



**Dementia
Australia®**

Aged Care Act Exposure Draft

Dementia Australia Submission

March 2024

Dementia Australia

Dementia Australia is the peak dementia advocacy organisation in Australia.

Our organisation engages with people with dementia, their families and carers in our activities, planning, policy and decision-making, ensuring we capture the diversity of the living experience of dementia across Australia.

Our advocacy amplifies the voices of people living with dementia by sharing their stories and helping inform and inspire others. As the trusted source of information, education, and support services, we advocate for positive change for people living with dementia, their families and carers, and support vital research across a range of dementia-related fields.

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Dementia in Australia

Dementia is the term used to describe the symptoms of a large group of complex neurocognitive conditions which cause progressive decline in a person's functioning.

Dementia is not just memory loss - symptoms can also include changes in speech, reasoning, visuospatial abilities, emotional responses, social skills and physical functioning. There are many types of dementia, including Alzheimer's disease, vascular dementia, frontotemporal dementia and Lewy body disease.

In 2024, it is estimated there are more than 421,000 people living with all forms of dementia. This figure is projected to increase to more than 812,500 by 2054, a projected percentage change of 93%. More than 1.6 million people in Australia are involved in the care of someone living with dementia.¹

Dementia is the leading cause of disease burden among Australians aged 65 and over. Dementia is the second leading cause of death for Australians and the leading cause of death of women.²

Aged care needs to get its 'act' together!

~ person living with dementia

¹ Dementia Australia (2024) *Prevalence Data* <https://www.dementia.org.au/information/statistics/prevalence-data>

² Australian Institute of Health and Welfare (2023) *Dementia in Australia, Summary, Impact* <https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/summary>

Dementia Australia's response

Dementia Australia welcomes the opportunity to provide advice on the Exposure Draft of the Aged Care Act, as it relates to people living with dementia. We also strongly support the joint submission made by national organisations working with older people and carers.

It is critical that the new Aged Care Act not only embed human rights but make these legally enforceable. Aged care providers must be required to uphold the human rights of people accessing the aged care system and embed choice and control, including for people who are living with dementia.

Dementia Australia reiterates that people living with dementia or cognitive impairment account for a significant majority of people receiving aged care services³. People living with dementia also have the highest care needs in aged care domains including activities of daily living, complex health care and cognition and behaviour⁴.

The Royal Commission into Aged Care Quality and Safety found that:

Substandard dementia care was a persistent theme in our inquiry. We are deeply concerned that so many aged care providers do not seem to have the skills and capacity required to care adequately for people living with dementia".⁵

The new Aged Care Act must respect the autonomy and rights of each individual and protect against poor quality care. To achieve this, the Aged Care Act must respond to the needs of people living with dementia, ensuring that the workforce is dementia capable and ensure delivery of quality care for people living with dementia across all service types.

It is essential that the Act require dementia education for all parts of the aged care workforce. This is a core condition which enables the delivery of rights-based care to the majority of people receiving aged care services.

³ National Institute of Labour Studies (2017) The Aged Care Workforce, March 2016.

⁴ AIHW, (2023) [Dementia in Australia](#).

⁵ Royal Commission into Aged Care Quality and Safety (2021). A Summary of the Final Report.

Our recommendations

- 1) Strengthen the Statement of Rights and make it enforceable.
- 2) Require all aged care services to provide quality dementia care by a skilled workforce with mandatory dementia education.
- 3) Clarify supported decision-making arrangements and require education of the aged care workforce in supported decision-making.
- 4) Embed safeguards that minimise the use of restrictive practices.
- 5) Ensure that younger people have a right to access to aged care services when needed.

Recommendation 1: Strengthen the Statement of Rights and make it enforceable

Dementia Australia supports the inclusion of the Statement of Rights and the creation of a human rights based legislative framework for aged care. However, the Act must oblige aged care providers to uphold these rights.

Object b) needs to be strengthened by including that the aged care system will uphold the rights of and deliver quality care to people with dementia or cognitive impairment, reflecting that dementia care should be core business in the aged care system.

Dementia Australia consulted with people living with dementia and carers about the Exposure Draft of the Aged Care Act. We heard that people were concerned that the how the Statement of Rights would be upheld and how breaches of rights would be addressed.

I am concerned with the proposed resolution methods in the case of breaches of our rights. A restorative engagement would be satisfactory in the cases where minor denials of rights had occurred, but I couldn't trust a "for-profit" provider to make significant changes following a serious breach, where that might have a major impact on the corporation's financial gain.

