



Alzheimers *New Zealand*

Addressing Stigma

Dr Kathy Peri

Director, Dementia Learning Centre

Dr Meg Spriggs

Senior Advisor, Dementia Friendly

What does stigma look like?

A recent survey of people with dementia highlighted that:

59% thought that others avoided spending time with them because of their diagnosis

41% wished they had more social contact with people in the community

57% were afraid of becoming lost in their local community

48% had difficulty in communicating with staff in stores

Alzheimer's Australia 2014. Living with dementia in the community: challenges and opportunities.

“I went to the local pub, a member of staff asked ‘What’s wrong with you?’, and I replied that I had dementia. The staff member then said ‘how come you’re talking then, you’re just like me’. He wouldn’t believe that I had dementia.”

“Nobody offers help, you’ve got to go and find it and ask for it. You have to go to your doctor and some doctors don’t want to give it [information on services] either, which to me is quite strange.”

What would life without stigma look like?



Dementia Declaration: Our Lives Matter

"We ALL want to be seen, valued, appreciated and loved for who we are."

As New Zealanders living with dementia, we are citizens whose lives matter. We have the same rights, privileges and obligations as everyone else. Our Declaration sets out what we need to live well.

We live our best possible lives when:



We have control over our lives; we have support to make decisions that are important to us.



We live in knowledgeable communities that include, accept and understand us.



We have consistent quality support, care and information which is timely and appropriate to us; it is provided with kindness by compassionate people who have the right skills and knowledge, our interests as a focus, and with whom we are comfortable.



We continue to be actively engaged in roles and activities which are meaningful and important to us.



We have the things we need to live well such as housing, privacy, an adequate standard of living, and ways of getting where we need to go.



A circle of support protects our wellbeing, allowing us to maintain strong mutual relationships with our families, whānau, friends, colleagues, and those who are important to us.



We are loved; our presence matters.

"I am still me."

This Declaration was developed by people living with dementia on Alzheimers New Zealand's Advisory Group.



He Whakapuaki mō te Mate Wareware: He Mea Nui Tō Mātou Noho i Te Ao

"E hiahia ana mātou KATOA kia kitea mai e te tangata kē, kia whakanuia, kia kia he tangata whai painga, kia arohaina mai mō tō mātou āhua tūturu."

Hei tāngata nō Aotearoa e noho tahi ana me te mate wareware, he kirirarau mātou, ā, he mea nui tō mātou noho i te ao nei. He rite tonu ō mātou tika, ō mātou whiwhinga, haepapa hoki ki ō ngā tāngata katoa. Tā tō mātou Whakapuaki he whakataki i ngā mea e hiahia ana mātou kia noho pai i te ao nei.

Ka eke mātou ki tō mātou tino teitei ina:



Noho tonu te mana mō mātou ki a mātou anō; kua kaha hoki ngā reo tautoko i ā mātou whakatau mō ngā mea hira ki a mātou.



Noho mātou i ngā hapori mōhio e awhi nei, e whakaae nei, e mārāma pū nei ki a mātou.



Tōkeke tonu te tautoko i a mātou, te tiaki me te whiwhi mōhiotanga i te wā tonu e tika ana, e hāngai ana hoki ki a mātou; e horaina mai ana i roto i te atawhai e te hunga ngākau pūaroa, he tāngata whai pūkenga tōtika, mātauranga tōtika e arotahi ana ki ō mātou hiahia, he pai tō mātou noho tahi me rātou.



Whakauru tonu mātou ki ngā tūranga me ngā mahi whai tikanga, hira hoki ki a mātou.



Tukua ki a mātou tonu ngā mea e hiahia ana mātou ki te noho pai, te tūmataitinga, kia whai moni e pai ai te noho, me ngā āhuatanga kawē i a mātou ki ngā wāhi e hiahia ana mātou ki te haere.



Karapotingia mātou e tēnei kāhui tautoko, he kāhui e ngāwari tonu ai te noho pipiri ki ō mātou whānau, ki ngā hoa, ki ō mātou hoa mahi, me te hunga e noho nei hei mea nui ki a mātou.



Aroha nuitia mātou; he mea nui tō mātou noho i te ao.

