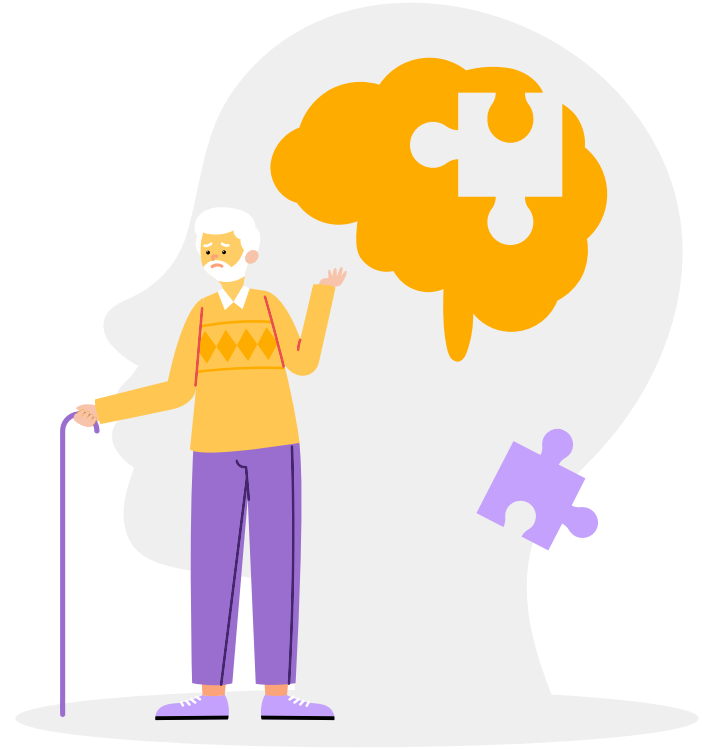


Repositioning dementia: a new start



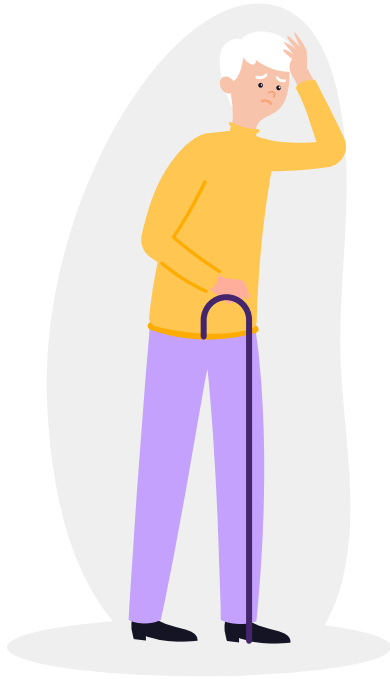
Languaging, Meanings, Translations

What does dementia mean for Pasifika in Aotearoa?



A case scenario

Grandpa (Solo) 79 years old and Granddaughter (Lina) 24 years old, visit to the GP



L : Papa, fai mai ua maua oe le Dementia
(Papa, the doctor said you have dementia)

S: O le a le ga mea?
(what is that thing?)

L: Fai mai ua leaga lou ulu
(He said your head is bad)

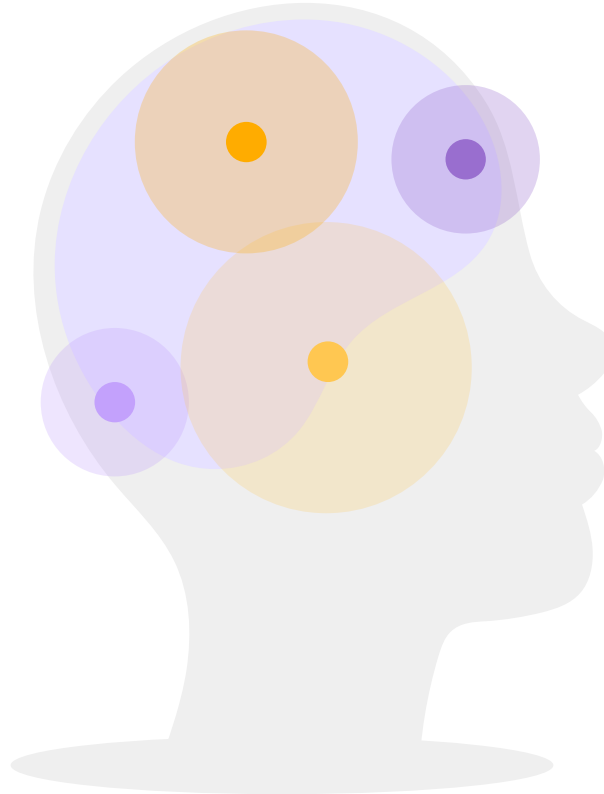
S: O le a lou guku?
What did you say?



