

Litmus

Research to strengthen services for people
living with dementia mate wareware

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Research questions



1. What **influence** do people living with dementia care workers have on services that support them to best meet their needs?
 2. What is the **impact of peer support** on people living with dementia care workers?
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Research methods



Ethics
approval

- Literature review
 - A survey with 10 Alzheimers organisations.
 - 29 qualitative interviews with people living with dementia mate wareware
 - 12 qualitative interviews with staff and managers from 6 organisations offering dementia services
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What influence do people living with dementia
mate wareware have on services that support
them to best meet their needs?



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.

We all benefit when people living with dementia make their views known and influence their services



People living with dementia

- improved self-esteem
- increased quality of life
- sense of empowerment
- connected to their community

Services

- Responsive
- Dementia-friendly

Community

- Reduced stigma
 - Inclusive and respectful
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People with living dementia have different influence levels





I feel like I have lost my independence because I have to rely on or ask people to take me somewhere. So [the feedback forms] makes me feel like I still have some independence and that's really important. (Person living with early onset dementia)

I need more information to offer meaningful suggestions.
(Person living with dementia)



I would need the confidence and to feel safe to speak to the group. (Person living with dementia)

Diagnosis and service access delays limits influence



We need to invite them to join us at this planning level much earlier on in their journey of dementia when they might feel they have the confidence to contribute. By the time, they start engaging with us in the day facility, they are not willing and often not able to participate in meetings and planning groups. (Provider)



A lack of resources limits involvement and influence

We do encourage as much as possible. We still don't have and I think most places still don't have people (living with dementia) actually designing it. Because that takes a lot more hands-on coordination. It is going to take a lot more time and resources to do that. (Provider)

People living with dementia influence our decisions within the bounds of resources available to us. Strongly influence our decisions if extra resources are not required. (Provider)



Inequities of access limit Māori from influencing mate wareware services

- Functioning in Te Ao Māori is critical for oranga wairua
- Kaumātua with mate wareware have influence
- Limited access to diagnosis, services and information, limits influence on dementia services
- Whānau-centred approaches needed to hear whānau Māori perspectives

More resources to strengthen the influence of people living with dementia make aware



- reduce the stigma and exclusions
 - early and equitable access to diagnosis and dementia services
 - pathways to build confidence
 - training, time and resources
 - culture of co-production
 - sharing innovative practices
 - appropriate support and processes
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What is the impact of peer support on people living with dementia mate wareware?





Peer support is

a structured approach that involves individuals with similar conditions supporting each other by sharing their time and experiences





Making friendships. It's really important. Because the majority of my friends aren't my friends anymore. They can't cope with me, so I don't have anything to do with them. That's why I started going. (Younger person living with dementia)

Difference types of peer support groups



- Formal and informal
 - In-person or online
 - Groups and one-on-one
 - Professional-, lay-, or peer-facilitated
 - Community or organisation-led
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Good peer support looks like

- user-led
 - focused on capacity building
 - facilitated through a community organisation
 - semi-structured and purposeful
 - community-based
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Peer support is part of other services

Only a few formal peer support programmes

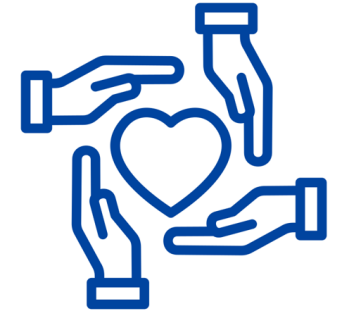
- One-on-one and group peer support through volunteers
 - Online peer support group
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Aotearoa has informal peer support; some alignment to best practice



- ✓ user-led
 - ✓ facilitated through a community organisation
 - X focused on capacity building
 - X semi-structured and purposeful
 - X community-based
-

Increased social engagement and emotional support



I think it's made a big difference for me. I tend to withdraw from the world so getting out there and meeting people with similar challenges as me. It has made me feel that I'm not the only one with the thing. (Person living with dementia mate wareware)

Ability to accept and cope



I like the companionship. At the beginning, my family were worried about me having Alzheimers. But there's no big deal about it. There's no worry about it. [The group] makes it normal. Going to the group makes what I've got okay.
(Person living with dementia mate wareware)



New knowledge and practical advice

The whole point of coming into the early onset peer support group for me is to ask questions like what do we think about driving? How are people coping? How do people remember? Do you use lists? What apps do you find useful? What peer support do you get in your area? (Younger person living with dementia mate wareware)

Informal peer support is beneficial



- increased social engagement and emotional support
 - sense of purpose, increased self-confidence
 - ability to accept and cope with having dementia mate wareware
 - new knowledge and practical advice
 - quality of life and wellbeing benefits
 - care partners have a break
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A structured approach to peer support



- a shared understanding
 - improved access to early diagnosis and services
 - increased focus on capability building
 - a more structured and purposeful approach
 - linking people to their wider community
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