"Ko au tonu ahau."

He mea tuhituhi tēnei Whakapuaki e te hunga e noho tahi ana me te mate wareware i roto i te Rōpū Tohutohu o Alzheimers New Zealand.

“Our lives matter. As New Zealanders living with dementia, we are citizens whose lives matter. We have the same rights, privileges and obligations as everyone else. We live our best possible lives when...we live in knowledgeable communities that include, accept, and understand us.”

Alzheimers NZ
Dementia Declaration

A dementia friendly New Zealand | Aotearoa, he aro nui ki te hunga mate wareware

Importance of education and awareness raising

Education serves as a powerful tool in dispelling myths, fostering understanding, and creating a more compassionate and informed society for individuals living with dementia mate wareware and their care partners.

Through the Dementia Learning Centre, the goals are:

- **Promote understanding:** Education helps people understand what dementia mate wareware is, its causes, and how it affects individuals. This understanding reduces the fear and stigma associated with the condition.
- **Clarify misconceptions:** Education addresses common misconceptions about dementia mate wareware, such as it being a normal part of aging or solely related to memory loss. Clearing up these misunderstandings aids in better communication and support.
- **Encourage empathy:** Learning about the challenges faced by people with dementia mate wareware fosters empathy among individuals, leading to more patient and compassionate interactions

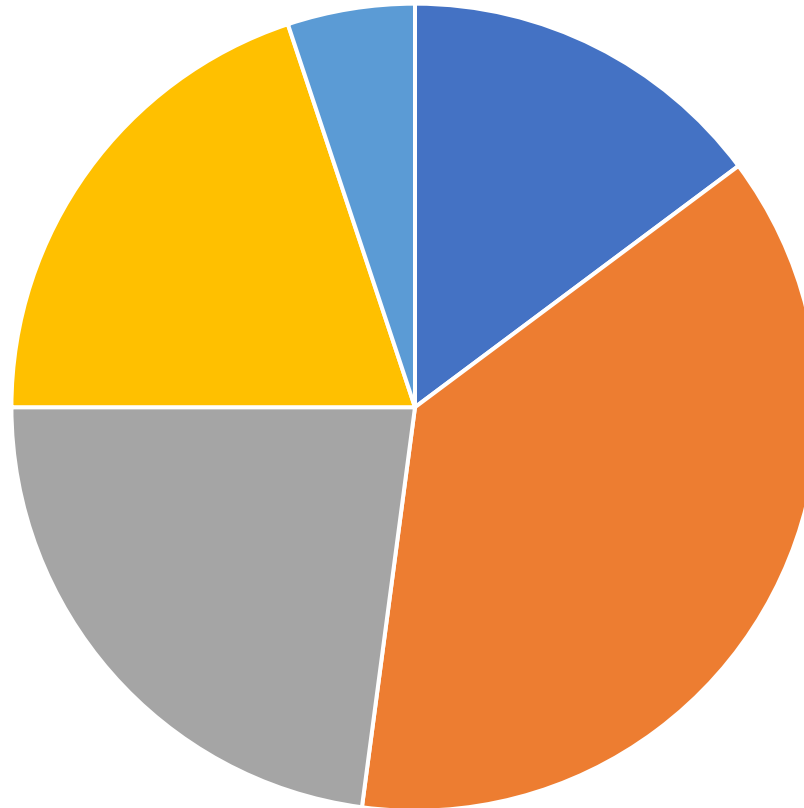
Educational Dementia Immersive Experience (EDIE)

Co-designed by people with dementia mate wareware, is valuable tool that illustrates a scenario of someone with dementia what they might experience.

