



**Dementia
Australia®**

NSW Anti-Discrimination Act Review

Dementia Australia Submission

29 September 2023

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 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.

Dementia is one of the largest health and social challenges facing Australia and the world. In 2023, it is estimated there are more than 400,000 people living with all forms of dementia in Australia. This number will continue to grow to nearly 850,000 by 2058.¹ In 2023 it is estimated there are almost 135,000 people living with all forms of dementia in NSW. This figure is projected to increase to more than 260,000 by 2058.

Dementia is now 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

¹ AIHW (2023) *Dementia in Australia*. <https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/summary>

² AIHW (2023) *Dementia in Australia, Summary, Impact* <https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/summary>

Dementia and discrimination

Dementia Australia is grateful for the opportunity to make a submission to the NSW Law Reform Commission's review of the Anti-Discrimination Act 1977 (NSW).

People living with dementia are regularly discriminated against and denied equal enjoyment of their rights. In 2019, Dementia Australia surveyed more than 5000 Australians to better understand dementia discrimination. The findings revealed how big the issue is and the impact discrimination has on people living with dementia, their families and carers.

All statistics are based on 5,767 survey respondents.

Discrimination is real

63%

of people living dementia believe **discrimination** against people living with dementia **is common**.

I feel like no one calls me anymore

74%

of people living with dementia say people **haven't kept in touch** like they used to.

“

I'm not invited any more”

- Family, friends and carers

71%

haven't been included in family activities.

80%

haven't been invited to social functions.

86%

say **discrimination came from friends** or other social circles.

Your words affect me

73%

say people **make jokes** at the expense of their friend or relative who lives with dementia.

96%

say people act as if they **don't know what to say** to their friend or relative who lives with dementia.

“

I don't feel welcome any more”

- Person living with dementia

90% of family, friends or carers say that their friend or relative who lives with dementia has been **treated with less respect than other people**.

81% of family, friends and carers felt that people in shops, cafes and restaurants **treat people with dementia differently**.

90% of professionals, volunteers and people not impacted by dementia believe people living with dementia were likely to be **treated differently**.

65% of people living with dementia say people they know have been **avoiding or excluding them**.

In preparing this submission, we consulted with people living with dementia and carers in NSW. They told us about a wide range of experiences of discrimination, stigma, hardship and denial of rights, and the profound impact of these experiences. Direct quotes from people living with dementia and their carers are included throughout this submission.

Despite their widespread experiences of discrimination, only 50 per cent of our seventeen survey respondents were familiar with the NSW Anti-Discrimination Act, and almost 70 per cent had never made a complaint about discrimination. Fifty per cent said they did not know how to.

Discrimination affects the breadth of public and social life and impacts upon people in all communities across the state. As such, we make a range of recommendations for the review of the Act that would strengthen protection from discrimination, harassment and vilification for people living with dementia and carers in all areas of public life.

The provisions of the Act should be based on a contemporary understanding of disability and a positive obligation to prevent inequality.

Discrimination means ignoring someone as though they are invisible or being treated as someone too stupid to follow a conversation or simple requests.

~ Carer of a person living with dementia

Discrimination means when other family members and friends choose to alienate or leave out that person with dementia in social situations.

~ Carer of a person with dementia

Recommendations

Our recommendations are summarised here, with further detail in the body of the submission:

- 1) Modernise the definition of disability to reflect the social model of disability, be broadly consistent with the United Nations Convention on the Rights of People with Disability and ensure that cognitive disabilities such as dementia are included.
- 2) Modernise the Act by simplifying the structure, defining a contemporary group of attributes to be protected from discrimination, and making complaints mechanisms more accessible.
- 3) Expand the scope of the Act to protect from discrimination, vilification and harassment in all areas of public life based on all defined attributes.
- 4) Include a positive obligation and require reasonable adjustments to eliminate discrimination, vilification and harassment across all aspects of public life. Positive obligations and reasonable adjustments should:
 - a) Require employers to make reasonable adjustments to support the person to continue in their employment.
 - b) Require employers to respect and accommodate family and caring responsibilities.
 - c) Include accessibility design that is suitable for people with cognitive disabilities such as dementia.

Equal respect and rights for every human.

~ Carer of a person with dementia

We tried to fight this, but I was too tired and worn out.

~ Carer of a person with dementia

Defining disability

Recommendation 1.

Modernise the definition of disability to reflect the social model of disability, be broadly consistent with the United Nations Convention on the Rights of People with Disability and ensure that cognitive disabilities such as dementia are included.

The current definition of disability in the Act does not reflect contemporary community understandings of the social model of disability and is not consistent with the definition under the United Nations Convention on the Right of People with a Disability. It is also important to recognise cognitive disabilities such as dementia which are often invisible.

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.

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

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.

We recommend that the following definition of disability be adopted:

disability is any impairment, including a physical, mental, intellectual, cognitive, neurological, learning, communication, or sensory impairment, or a functional limitation whether permanent, temporary, or episodic in nature, whether evident or not, that, in interaction with a barrier, hinders a person’s full and equal participation in society.

We believe the inclusion of ‘whether evident or not’ is an important acknowledgement of the invisible nature of some disabilities such as dementia.

Stop making assumptions about me.

~ Person living with dementia

³ Childhood Dementia Initiative, 2023. [Childhood dementia. The Facts.](#)

Modernise, simplify and contemporise the Act

Recommendation 2.

Modernise the Act by simplifying the structure, defining a contemporary group of attributes to be protected from discrimination, and making complaints mechanisms more accessible.

A person's age, gender, illness or disability should not matter.

