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Review of Adult Decision-Making Capacity Law
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Tēnā koutou

Submission on the Review of Adult Decision-Making Capacity Law Second Issues Paper

Alzheimers NZ welcomes the opportunity to make a submission to the Review of Adult Decision-Making Capacity Law Second Issues Paper (the Review). This submission aligns with our submission to the preliminary paper in 2023.

Alzheimers NZ represents people living with dementia mate wareware and their care partners. We raise awareness of dementia mate wareware, provide information and resources, advocate for high quality services, and promote research about prevention, treatment, cure, and care. We support local community based Alzheimers organisations throughout Aotearoa New Zealand. These organisations provide support, education, information, and related services directly to members of their communities who are affected by dementia mate wareware.

Dementia mate wareware in Aotearoa New Zealand

The Aotearoa New Zealand population is ageing. With a rapidly ageing population, the number of people living with dementia mate wareware is also increasing at an unprecedented rate. Dementia mate wareware is one of the 21st century's health challenges. There is no cure, and none is currently on the horizon. Research suggests the number of people living with dementia mate wareware [will increase by 240 per cent in 30 years](#). The number of people living with dementia mate wareware is increasing rapidly among Māori, Pacific Peoples, and Asian communities.

Around one million New Zealanders [will be aged 65 years and over in 2028](#). Ninety percent of people living with dementia mate wareware are over 65 years old, with Alzheimer's disease being the most common form, affecting around two-thirds of people living with dementia mate wareware.

Dementia mate wareware and decision-making capacity

Dementia mate wareware affects memory, cognitive abilities, and behaviour. It is progressive which means that it gets worse over time. For most people, this condition affects their ability to make decisions and express themselves, with the result that their needs and preferences are often ignored or overlooked.

People living with dementia mate wareware do not always benefit from the same rights, privileges, and opportunities as other people. This is not only because of the difficulties they experience as a result of various impairments, but also because of practices, attitudes and the way things are organised.

The NZ Government ratified the United Nations [Convention on the Rights of Persons with Disabilities](#) (the Convention) in 2008. This Convention intends to protect the rights and dignity of disabled people, including people living with dementia mate wareware. [Article 12 of the Convention](#) acknowledges people with disability have a legal capacity on an equal basis with others.

Alzheimers NZ's positions

Alzheimers NZ believes people living with dementia mate wareware have the same rights, privileges, and obligations as everyone else, including the right to make their own decisions with reasonable support in exercising their legal capacity. The Alzheimers NZ's Advisory Group developed the [Dementia Declaration](#) that sets out what they need to live well.

Alzheimers NZ supports the recommendations of the Review that will allow people living with dementia mate wareware and other people with disability to continue their participation in society. In this submission, we outline our comments and recommendations supporting this review.

Reform of the Protection of Personal and Property Rights Act 1988 (PPPR Act) and the recognition of Te Tiriti o Waitangi in a new Act

Alzheimers NZ supports the Law Commission's recommendation to Government to reform the current PPPR Act to ensure proper respect for a person's rights, will and preferences, and ultimately to address equity issues. Our view is that any new legislation should recognise Te Tiriti o Waitangi and reflect the requirements of the Convention to provide access and support for individuals who need to exercise their legal capacity.

We strongly recommend that a public education campaign to increase awareness of and provide information on a new Act is undertaken across multiple channels and in relevant languages. That would include information about what changes to expect and the available supports to facilitate people living with dementia mate wareware in exercising their decision-making capacity.

Decision making support

It is an ethical priority to maximise the opportunity for people living with dementia mate wareware to be the central role in decision making and continue to make decisions about their lives.

Alzheimers NZ strongly supports supported decision-making and proposes 'a principled' approach as the preferred way of conceptualising supported decision-making. The [principled approach](#) recognises that when a supporter has not been able to elicit a person's will and preferences, a decision should be based on their best interpretation of what the person's will and preferences would be.

This continuum of decision-making support is a shift from a binary approach that enables the activation of substitute decision-making based on the person's best interests if a person is deemed lacking the capacity to make a decision and communicate their will and preferences.

A principled approach accommodates people with the most severe cognitive impairments within the supported decision-making process. It also recognises the reality that supported decision-making will inevitably at times require another person making a decision on behalf of a person with a cognitive disability.

We also support the recommendation to maintain presumption of decision-making capacity in a new Act. This is important to reduce the risk of an assessor assuming or wrongly determining that a person does not have decision-making capacity. While decision making can become more difficult as the condition progresses, we should not assume people living with dementia mate wareware are incapable of making decisions. [Evidence suggests](#) that many people living with dementia mate wareware, even those in the more advanced stages, can still articulate their values, preferences, and choices in a reliable manner. It also suggests that they maintain a strong desire to remain central in decision-making processes that directly impact their lives.

Barriers and ways to improve decision making capacity

There are barriers that prevent people living with dementia mate wareware from getting good decision-making support. These include the stigma and misunderstanding associated with this health condition, and limited social networks the individuals have within their family and community.

Tackling stigma and discrimination, raising awareness of dementia mate wareware and its impacts, and building inclusive and accepting communities will be essential if people living with dementia mate wareware are going to be able to make the decisions that are important to them.