- **The virtual reality experience is one way that we can grow more comfortable in understanding what dementia is like and to start a conversation.**

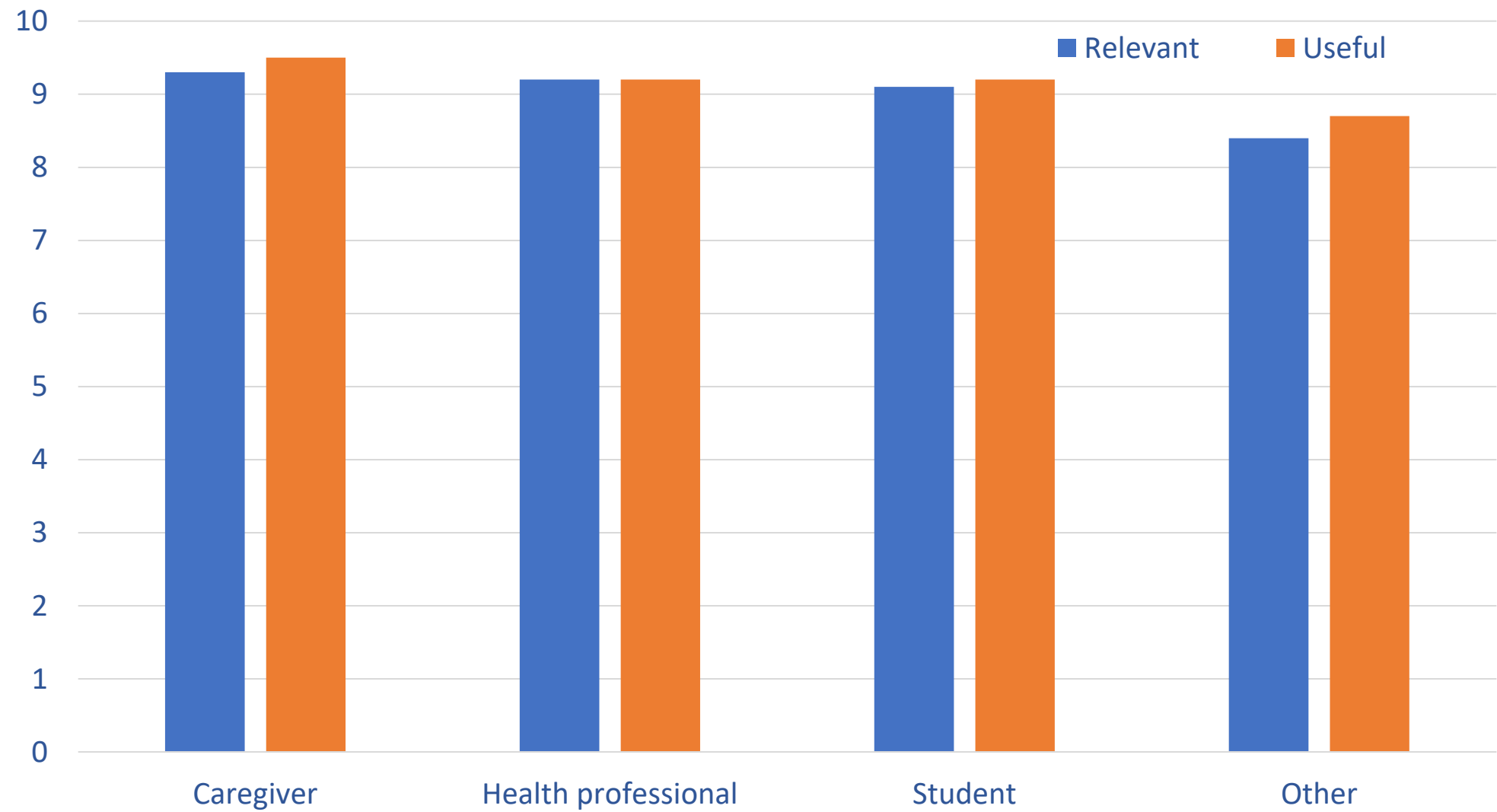


Participants



■ Caregiver (15%) ■ Health professional (37%) ■ Student (23%) ■ Other (20%) ■ Unknown (5%)

