Dementia Australia Submission – Review of the Disability Discrimination Act 1992 here

October 2025

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.

Dementia in Australia

Dementia is the term used to describe the symptoms of a large group of 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. Dementia is ultimately a terminal condition. In 2025, it is estimated there are 433,300 people living with all forms of dementia in Australia. Without a significant medical breakthrough, this figure is projected to increase to an estimated 812,500 by 2054.[1] Dementia is a major public health concern and a leading cause of disease burden among Australians aged 65 and over.[2] Dementia is also the leading cause of death for all Australians according to the AIHW.[2]

Introduction

Dementia Australia welcomes the opportunity to contribute to the Review of the Disability Discrimination Act 1992 (DDA).

We strongly support the Australian Government's intention to strengthen protections for people with disability, modernise the DDA, and align it with the Convention on the Rights of Persons with Disabilities (CRPD) and findings from the Disability Royal Commission.

Many people living with dementia experience discrimination in employment, health, education, housing, and services and struggle to access supports due to cognitive and systemic barriers. The understanding of dementia as a disability is critical to ensuring that people living with dementia have full realisation of their human rights and full equality in the community.

Dementia is a cognitive disability which affects people of all ages, causing difficulties with thinking, memory and behaviour. Dementia describes a collection of symptoms caused by disorders affecting the brain. It is not one specific disease. Dementia affects people of all ages including in childhood. Around one in 2,800 babies are born with a condition that causes childhood dementia.[3]

This submission is informed by the lived experiences of participants in our Dementia Advocates Program, a national initiative where people living with dementia, carers and former carers influence policy, practice, and service design.

Updating the definition of disability

We support the consultation's aim to modernise definitions away from deficit-based language and toward social/human-rights models. The Issues Paper recognises the need to update language and simplify legal tests (comparator/burden; reasonableness/unjustifiable hardship).

People living with dementia can be excluded from disability identification due to misunderstanding of dementia as a normal part ageing rather than a progressive neurological condition that causes cognitive disability. This perpetuates stigma and limits access to adjustments, employment protections, and supports.

Community awareness of dementia as a disability is limited. The cognitive and other changes that are associated with the condition are often not recognised. People living with dementia relate the common experience of being told that they 'can't possibly have dementia' because they don't appear, speak or act in a way that corresponds with community expectations or understanding of the disabling nature of dementia.

Additionally, people with dementia can experience fluctuating and situational capacity, where cognitive abilities can vary depending on the environment, time of day, stress, fatigue, or complexity of information. This means that a person may be able to make decisions or participate fully in one context, but require support, adjustments, or different communication approaches in another. Recognising fluctuating capacity in the DDA definition is critical to ensuring that people with dementia are included in decision-making, provided reasonable adjustments, or assessed unfairly based on a single moment in time. To uphold autonomy and align with the CRPD, the Act should embed supported decision-making, so that people with cognitive disability are assisted to understand, consider and communicate their choices and make decisions based on their wills and preferences, rather than having decisions made in their best interest. A modernised definition should reflect that capacity is not static, and that people with dementia can and do continue to exercise choice, control, and autonomy when supported appropriately.

Recommendations

- Explicitly recognise cognitive, neurological and progressive conditions, including dementia as disabilities.
- Acknowledge fluctuating and situational capacity within the definition and embed supported decision-making for people whose cognitive abilities change over time.

Positive duty to eliminate discrimination.

The current system places the onus on individuals to make complaints rather than requiring duty holder to proactively prevent discrimination. This set up can be challenging for people with dementia who may have difficulty recognising discrimination, navigating legal processes, or feel uncomfortable making a complaint due to fear of retribution.

> *"People with a disability often are unable or unwilling to speak out about mistreatment in the workplace, so nobody is made aware of the issues." Person with dementia*

> *"The fear of retribution is real, so it does not encourage an elderly woman without support to lodge a complaint of discrimination." Carer of person with dementia*

Dementia Australia supports the introduction of a positive duty that requires duty holders to take reasonable and proportionate steps to proactively eliminate discrimination. However, the Issues Paper doesn't yet specify what "reasonable and proportionate" looks like for cognitive and neurodegenerative disability (e.g., wayfinding, signage, lighting, quiet spaces, simplified information, flexible processes).

Dementia Australia's research has found that people who share their diagnosis with their employers are less likely to receive the same level of support to continue to work or transition out of work as people who are diagnosed with other chronic diseases do. Additionally, people who care for or support a person living with dementia also experience discrimination, stigma and exclusion because of their association with disability and research has found that carers of people living with dementia are less likely to receive support from employers and potentially experience heightened financial and mental health impacts.[4]

A positive duty would shift responsibility to employers, service providers and public bodies to actively prevent discrimination. This includes considering and acknowledging the right to request workplace modifications, flexibility and adaptions to support people to continue to work, and sensitively and respectfully transition out of employment if necessary.