Assessment process

Health professionals such as general practitioners and physicians have the responsibility for decision-making capacity assessments. We recommend that decision-making capacity assessments be carried out by broader groups of health professionals such as registered nurses, occupational therapists, and social workers who have completed a relevant course.

Due to a range of factors and the complexity in assessing capacity, we also recommend that specific curriculum and training resources for health professionals be developed to improve their skills and knowledge in decision-making capacity assessments and assistance. The assessment process should use all available initiatives and incorporate ways that make the process clear and reflective of the needs of our diverse community.

In conducting decision-making assessment, health professionals should assess the individual for their ability to make a decision, not for the outcome of the decision they want to make. Health professionals should also recognise that a person's decision-making ability may evolve or fluctuate over time. This is particularly true for people living with dementia mate wareware where their ability to make decision can be influenced by a variety of physical, psychological, social, and environmental factors.

We support the suggestion that a new Act should provide a single test for decision-making capacity, which consists of four elements that reflect current understandings of decision-making capacity. This approach will maintain consistency in practice and reduce confusion and cost.

Supporting arrangements

Due to their conditions and circumstances, people living with dementia mate wareware may require supporters to help, communicate, and participate in decision making. Supporters must help them to express and make decisions in accordance with their will and preferences. In communicating will and preferences, people living with dementia mate wareware are entitled to communicate by any means that enable them to be understood and have their cultural and linguistic circumstances recognised and respected. We recommend that information and guidance are made available to help supporters and professionals improving their decision-making capacity support.

We agree with the recommendation that to improve access to support, a person with dementia mate wareware with affected decision-making can appoint a formal decision-making supporter, such as an enduring power of attorney (an EPOA). This means it requires them to enter into some forms of legal agreement. While this arrangement may improve the ability of support people to make their decision, it involves time and expenses. The administration legal fee should be capped to remove financial burdens for their families and whānau, and the forms and process need to be simpler and easier.

Providing community education that is responsive to different cultural backgrounds, training sessions about the court process, and an agency where people can get legal advice on appointing formal decision-making supporters could also improve support.

Safeguard

Decision making arrangements may not function as they should. Appropriate and effective safeguards to prevent abuse of and undue influence over people living with dementia mate wareware who may require decision-making support should be included in a new Act.

Procedural safeguards governing how such decisions are made, who makes them, and how they are made should be in place to control and prevent abuse in exercising legal arrangement. These safeguards would, for example, ensure EPOAs are only making decisions when they are legally authorised to do so, and that they are permitted to make decisions only if people living with dementia mate wareware are assessed as no longer having decision-making capacity. When decision making based on will and preference is not possible, EPOAs must act consistently with the person's human rights and the decisions must be based on their best interpretation of what the person's will and preferences would be.

The current legal safeguards could be enhanced by appointing an independent agency/body to monitor compliance to conduct some 'check and balance' or to act as an advocate for people who cannot represent themselves in the safeguarding process. We also support a submission by Age Concern NZ on elder abuse regarding an organisation or a public body to help elderly people or abuse survivors to get help and make a claim.

Recommendations

While supporting the recommendation of the Review, Alzheimers NZ recommends that:

- The approach for supported decision-making is shifted from 'a binary' approach which enables the activation of substitute decision-making to 'a principled' approach which provides continuum of decision-making supports.
- A public education campaign, or similar measures, should be conducted to ensure the availability and accessibility of information about decision-making arrangements under a new Act.
- Initiatives to address stigma and discrimination and raise awareness of dementia mate wareware should be widely created to empower people living with this health condition to continue their ability to make the decisions that are important to them.
- Health professional groups who can conduct decision-making capacity assessments should be broadened to include practitioners who have completed a relevant course. Training in decision-making capacity assessments and support for health professionals should be developed to improve their skills and knowledge.
- While formal decision-making supporters e.g. an enduring power of attorney may increase the ability of support people to make their decision, the legal agreement process should not add financial burdens for their families and whānau, and it should be simpler and responsive to different cultural backgrounds.
- The current legal safeguards should be enhanced by establishing an independent agency to monitor compliance, intervene and prevent abuse, and to ensure individuals' wills and preferences are respected.
- Information or guidance to improve decision-making capacity support should be made available to help supporters and professionals.

Conclusion

Alzheimers NZ supports the recommendations of the Law Commission to reform the Protection of Personal and Property Rights Act 1988 with the aim of changing practices in recognising and providing access to support individuals exercising their legal capacity. We applaud the recommendation that a new Act honour Te Tiriti o Waitangi to enable Māori to make culturally safe decisions according to tikanga.

Alzheimers NZ strongly supports supported decision-making that is based on ‘a principled’ approach that provides continuum of support for people with cognitive impairments, such as people living with dementia mate wareware.

To support and improve the implementation of a new Act, we recommended several actions. These include addressing barriers and improving the supported decision-making processes, conducting public education campaigns to provide information on supported decision-making, and addressing stigma and discrimination against people with disability including people living with dementia mate wareware and ethnic populations. We also recommend that procedural safeguards in a new Act could be enhanced to prevent abuse.

Ngā mihi,

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Chief Executive