~ carer of a person living with dementia.

The rights and principles need to be accessible, in an appropriate format for people living with dementia or cognitive impairment.

If the person living with dementia doesn't grasp the fundamentals of the Statement of Rights prior to entering a more advanced stage of dementia, and may not have an advocate, or voice, then the statement is worthless.

~carer of a person living with dementia.

We also heard that there needs to be education and capacity building for the aged care sector, to support application of the Statement of Rights and principles in aged care services of all types.

There needs to be major training programs in this arena. I applaud the link to principle but again service providers and their employees must fully understand how these rights and principles apply to those they work with. These rights and principles must be supplied in easy to understand and appropriate format to consumers of their programs.

~ carer of a person living with dementia.

Currently, the Act does not provide a robust framework for upholding rights, particularly where it is not mapped to the Code of Conduct or Standards. We recommend that the Code of Conduct be amended to include the requirement to uphold and implement the Statement of Rights. The Code of Conduct should also be included into the Aged Care Act.

Dementia Australia notes and appreciates the inclusion in the Statement of Rights for people to have access to assessment of their need for funded services in manner that is accessible and suitable for people living with dementia or other cognitive impairment.

However, we again argue that because this right is not mapped to the Aged Care Quality Standards or Code of Conduct, there is no means of enforcement. We recommend that there be process for response to breaches of this right.

The new Act suggests a principle of rights. These need to be legislated and made law. Otherwise, there will be no change in the way aged care providers and workers take their obligations truthfully. There has been a version of the Charter of Rights, and this meant nothing as the Complaints Commission etc would not uphold breaches of non-compliance.

~ carer of a person living with dementia.

Lastly, Dementia Australia is disappointed that the Exposure Draft of the Act does not include a right for carers to support. Carers access a range of funded services from the aged care system including respite, counselling, education and support.

The Royal Commission recommended under Recommendation 3, Key Principles, that informal carers of older people should have the certainty that they will receive timely and high quality supports in accordance with assessed need.

Carer rights needs to be included in the new Aged Care Act, in recognition of their right to access support, and the essential role they play in the sustainability of Australia's aged care system.

A carer of a person living with dementia expressed their concerns about the lack of recognition of carers in the Statement of Rights:

There is no universal right of access to funded aged care services. It does not address the rights of carers, even though it says this is legislated elsewhere. Without support from informal carers people with dementia would fall through the cracks.

Equally the needs of carers are not significantly addressed elsewhere. Carers are not supported adequately at all. The Carer Gateway falls short of providing any meaningful ongoing support for carers, for families, for carers of people with dementia. More support, or a section of Carer Gateway, needs to be set up to meet the needs of carers.

Often carers are the ageing spouses of their loved one with dementia. This is my situation, and I don't know how much longer I can continue providing the amount of help I need to give. My health needs are deteriorating. My quality of life has diminished. I'm worn out.

Persons with dementia decline and with it the need for care increases. This has not been addressed in the Act.

~ Carer of a person living with dementia

Recommendation 2: Require aged care services to provide quality dementia care by a skilled workforce with mandatory dementia education.

The Exposure Draft of the Aged Care Act does not mandate dementia education of the aged care workforce. We call on the Department of Health and Ageing to find a means to legislate for mandatory dementia education or risk failing in its responsibility to deliver a system which provides quality aged care to people living with dementia.

Widespread examples of poor-quality care support Dementia Australia's position that mandatory dementia education is essential for all parts of the aged care workforce.

My husband lives in a house of eight people. Five of those people are completely double incontinent. And they are not toileted properly or regularly and often walk around with visibly wet clothes.

One resident if he can, will urinate or defecate in public areas. He doesn't know where his toilet is and has no ability to manage or control that side of his life any longer.

When that happens, and staff take him to his room, he gets very distressed because he can't understand what's happening. Staff don't have the skills. He cries and shouts and swears for between fifteen and thirty minutes while two carers try to assist him.

That is very loud and is heard throughout the house by all other residents. It's very distressing for him and for everybody.

~ Carer of a person living with dementia

Delivering a truly person-centred care system, in accordance with the Statement of Rights, requires a dementia capable workforce with a strong understanding of the impact of different types of dementia and how to care holistically for the individual in accordance with their choices.