~ Carer of a person living with dementia

The current Act does not have a contemporary and inclusive definition of the attributes that should be protected from discrimination. The current definition applies inconsistently and to a limited group. We recommend developing a comprehensive, consistent and modern definition of the attributes which the Act applies to, to make it more inclusive of contemporary experiences, simpler to understand and easier to seek recourse under.

A fair and reasonable outcome on a more individual basis.

~ Carer of a person living with dementia

A simplified and contemporary definition will assist people living with dementia and their carers to understand their rights under the Act. This is relevant as it applies to disability discrimination, ageism and carer responsibilities, as well as other areas of discrimination which affect the lives of people living with dementia and their carers.

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

The Act should also prohibit future discrimination, either as a stated intent to discriminate or as a presumption of a person's future attributes. This is important to ensure equality for people living with progressive disabilities such as dementia.

While dementia is a terminal condition and causes a deterioration in neurological function over time, each person's experience is different. The type of dementia, age of the person and a range of other factors influence each person's individual experience of dementia over time. Discrimination based on the presumed attributes of a person in the future should be prohibited under the Act.

We also note that the structure and language of the Act could be modernised and simplified to make it easier to interpret. Similarly, complaints mechanisms need to be easy to understand and access, including for people with cognitive disabilities such as dementia. The

burden of proof should not put undue disadvantage on the complainant. The Act should mandate that support be given to people who need assistance to access justice under the Act.

We need free legal advice and guidance.

~ Carer of a person with dementia

Easy access to means of raising complaints and active support through the complaints process until it is resolved.

~ Person living with dementia

Apply to all areas of public life

Recommendation 3.

Expand the scope of the Act to protect from discrimination, vilification and harassment in all areas of public life based on all defined attributes.

People living with dementia and their carers in NSW told us that discrimination affected a wide range of areas in their lives. More than half of our survey respondents said that it affected their emotional wellbeing or mental health, and almost half said they had experienced stigma. More than a quarter said they had experienced harassment, abuse or assault.

It was reported that discrimination affected people's finances and superannuation, their access to health care and services, their physical health and their ability to make their own decisions, as well as a range of other issues.

The doctor would not address mum directly and only spoke to me.

~ Carer of a person with dementia

My husband and I were refused respite.

~ Carer of a person with dementia

It has caused and continues to exacerbate my PTSD symptoms.

~ Carer of a person with dementia

Discrimination occurs in all areas of public life, and the Act should also apply in these contexts to ensure that people living with dementia and other disabilities, older people and carers experience equality of opportunity.

Stronger protections across all parts of public life will mean that employers are required to increase their knowledge and understanding of their obligations and the human rights of their employees diagnosed with dementia. This include considering and acknowledging the right to request workplace modifications, flexibility and adaptations to support them to continue to work, and sensitively and respectfully transition out of employment as symptoms progress.

Employers of carers of people living with dementia can increase their knowledge and understanding of their obligations and respect the needs of carers to request flexible work to enable them to balance their caring and employment responsibilities.

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. It has also been 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

Further, we note that exemptions to the Act should be minimised, and religious institutions should not be exempt when delivering public services funded by government.

The charitable and non-government sector plays a significant role in the delivery of support services to people living with dementia, in disability, health and aged care contexts. Religious institutions providing these services are expected to provide services which meet national and state quality standards and are subject to government regulation.

Any agency which accepts government funding to deliver public services such as disability, health or aged care, should also be subject to anti-discrimination law to ensure that services are delivered equitably and give full realisation to the human rights of service recipients.

When my work became aware of my diagnosis, their first interaction with me was to send me a letter terminating my employment. At the time I didn't think about what are my rights under the Act.

Okay I may not be able to do what I was doing before but can I do something else? I really wasn't ready to give up what I was doing.

I had just copped a diagnosis that said you've got the features of early onset dementia. When that diagnosis was made, it was like setting fire to my brain.

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

⁴ Dementia Australia, 2021. Discrimination and Dementia – [Enough is Enough](#).

Positive obligation and reasonable adjustments

Recommendation 4.

Include a positive obligation and require reasonable adjustments to eliminate discrimination, vilification and harassment across all aspects of public life. Positive obligations and reasonable adjustments should:

- a. Require employers to make reasonable adjustments to support the person to continue in their employment.**
- b. Require employers to respect and accommodate family and caring responsibilities.**
- c. Include accessibility design that is suitable for people with cognitive disabilities such as dementia.**

The current Act does not include a positive obligation on organisations to make reasonable adjustments to elimination discrimination and promote equal opportunity and participation. Making reasonable adjustments is an effective way that organisations can address some of the structural or systemic causes of discrimination.

Including positive obligations for employers would mean that people living with dementia and their carers can more fully participate in employment and minimise some of the financial disadvantage that they experience. Financial disadvantage is commonly reported by people living with dementia and their carers because of their experiences with employment and financial institutions.

The expectation of being able to continue to live as before diagnosis, with the assistance of others. Continued and supported employment would be a good starting point.

~ Person living with dementia

This can be especially acute for people living with younger onset dementia, which is dementia diagnosed before the age of 65. People with younger onset dementia and their partners are more likely to be actively raising children or paying off a mortgage. Interruption to employment and early retirement can cause significant financial disadvantage.

Told to retire when diagnosed, age 58

~ Person living with dementia

Reasonable adjustment should include accessible design for people with cognitive and other disabilities, including dementia. There are a range of design strategies that can be implemented to improve accessibility for people living with dementia. People living with dementia can experience their surroundings as confusing, disorienting or disabling. Good

design should provide essential prompts for wayfinding, maximise accessibility and reduce risks.

Conclusion

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.

Thank you for considering our submission. We would be happy to discuss any aspect of our submission in more detail. The Dementia Australia Policy team can be contacted on