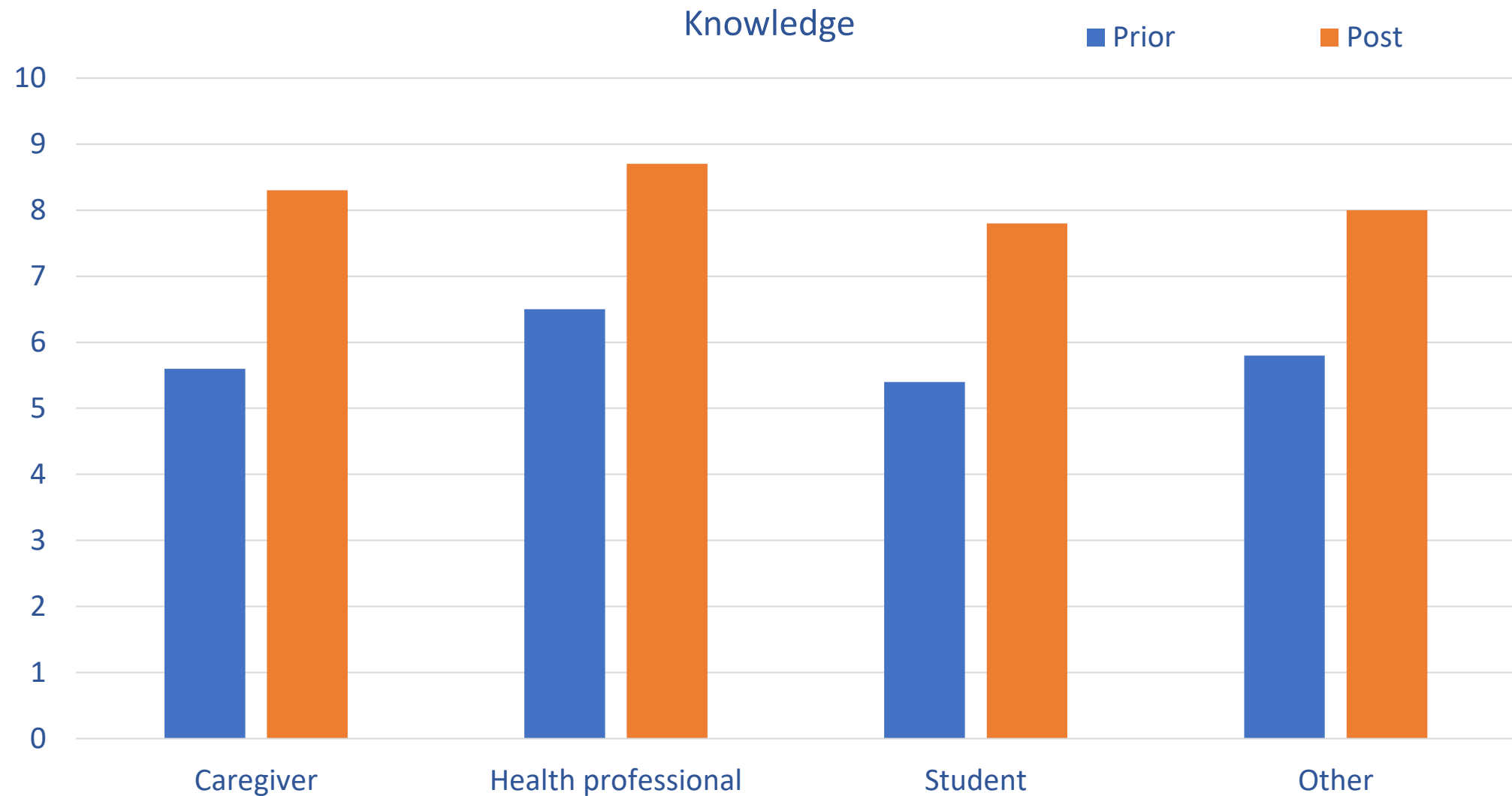
Content of workshops



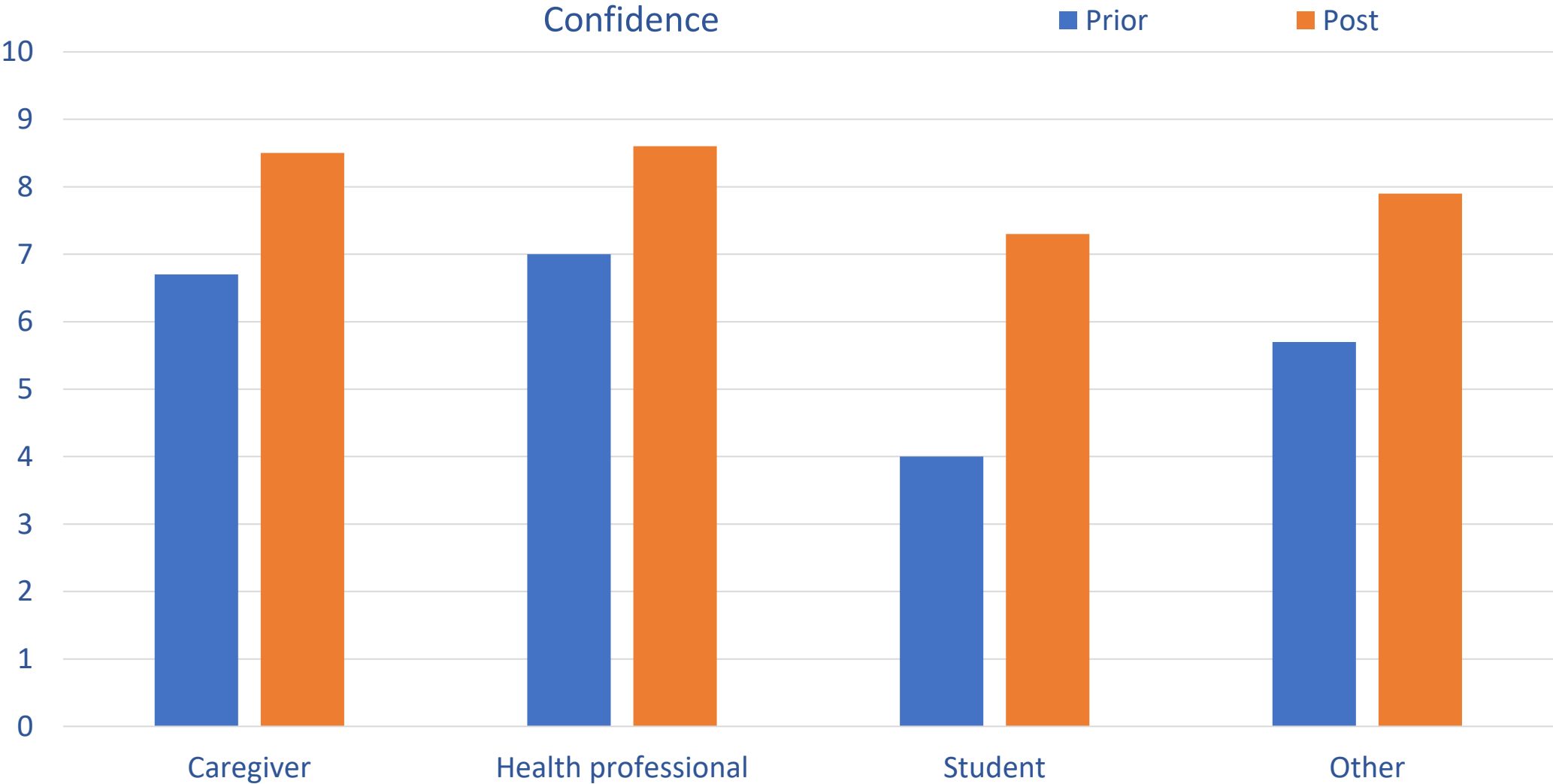
Parts people found most useful

Caregivers	Health professionals	Students	Other
VR experience (16)	Experiencing PWD (20)	Experiencing PWD (20)	Experiencing PWD (20)
Experiencing PWD (4)	VR experience (17)	VR experience (17)	VR experience (12)
Discussion (4)	Change environment (13)	Discussion (8)	How to better support PWD (4)
Change environment (4)	Discussion (7)	How to better support PWD (4)	Change environment (2)
How to better support PWD (1)	How to better support PWD (4)	Change environment (4)	Discussion (1)

