



Alzheimers New Zealand

1. Alzheimers New Zealand is a lead organisation at a national level representing people and their families living with dementia. People living with dementia are at the center of everything we do. Our work is shaped by the Dementia Declaration and advice from the Alzheimers NZ Advisory Group.
2. Our role includes raising awareness of dementia, providing information and resources, advocating for high quality services, providing practical tools to support a dementia friendly New Zealand, and promoting research. Alzheimers NZ was established in 1986.
3. We support local Alzheimers NZ organisations throughout New Zealand, each of which is a member of Alzheimers NZ. The local Alzheimers organisations provide support, education, information, and related services directly to members of their communities who are affected by dementia. These services include but are not limited to:
 - a. Provide information and education to assist with understanding and living with a dementia diagnosis.
 - b. Support for family and friends coping with the demands of caring.
 - c. Support groups and day programs for people affected by dementia.
4. We work in partnership with other organisations, including New Zealand Carers' Alliance, Neurological, Health Coalition Aotearoa, Federation of Primary Health, and New Zealand Coalition to End Loneliness. We are also a member of the global dementia community as members of Alzheimer's Disease International.
5. Thank you for considering our submission. Our submission relates to recommendations for persons with disabilities including indigenous rights and ethnic minorities, and based on issues where immediate change can occur:
 - a. Inadequate health care services for people with dementia and older people.
 - b. Lack of national data as a barrier to understand the scope of the dementia problem.

Health care services and support for people with dementia

Introduction: Dementia is a significant human rights issue

6. Dementia is one of the 21st century's health challenges. There is no cure, and none is currently on the horizon. Dementia has an enormous impact on the lives of people affected by it, their families and care partners, the health system, and the economy. While dementia is not an inevitable part of ageing, age is the most significant risk factor. With an ageing population, the number of people with dementia is also increasing.
7. Dementia is a major cause of disability and dependency among older adults, affecting memory, cognitive abilities, and behaviour, and ultimately interfering with a person's ability to look after themselves.
8. Dementia affects cognitive function that limits people with this health condition from expressing themselves, making their needs are often ignored or overlooked. People with dementia are often denied the ability or the opportunity to make their own decisions. They face considerable stigma and discrimination which creates even more barriers to accessing services and support. There is a limited approach to establishing dementia and age friendly communities.
9. People with dementia are protected by the United Nations Convention on the Rights of Persons with Disabilities because dementia is a major cause of disability and dependency influenced by symptoms, environments, discrimination, and inequality.

Issues

Inadequate health care services for people with dementia and older people

10. Alzheimers NZ does not believe that current health services for people with dementia and older people in New Zealand are adequate. Services are fragmented, inconsistent, and inequitable - and often underfunded.
11. In New Zealand, 70,000 people living with dementia in 2020 and due to the growing ageing population, this number is expected to reach 170,000 by 2050. The increase will be more significant among Māori, Pacific Peoples and Asian communities who experience both earlier onset and greater prevalence than other ethnicities. Dementia also cost New Zealand economy \$2.5 billion in 2020. It will reach almost \$6 billion by

2050 in today's dollars. Aged residential care accounts for half of the economic cost of dementia borne by the Government (\$1.21 billion).¹