Dementia education is required so that the aged care system can respond to vulnerability, safeguard choice and control and protect human rights of each individual living with dementia.

The rights of a person living with dementia must include the right to be cared for by specifically trained dementia staff. There should be no stigmas associated with care of a person living with dementia. All people living with dementia should have access to these rights, be they culturally and linguistically diverse, or Aboriginal and Torres Strait Islander, or from other minority groups.

~ person living with dementia.

Staff need communication skills, compassion and empathy, as well as the ability to understand and respond appropriately to changed behaviour. There needs to be sufficient workforce development to ensure that qualified, dementia-capable staff provide consistent care that upholds the human rights of each individual.

The lack of qualified staff is a major issue. All staff should be dementia trained and also participate in ongoing training. Not just care staff, but nursing and managers.

~ carer of a person living with dementia.

Paid carers in residential care facilities looking after people with dementia must have a minimum of a Certificate of Dementia acquired from a national registered training organisation. It must be legislated in the Act that residential aged care providers looking after people with dementia must employ staff with the minimum of a Certificate in dementia care from a registered training organisation.

~ carer of a person living with dementia.

Dementia Australia also notes that there is currently no regulatory mechanism to ensure that all home support services are required to deliver quality care to people living with dementia which upholds their human rights, including for services considered 'low risk' in the new regulatory framework.

I have been fighting for my rights to live at home in safety from the so-called people who come to give care, even if it's those who come for the garden. I have to fight, fight, fight.

~ person living with dementia

Recommendation 3: Clarify supported decision-making arrangements and require education of the aged care workforce in supported decision-making.

Dementia Australia is concerned that the Exposure Draft of the Aged Care Act does not give full effect to a supported decision-making model of care in daily life. In addition, the arrangements for supporters and representative are confusing and their relationship with state and territory legislation is still difficult to comprehend.

In our consultation with people living with dementia and carers, we heard that while there was some optimism about supported decision-making being included in the Act, the proposed model may be difficult to enact for people living with dementia and their carers.

If a person were to be diagnosed as being in a more advanced level of dementia, then there may be some difficulties in understanding their concerns, needs and desires. This may be due to variety of conditions like a lack of speech or a lack of understanding. Not everyone has a power of attorney, or even a will.

~ carer of a person living with dementia.

It adds to confusion. We will have multiple representatives, supporters, and advocates, but only one at a time. This raises potential for increased family feuds rather than fewer.

~ carer of a person living with dementia.

Respondents to our survey told us that supported decision-making for people living with dementia needs to be supported with planning and documentation. There was concern that it may be difficult to discern the will and preferences of a person living with advanced dementia if that was not already known. The proposed supported decision-making model could be burdensome for people living with dementia and carers, creating more administrative burden and confusion.

It is important that the person living with dementia has someone who they know or have given authority to act on their behalf. The Advanced Care Directive must be adhered to, where someone has been given authority to act on the person's behalf, this person, not a government official can made informed decisions on behalf of a person who no longer has capacity to make their own decisions. These people are the ones who know the wishes of the person living with dementia.

~ person living with dementia.

This is still a problematic area, particularly in the area of dementia. I believe an education program for one's aged care should be uppermost in all persons pre-planning. A will, enduring power of attorney and enduring power of guardianship would ensure there is a valid supporter/representative is in place prior to any catastrophic illness or need.

~ carer of a person living with dementia.

Dementia Australia notes that people living with dementia should always have access to visits from a chosen support person or supported decision-making partner, and that if access is prevented, for example during an infection outbreak, the person's capacity to make choices, and right to decision-making support may not be realised.

The Act should ensure that people living with dementia have information and access to advocacy and support to ensure that their rights and choices are realised.

To maintain the rights of a person living with dementia, it may be necessary to use supported decision-making and Advanced Care Directives to ensure the rights of these people are not overlooked! I don't want someone who doesn't know me making any important decisions about my care and life.

~ person living with dementia.

Dementia Australia also argues that the Statement of Rights cannot be realised unless the workforce has dementia education and training to implement supported decision-making models in day-to-day life. The aged care system needs an educated workforce and culture of leadership for quality dementia care, to give full effect to the provisions for supported decision-making under the Act.

All people who are involved with people living with dementia and delivering any form of services must have the relevant dementia training. The Aged Care workforce, in general must be dementia trained. It is the right of all people living with dementia to have appropriately trained dementia staff.