Change in knowledge

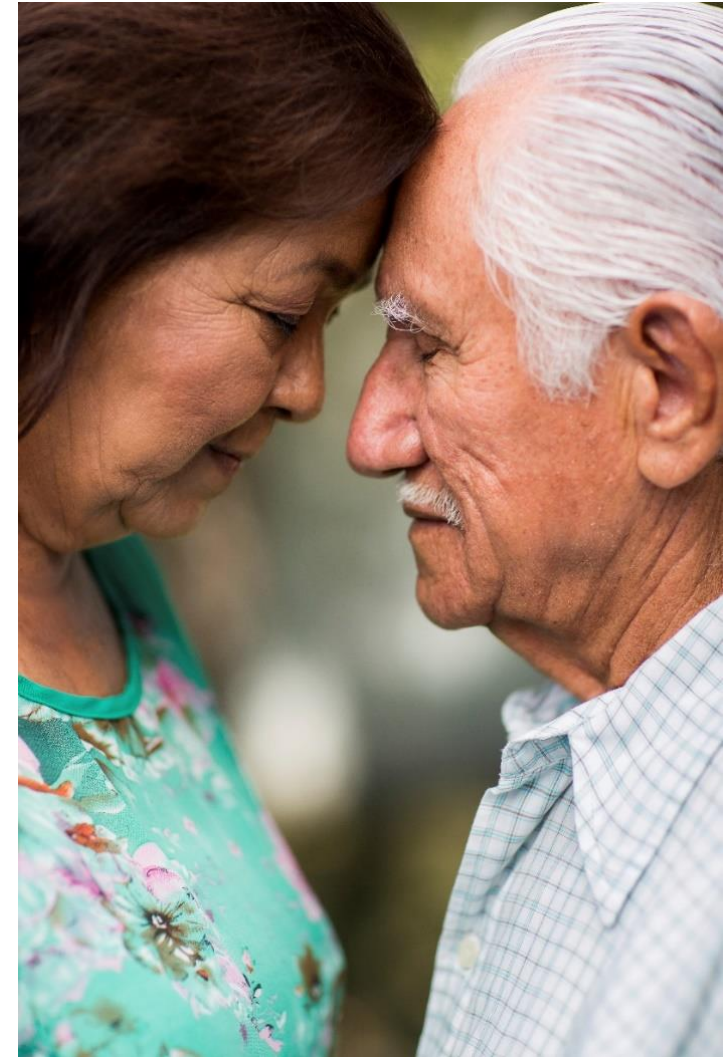


Change in confidence in skills



Conclusion

One of the challenges about being diagnosed with dementia is other people's reactions... Acceptance brings its own gift of peace... If we all lived in a more dementia friendly community, everyone with dementia would receive this gift of acceptance.