12. New Zealand has the Dementia Mate Wareware Action Plan 2020-2025² but this Action Plan has not been fully implemented. The Action Plan has four priority areas:
 - a. Reducing the incidence of dementia.
 - b. Better supporting those living with it, and their care partners.
 - c. Building dementia friendly and inclusive communities.
 - d. Strengthening leadership and capability across the sector.
13. Alzheimers and dementia organisations are the primary source of dementia service in the community across New Zealand. However, because of the increasing demand, accessing post-diagnostic support from these services is challenging. Only 20-50 per cent of people with dementia received a formal diagnosis³ and as many as 30,000 people with dementia in New Zealand cannot get support from community-based dementia services.^{Error! Bookmark not defined.} Access to services is even more inequitable for Māori, Pacific People, and Asian communities, and those in rural areas.
14. Without support, people with dementia are likely to experience a faster decline of their cognitive function, more acute events and admissions to secondary services, increased lengths of stay, failed discharges, increased need for aged residential care and for higher levels of that care, and health system harms, especially falls and medication harms.
15. Families also struggle to support their loved ones with dementia. Reports shows that carers provide over one million hours of unpaid care every week^{Error! Bookmark not defined.} and about one million carers are struggling, under pressure and do not feel valued.⁴
16. People with dementia and their care partners, as well as older people also need to navigate through the myriad of individuals and organisations when accessing services due to inconsistency and disintegration of health services.
17. Access to healthcare and support services plays a critical role in the health equity and the human rights of people with dementia. Unless action is taken to address disparities in accessing healthcare and support services

at the population level, health inequities and human rights issues faced by people with dementia will continue to grow.

18. People with dementia are entitled to enjoy the highest attainable standard of health without discrimination on the basis of disability. They are also entitled to health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimise and prevent further disabilities, including among older persons (UNCRPD article 25).
19. People with dementia should be empowered to live in the community and to receive care aligned with their wishes and preferences. They are entitled to care services that recognise and respond to their unique needs to maintain a level of functional ability consistent with their basic rights, fundamental freedoms, and human dignity.
20. We recommend that the New Zealand Government implement the WHO Global on the Public Health recommendation to develop a pathway of efficient, coordinated care for people with dementia that is embedded in the health and social care system, including long term care, to provide integrated, person-centred care as and when it is required. This action will contribute to achieving equitable health outcomes and protecting the human rights of people with dementia.

Lack of national data as a barrier to understand the scope of the dementia problem.

21. New Zealand Government collects national data on health conditions, such as heart disease and cancer, but it does not collect data on dementia. Current estimates data on dementia are obtained by Alzheimers NZ.
22. The lack of a formal national disaggregated data collection on dementia impacts on our understanding of how dementia impacts on the social and economic welfare of people affected by this health condition in New Zealand, the supply and demand of appropriate services, and people's ability to access human rights. These include creating barriers to seek the voices representing people with dementia themselves, access information of benefit for them, and control over their own lives and alternative choices.

23. The lack of data limits New Zealand’s ability to meet its obligations under the United Nation Convention on the Rights of Persons with Disabilities.
24. We recommend that the New Zealand government follow the WHO Global Action Plan on the Public Health recommendation to collect and use the necessary data on epidemiology, care and resources relating to implement relevant policies and plans.

Conclusion

25. Alzheimers NZ is concerned that despite being one of the leading causes of health loss in New Zealand⁵, dementia has not been made a public health priority. We hope that our recommendations will be seriously considered and implemented to meet New Zealand’s obligations to the WHO’s Global action plan on the public health response to dementia 2017 – 2025.⁶ The progress made from our recommendations will be a symbol of recognising the rights of people with dementia to access health care and achieve equitable health outcomes for people with dementia in New Zealand.

¹ Ma’u E, et al. Dementia Economic Impact Report 2020. Auckland, New Zealand: University of Auckland. 2021. [Link](#).

² Alzheimers NZ. Dementia Mate Wareware Action Plan 2020-2025. Wellington, New Zealand. 2020. [Link](#).

³ Price M, et al. Alzheimer’s Disease International World Alzheimer Report. The benefits of early diagnosis and intervention. Institute of Psychiatry, King’s College London. UK. 2011. [Link](#).

⁴ Carers NZ. The State of caring in Aotearoa. Wellington, New Zealand. 2022. [Link](#).

⁵ Ministry of Health. 2013. Health Loss in New Zealand: A report from the New Zealand Burden of Diseases, Injuries and Risk Factors Study, 2006–2016. Wellington: Ministry of Health. [Link](#).

⁶ The WHO. Global action plan on the public health response to dementia 2017–2025. Geneva: World Health Organization; 2017. Licence: CC BY-NC-SA 3.0 IGO. [Link](#).