Dementia or major neurocognitive disorder

Dementia is a common late-life neurodegenerative disorder characterized by cognitive and functional impairment

(Cheung et al., 2022; Cullum et al., 2017).



Diagnosing dementia includes:

- **Memory impairment**
- **Language disturbance**
- **Problems with motor activities**
- **Failure to recognise things**
- **Failure of executive function** (Perkins, 2013).

Some key facts of Dementia in New Zealand

**70,000
Kiwis**

Almost 70,000 Kiwis are living with dementia today.

**170,000
Kiwis**

Almost 170,000 Kiwis are likely to be living with dementia by 2050.

**4/5
Zealanders**

Four out of five New Zealanders know or have known someone living with dementia.

**30%
higher in
women**

Dementia impacts more women than men – around 30% higher.

**\$5.9b by
2050**

The total cost of dementia to Aotearoa is now around \$2.5b and will reach around \$5.9b by 2050

\$1.21b

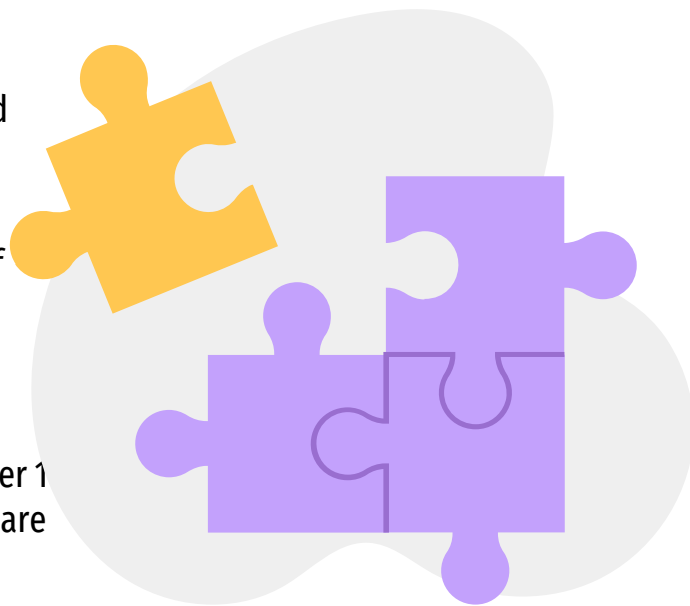
Residential care currently accounts for around half of the economic cost of dementia borne by government (\$1.21b).

**Over 1
million
hours of
unpaid care**

Care partners provide over 1 million hours of unpaid care every week.

**Māori,
Pasifika and
Asian are at
higher risk**

Dementia numbers are increasing at a faster rate among Māori, Pasifika and Asian populations than those of European New Zealanders (Ma'u et al., 2021).



Recent NZ-based dementia studies among minority populations (Māori and Pacific peoples)

8.5 and 5.3
years
younger



Māori and Pacific peoples with dementia presented to an NZ memory service at a younger age than NZ Europeans, **and Pacific peoples presented with more advanced dementia** (Māori and Pacific patients were 8.5 and 5.3 years younger than NZ European patients) (Cullum et al., 2018).