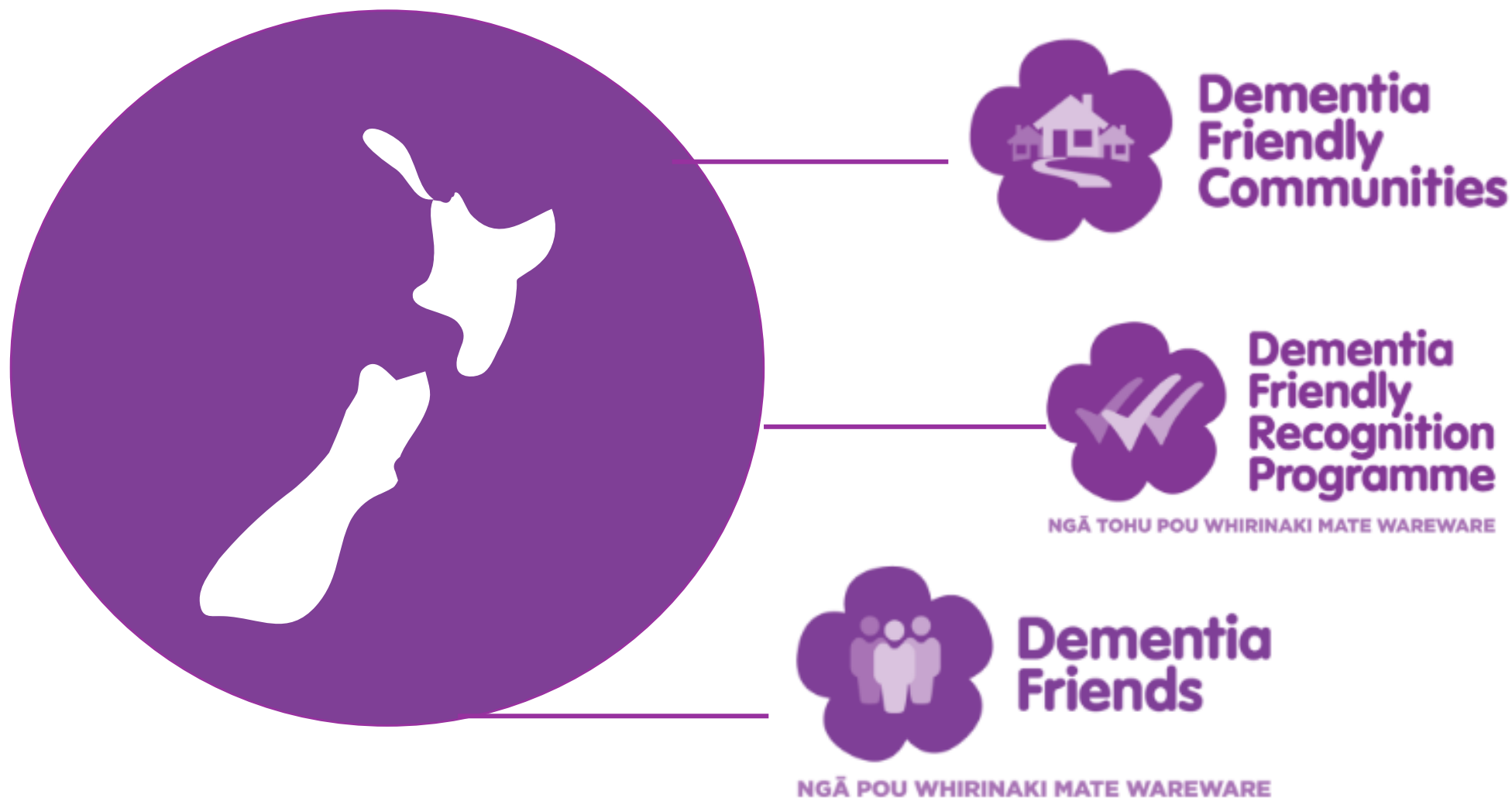


What is a Dementia Friendly?

An Aotearoa New Zealand in which people living with dementia mate wareware can exercise their human rights to be included and valued, to contribute and participate, to live independently in the community for as long as is possible for them, and to get the help and support they need



Dementia Friendly Aotearoa New Zealand



Dementia Friends



**Dementia
Friends**

NGĀ POU WHIRINAKI MATE WAREWARE

“The Dementia Friendly training has really helped me understand how to communicate with people with dementia.”

Almost **18,000** Dementia Friends
across Aotearoa New Zealand!
Join the growing community on our
website!

“I was grateful to have learned more about dementia and it gave me some tools to begin a conversation with both my Mum and Dad.”

Dementia Friendly Recognition Programme

Opportunity for organisations to show their commitment to being Dementia Friendly



**Recognised Working to be
Dementia Friendly**
9 organisations

Dementia Friendly Accredited
9 organisations

Enrolled
18 organisations

“Becoming Dementia Friendly aligns perfectly with our purpose, as it allows us to support and serve all members of the community.”

Michael Severn, Audika General Manager





“We believe everyone deserves to be treated with respect and dignity. That’s why we have made it our mission to create an inclusive environment that supports people living with dementia.”

Liz Smith, Litmus Partner

Dementia Friendly Communities

People living with dementia mate wareware can:

- ✓ Maintain independence and control
- ✓ Be an active member of the community
- ✓ Access everyday services designed with their needs in mind
- ✓ Access housing and support to live as they choose
- ✓ Feel a sense of belonging





“The Dementia Friendly Programme has also had the added benefit of developing a positive and constructive relationship between the local police prevention team and the Marlborough Alzheimers team. We have found our involvement... to be of benefit to us in our prevention roles, but also an enlightening and engaging process.”

Russell Smith, Blenheim Police

Ngā mihi nui

Dr Kathy Peri

education@alzheimers.org.nz

Dr Meg Spriggs

dementiafriendlynz@alzheimers.org.nz