~ person living with dementia.

Recommendation 4: Embed safeguards that minimise the use of restrictive practices.

Restrictive practices should be a last resort and there must be safeguards in place to ensure that restriction is used minimally and with appropriate consultation, approval and review. The Act should embed safeguards to protect against inappropriate restrictive practices and require a focus on the prevention.

Restrictive practices must be the last form of treatment for people living with dementia. There are other methods of treatment that can be used first. Using person centred care can help in avoiding restrictive practices.

~ person living with dementia.

The Aged Care Act must require providers to involve and engage with people living with dementia, their family, carers and legally appointed decision-making representatives when considering restrictive practices. Providers should be required to implement strategies to minimise the use of restrictive practices and ensure safety. There must be a requirement for effective communication about the risk and rationale for proposed restrictive practices, and an avenue for alternatives to be discussed and implemented.

Recognising whose interests are being served... the service provider, carer or patient? Is therapy a better option? Should there be a higher staff/resident ratio? Are health issues being met properly? For example, dementia patients may respond to pain in behavioural ways. Consultation with all persons involved in care, all care staff, client representative, medical team.

~ carer of a person living with dementia.

An important consideration is that the aged care providers work together with the person living with dementia, carer and family, to develop a support plan which is adapted as the person's dementia progresses. In our consultation we heard that:

[Carers] should be notified and consulted right from the beginning and be involved in all stages of the decision-making process regarding the use of restrictive practices. It should be explained to them clearly why restrictive practices are being proposed. Carers may have very useful information and experiences of how to deal with difficult behaviour on the part of their loved one and this should be included when restrictive practices are being considered.

~ carer of a person living with dementia.

Carers should absolutely be involved at all stages, but particularly when there is a change to circumstances in the nature of care or accommodation style. The carer should be consulted before such action is taken, not afterwards. There may be circumstances where emergency action needs to be taken but this can be covered by carers agreeing in a future directions statement which poses 'what if' situations.

~ carer of a person living with dementia.

The clinical care standard for use of psychotropic medicines provides alternative suggestions, such as more effective behaviour support plans. Therefore carers - who generally know the client best - should be in good communication with a receptive care home to develop and review as required a behaviour support plan initially and as behaviour changes.

~ carer of a person living with dementia

... restrictive practices should only be used as a last resort. Behavioural management plan must be in place and appropriate 'experiential' therapies, such as sensory modulation, must be a significant component. The Aged Care and Quality Safety Commission has good procedures about their use and the involvement of clinicians, nursing staff, carers, allied health staff, medical staff, including psychiatrists, and significant others, including carers. Using of restrictive practices should be referred to [civil and administrative tribunals] as well as a responsible authority, such as the Chief Psychiatrist or an aged care advocate.

~ carer of a person living with dementia

Dementia Australia reiterates that for the aged care system to be capable of minimising restrictive practices, mandatory workforce education in dementia is essential. The workforce must understand the impact of different types of dementia on the individual, be able to assess and respond to pain, communicate effectively, understand changed behaviour, and provide holistic support to each person based on their choices and preferences.

The person with dementia should be considered. Why are restrictions needed? Every effort must be made to keep people living with dementia calm and content. With the right training, all professional carers ought to have the skills to manage the behaviours associated with dementia without resorting to any restraints...physical or chemical.

~ carer of a person living with dementia.

Recommendation 5: Ensure that younger people have a right to access to aged care services when needed.

While Dementia Australia agrees that the support needs of younger people would ideally be met outside the aged care system, the unfortunate reality is that these supports very often do not exist. This may especially be the case for people in regional and rural areas.

The Aged Care Act needs to continue to ensure that younger people have a right to access aged care supports under S40(c) of the Act and this right needs to be embedded in rules that govern assessment and allocation of places. It must be clear that younger people cannot be refused aged care services if this is their choice, and if it best meets their needs due to disability progression or onset of disease affecting care and support needs.

There are also needs to be significant intergovernmental policy cooperation and interface development to ensure that people are not discriminated against because of age or disability when accessing supports from either the disability or aged care systems.

Thank you for considering Dementia Australia's submission on the exposure draft of the Aged Care Act.

We urge the Department of Health and Aged Care to find a means to legislate for mandatory dementia education in the aged care workforce. This is the starting point to ensure that the new aged care system upholds the rights of people living with dementia through the delivery of truly person-centred and high-quality care.