Recommendations

- Clear guidance on what "reasonable and proportionate" means for cognitive and neurodegenerative conditions (e.g. cognitive accessibility, dementia awareness training, flexible processes, supported decision-making).
- Promote education, awareness and guidance on cognitive impairment and supported decision-making.
- Strengthen compliance oversight by the Australian Human Rights Commission

"Organisations have got to learn more about dementia and understand it, and they've also got to have a commitment to ensuring that there's a safe environment for somebody to work". Person living with dementia

Employment, reasonable adjustments and "unjustifiable hardship"

Employment discrimination has been reported by dementia advocates. For people with dementia, the lack of awareness among employers that dementia qualifies as a disability may lead to loss of employment, income and identity, often shortly after diagnosis.

People with dementia have reported being denied employment, dismissed after diagnosis, or refused adjustments, flexible work or redeployment. Employers may rely on "inherent requirements" or claim "unjustifiable hardship" without meaningful consultation or proper consideration of adjustments that would enable continued employment.

People with dementia, especially those with younger onset, can face systemic barriers including forced resignation, refusal of adjustments, exclusion from education, and discriminatory assumptions about their capacity.

"I requested tasks be emailed to me as I found it easier to remember and could refer back to them. The employer would not do this for me. He claimed he was too busy, and I would have to cope." Person with dementia

"My dementia diagnosis, once identified by my employer (a government department), resulted in my employment being terminated overnight with absolutely no support offered whatsoever." Person with dementia

"These people turned around and said to me and without any communication, any conversation, any support, said you don't have a job." Person living with dementia

Employment discrimination also extends to carers of people living with dementia who report being denied employment or flexible work arrangement because of caring responsibilities, occasionally leading to termination of their employment.

"Reduced hours, less wages, lost employment." Carer

"While I was a manager, I could organise all my work meetings around my father's caring and appointments. But then when I was no longer a manager my father's commitments caused me to miss work meetings and eventually, I lost my job."

Dementia Australia supports reforms that require consultation as part of the inherent requirements and unjustifiable hardship tests. For people with dementia, meaningful consultation alongside supported decision-making is essential to ensure decisions are based on the person's abilities with adjustments in place, not assumptions about diagnosis.

Recommendations

- Clarify that reasonable adjustments include cognitive and environmental modifications, assistive technology, and flexible task design.
- Define unjustifiable hardship in line with the CRPD, ensuring employers consider the person's rights, available supports, and proportional impact.

- Strengthen employer guidance to prevent blanket exclusions or medical retirement due to dementia.
- Dementia Australia recommends that the revised DDA explicitly clarify and strengthen protections relating to discrimination by association so that carers are protected.
- Promote flexible work design, gradual transitions and mentorship roles for employees with dementia and carers.
- Encourage employer education campaigns to improve understanding of dementia as a disability under the DDA.

"Education of employers so that they would be more understanding and more likely to modify tasks to enable the person with a disability." Person living with dementia

Modernising and enforcing disability action plans

Dementia-friendly design and inclusion are critical to full participation, yet few public or private organisations incorporate dementia into their Disability Action Plans.

Recommendations

- Require Disability Action Plans to address cognitive accessibility, dementia-friendly design, and staff awareness.

Conclusion

The Disability Discrimination Act is key to promoting equality for people with disability.

Dementia Australia supports calls for the introduction of a national Human Rights Act, noting that such an Act would complement and strengthen the operation of a modernised Disability Discrimination Act. A Human Rights Act would provide a framework that embeds CRPD principles and the opportunity to bring Australia's anti-discrimination framework in line with the CRPD.

The revised Act should ensure that all people living with dementia are protected to live with dignity and fully participate in society by embedding modern definitions, proactive duties, supported decision-making, and dementia-specific recognition.

Dementia Australia has developed a guide to meaningful engagement of people living with dementia, which can be found at **Half the Story**. We recommend referring to this guide to ensure that any further consultation during the review of the Act is dementia-friendly.

1. Dementia Australia. *Facts and Figures* 2025; Available from: **https://www.dementia.org.au/about-dementia/dementia-facts-and-figures**.
2. Australian Institute of Health and Welfare, *Dementia in Australia*. 2025, Australian Government
3. Childhood Dementia Initiative. *Childhood dementia facts and statistics*. 2025; Available from: **https://www.childhooddementia.org/health-professionals/understanding-childhood-dementia**.

4. Australia, D., *Discrimination and dementia – enough is enough*. 2021.