Less likely to
enter aged
residential care



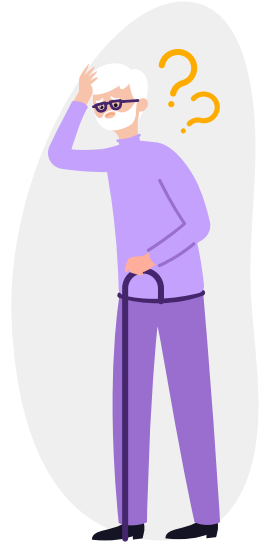
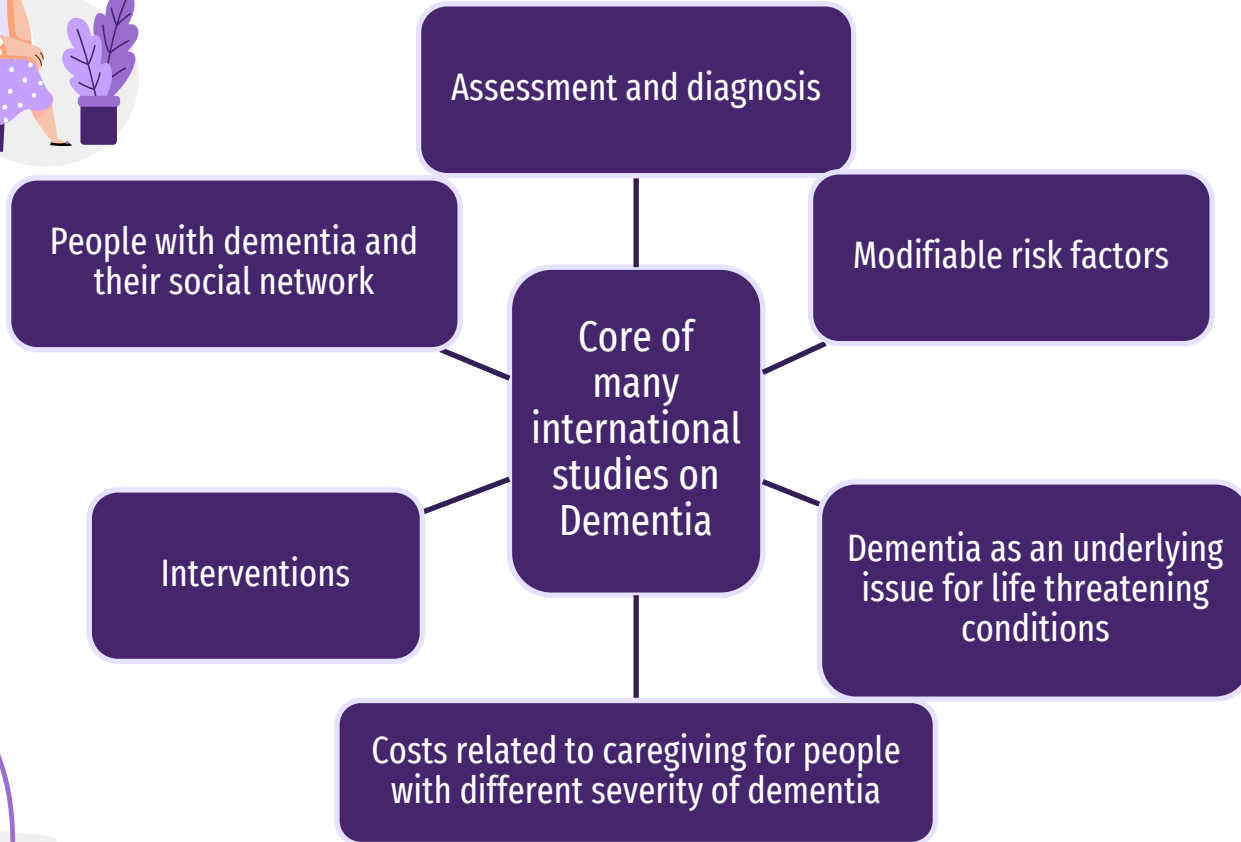
Māori and Pacifica people living with dementia **were less likely to enter aged residential care** despite having more severe dementia and higher levels of comorbidity (Ma'u, E., Saeed et al., 2022).

