



Alzheimers New Zealand

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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

Alzheimers NZ welcomes the opportunity to submit on the Review of Adult Decision-Making Capacity Law (the Review).

Alzheimers NZ represents people 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 and dementia mate wareware 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

Dementia mate wareware is a major issue for Aotearoa New Zealand. Seventy thousand New Zealanders were living with dementia mate wareware in 2020, this number is expected to reach 170,000 by 2050.¹ The number of people living with dementia mate wareware is increasing rapidly among Māori, Pasifika, and Asian populations.

The risk of dementia mate wareware increases with age. Dementia mate wareware impacts more women than men, about 30 percent higher. Ninety percent of people living with dementia mate wareware are over 65 with Alzheimers disease being the most common form, affecting around two-thirds of people living with dementia mate wareware.

Dementia mate wareware and decision-making capacity

The United Nations Convention on the Rights of Persons with Disabilities² (the Convention) has the intent of protecting the rights and dignity of disabled people, including people with dementia mate wareware. It acknowledges that disabled people have legal capacity regardless of their impairments.

People with dementia mate wareware are often denied the opportunity to make their own decisions, as it is often incorrectly assumed they cannot make decisions for themselves. Alzheimers NZ believes people with dementia mate wareware have the right to make their own decisions with the appropriate level of support required for them to do so.

Alzheimers NZ support and recommendations

Alzheimers NZ believes the Convention represents an important recognition of the rights of people with a cognitive disability to make decisions about all aspects of their lives.

Alzheimers NZ supports the Review and makes some recommendations to the Law Commission to consider how the law should approach issues relating to affected decision-making of adults. Our comment and recommendations are outlined below.

Terminology and language

Alzheimers NZ supports most of the proposed terminology outlined in the Preliminary Issues Paper. The terminology will help people across various sectors to understand specific matters, communicate more efficiently, maintain consistency and improve quality information to support people exercising their right to make their own decisions.

However, Alzheimers NZ does not support the proposal to use the term ‘learning disability’ to include conditions such as ‘cognitive impairment’, ‘learning disability’, ‘cognitive disability’ and ‘intellectual disability’ used interchangeably. Those conditions should have different definitions.

As an example, people with cognitive impairment do not necessarily experience a decrease in their learning capability. They may be capable of continuing to acquire knowledge and skills but their ability to, for example, communicate this knowledge might be impaired.

Te Ao Māori and Tikanga Māori

Te Tiriti o Waitangi is a founding document that is fundamental to social and health policy in Aotearoa New Zealand. Alzheimers NZ recognises the significance of Te

Tiriti o Waitangi and commits to meeting its responsibilities and ensuring the principles guide all aspects of our mahi.

It is disheartening the current law does not take into account Te Tiriti o Waitangi and the multicultural nature of Aotearoa New Zealand.

The Dementia Economic Impact Report 2020 (DEIR)¹ shows the numbers of people with dementia mate wareware are increasing at a faster rate among Māori, Pasifika, and Asian populations than those of European New Zealanders. The report confirms the situation causing significant equity issues in these communities.

Alzheimers NZ supports the Review recognising the role of Te Tiriti o Waitangi and providing for Tikanga Māori. We recommend the law integrates Tikanga Māori and Māori concepts relevant to adult decision-making, rather than to only consider it.

Weaving the strands of Te Tiriti o Waitangi, Te Ao Māori and Tikanga Māori will contribute to improving the ability of tāngata whaikaha including Māori people living with dementia mate wareware to make their decision supported by their whānau, hapu, iwi, and aligned with their culture and tradition. It also brings the value that focuses on the importance of relationships, peoples' dignity, and obligation to care for one's own.

The Guiding Principles

Alzheimers NZ agrees with the proposed seven guiding principles to consider options for law relating to adult decision-making. The proposed principles are sufficient to making the law work effectively.

Our view is the guiding principles should be understood as a coherent whole and should be read individually and collectively. This is to ensure the review process can achieve its objective to improve the human rights standards and practices for disabled people.

The guiding principles should also be implemented in a non-discriminatory manner. Particularly on attention to the rights and needs of, and the challenges faced by, disabled people that may be at heightened risk of becoming vulnerable or marginalised. We also recommend appropriate processes to consider specific issues faced by religious and ethnic communities are in place while implementing these principles.

Decision-making arrangements and accountability mechanisms

Alzheimers NZ strongly supports the principles of supported decision-making for disabled people, including people living with dementia mate wareware, because this approach places disabled people at the centre of the decision-making process. However, we also understand significant challenges in the legal interpretation and implementation of the process.

People with dementia mate wareware need different types of support at different stages of their conditions, and they need to be person centred and person specific. Dementia mate wareware is a progressive condition, therefore we recognise that there will be contexts and conditions in which substitute decision-making could be an appropriate approach.

Alzheimers NZ believes that people with dementia mate wareware and/or disabled people should be supported to make their decisions whatever decision-making arrangements are made; whether it be through an enduring power of attorney, under a court order, or collective decision-making processes and decisions.

We believe that supported decision-making processes can play an influential role in educating the community about recognising and supporting the strengths and abilities of the person with dementia mate wareware, including their decision-making capacities.

Recommendations

While supporting the Review, Alzheimers NZ makes several recommendations:

- The Law should provide a better terminology to determine health conditions of disabled people.
- The Law should honour Te Tiriti O Waitangi and acknowledge Te Ao Māori and Tikanga Māori.
- The Law should have appropriate processes to implement the Guidance Principles.
- The regulation should provide clear guidance to establish decision-making arrangement mechanisms that are simpler and work better. These could be by providing information about setting up and execution of the plan should decision-making support be needed or creating legislation to clarify advance directives and the power of enduring power of attorney.
- Consultation with relevant sectors and the public should be conducted to ensure the creation of law is useful in Aotearoa New Zealand.

Conclusion

Dementia mate wareware is a progressive condition that causes a change in cognitive ability over time. For people living with dementia mate wareware, it can be challenging to remain involved in decision making. Their decision-making ability can be influenced by a variety of physical, psychological, and environmental factors.

Alzheimers NZ supports the Review of Adult Decision-Making Capacity Law to ensure disabled people, including people with dementia mate wareware, are supported to make decisions about their life.

We support the supported decision-making approach. However, we acknowledge that people with dementia mate wareware will require different levels and types of support to maximise involvement in decision-making for as long as possible and in different situations. Therefore, both supported and substitute decision-making approaches might be required at different times, and in relation to different decisions.

We recognise the diversity and support the integration of Te Ao Māori and Tikanga Māori. Honouring Te Tiriti o Waitangi and implementing its principles are driving transformational change across Aotearoa New Zealand society and striving towards equitable outcomes for tāngata whaikaha and their whānau.

Alzheimers NZ looks forward to the legislation that meets the Convention as well as that disabled people including people with dementia mate wareware have the right, the opportunity, and the support necessary to ensure they have their voice into decisions that affect them.

Nāku noa, nā,

Catherine Hall
Chief Executive

¹ Ma'u E, Cullum S, Yates S, Te Ao B, Cheung G, Burholt V, Dudley M, Krishnamurthi R, Kerse N. Dementia Economic Impact Report 2020. Auckland, New Zealand: University of Auckland; 2021.

² United Nations. Convention on the Rights of Persons with Disabilities (CRPD)

www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html