More likely to
receive no
formal care



Māori (55.8%) and Pacific peoples (58.7%) more **likely to receive no formal care** compared to Europeans (36.1%) (Ma'u et al., 2022).

Studies on dementia



The LIDIA Project

- Living with Dementia Study: a multi disciplined and multi ethnic group project
 - Qualitative (15 participants)
 - 5 caregivers for patients with severe dementia
 - 5 mild patients
 - 5 caregivers for patients with mild dementia
 - Samoa sample – 25 participants
- Validity Study (Translation and adaptation of 10/66)
 - 15 with dementia and 15 without dementia
 - Completed: 11 Samoan, 6 Tongan
- Feasibility : door knocking (Favona and Mangere regions)
 - 6 Samoan
 - 0 Tongan

Incomplete



Key findings from the LIDIA Study

Diverse understanding: languaging, meanings and translations

- Different houses of knowledge
 - *Island and New Zealand born*
 - *Older and younger generations*

Concepts and interpretations

- No Samoan or Pacific word
End of one's purpose in life – fatalistic approach
 - *Part of old age*

Formal diagnosis impacts

- Fear for caregivers
Loss of Independence for elders
Stigma in the community
Isolation from support network
Intergenerational differences in care

Support and Services

- Care for elders at home
- Culturally appropriate services
Trust of services
- Contents and language use in services
Utilisation of services
- Care assistants with cultural awareness or knowledge

Samoan older people and caregivers

There is no Samoan word for this palagi illness. Forgetfulness is a sign of old age, (83 years old).

O le valevale matua - Getting old is the end of one's life journey, we complete our duties and what we needed to do, there is nothing else left for us; hence, the changes in our strength and life as human beings (86 years old).

We still take our dad to see other doctors such as the Samoan cultural spiritual healers, Māori tohunga and we even tried the Chinese herbal drinks. For us, we will do anything that will help dad live and enjoy us. We take him to places and we also try and keep his routines with his church and all that (43 years old caregiver).

It is very hard now, but as kids, we must put a plan in place to take care of our parents, especially mum. It is our duty, but it is also challenging because we need to work and provide for our families (56 years old caregiver).

Project 1: HRC 2023 Pacific Study: What does dementia mean for Pacific?

Aim: Focus on *Samoa, Tonga, Cook Island, and Niue*

- To develop a theory of dementia for Pacific
- To develop Pacific responsive screening and assessment tools

How: Assign a Research lead and research assistant from each four groups

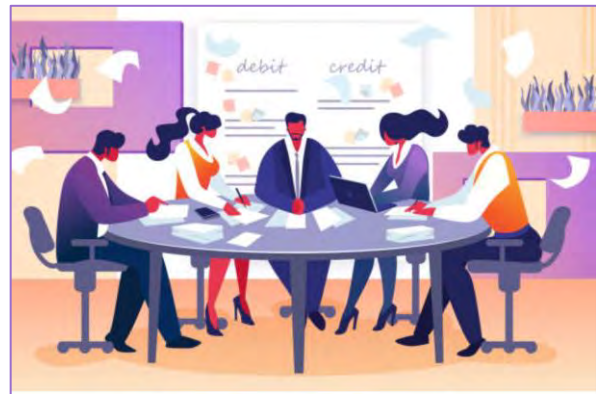
Recruit cultural and language expert groups – from each of the four ethnic groups

5 members: clinicians, spiritual leaders, orators and/or elders

Data Collection: 8 Fa'afaletui with older peoples from four ethnic group
Talanoa with 20 family carers for family members diagnosed with dementia

Tools development by the: Research lead and research assistant with the cultural and language ethnic groups

Dementia
expert
advisory
group



Project 2 HRC 2025 Project: To Validate the tools

- Pacific Communities: Older people, caregivers, cultural and language experts, lay people
 - Validate the languaging, concepts, meanings, relevance
- Pacific and other clinicians
 - Validate the appropriateness and validity of the tools



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