

# **Review of the South Australian Disability Inclusion Act**

Dementia Australia Submission

December 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.

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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.

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 more than 800,000 by 2058.<sup>1</sup>

In February, the Australian Institute of Health and Welfare released data showing 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<sup>2</sup>.

There are few families that are untouched by dementia.

**There are estimated to be more than 33,300 people living with all forms of dementia in South Australia and this is expected to increase to more than 55,000 by 2058.<sup>3</sup>**

Dementia does not just affect older people. There are thought to be around 2,000 people living with younger onset dementia in South Australia, which is dementia diagnosed under the age of 65. There are also children living with dementia, arising from a broad range of genetic disorders. In fact, childhood dementia is more common than well-known disorders like cystic fibrosis and causes a similar number of deaths each year as childhood cancer.<sup>4</sup>

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<sup>1</sup> AIHW (2023) [Dementia in Australia](#).

<sup>2</sup> AIHW (2023) [Dementia in Australia, Summary, Impact](#)

<sup>3</sup> Dementia Australia (2023) [Dementia in Australia 2023-2058 – Dementia Prevalence Data Estimates and Projections](#).

<sup>4</sup> Childhood Dementia Initiative (2023) [What is childhood dementia?](#)

## Dementia is a disability

Dementia Australia is grateful for the opportunity to provide feedback to the review of the South Australian Disability Inclusion Act and Plan. In this submission, we outline some of the unique inclusion challenges experienced by people living with dementia.

**Key to understanding these challenges is knowing that dementia is a cognitive disability which affects people of all ages and is not a normal part of ageing.**

Dementia describes a collection of symptoms caused by disorders affecting the brain. It is not one specific disease. Dementia is degenerative, and a terminal condition. Dementia can be understood as a cognitive disability causing difficulties with thinking, memory and behaviour. People with cognitive disability may have challenges with remembering, learning, concentrating, decision-making, attention, communication and problem-solving, among other difficulties.<sup>5</sup>

There is limited community understanding that dementia is a disability. The cognitive and other changes that are associated with the condition are often not recognised, and it is often misunderstood as a normal part of ageing.

People living with dementia relate the common experience of being told that they cannot possibly have dementia, because they don't appear, speak or act in a way that corresponds with common misconceptions of the condition.

We believe that the Disability Inclusion Act should include a definition of disability which is broadly consistent with the United Nations Convention on the Rights of People with Disability and ensures that cognitive and neurological disabilities such as dementia are recognised. For example:

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.

The inclusion of 'whether evident or not' is an important acknowledgement of the invisible nature of some disabilities such as dementia.

**Understanding dementia as a disability is critical to ensuring that South Australians living with dementia have full realisation of their rights and full inclusion across all parts of the community.**

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<sup>5</sup> [Cognitive Impairment, Identifying and managing cognitive impairment, Indefinite detention of people with cognitive and psychiatric impairment in Australia, Issues Paper: Health Care for People with Cognitive Disability, Cognitive Impairment and the NDIS.](#)

## Scope of the revised Disability Inclusion Act and Plan

Dementia Australia supports a focus on understanding the diverse experiences of South Australians with disability, including those of all ages who live with dementia

We believe the principles and approaches of the Act and Plan should apply more broadly than the disability services sector. They should apply to the broad range of contexts in South Australia that people with disability interact with, including aged care, health, community, employment, education, transport, planning and built design.

We support a state-wide Disability Inclusion Plan which coordinates government action to advance inclusion of people with disability across the state. We reiterate that people living with dementia, as with all people with disability, access services and supports from a range of government agencies, including multiple state government funded entities.

The Disability Inclusion Plan should seek to engage this broad range of entities, not only within state government, but also including Commonwealth-funded disability, aged and primary health care services, and local government.

Engaging these agencies as partners in the Disability Inclusion Plan will make a significant contribution to promoting access and inclusion in South Australia, including for people living with dementia. The Disability Inclusion Plan should outline how disability, health, primary care, aged care, community, housing, education and emergency response sectors will work together to deliver on the Objects of the Act, as well as a range of other community services and agencies.

We also recommend that all consultation on the development of the state-wide Plan, and agency-specific planning, should include engagement of people with different types of disability, including cognitive and neurological disabilities.

The new Disability Inclusion Plan developed must be transparent and accessible to people with cognitive disabilities, including dementia. This means ensuring that there are varied communication channels and formats which are accessible and appropriate to people with a range of communication needs. Accountability and complaints mechanisms should also be appropriate and accessible to people with a cognitive disability.

## Accessibility and inclusion

Around 70% of people living with dementia live in the community, rather than in residential care facilities. Many people with younger onset dementia live at home with their families. They may be parents, continue to work and to be involved in community and social activities.

Our communities need to support people with cognitive and neurological disabilities to live, participate and be included in their own communities if they choose to. We need accessible environments and communities that support meaningful connection and engagement.

**People experiencing dementia should not feel isolated at home. People living with dementia should be supported within the community.**

## Specific designs should exist within society, enabling people living with dementia, to participate in society...

### ~ Dementia advocate

People living with dementia experience a wide range of barriers and challenges to inclusion across the community. They are regularly discriminated against and denied equal enjoyment of their rights. To advance the social inclusion of people living with dementia, we need to understand their experiences of discrimination and exclusion and the profound impacts of these experiences.

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. This is outlined in the following graphic:

All statistics are based on 5,767 survey respondents.



People living with dementia regularly have experiences of:

- Stigma and discrimination, with poor community understanding of dementia and its impacts.
- Social isolation, as community members or social networks treat them differently.
- Difficulty in accessing and navigating appropriate and quality health and care supports in their communities, particularly in regional and remote areas.
- Being denied autonomy in decision-making, and choice and control over their lives.
- Discrimination in staying in employment, especially for people with younger onset dementia, with employers ending employment or not accommodating for the progression of dementia.
- Built environments, transport and other public services which are not dementia-friendly, reducing access to the community.

**When my work became aware of my diagnosis, their first interaction with me was to send me a letter terminating my employment....**

**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...**

**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

Carers for people living dementia also experience a range of challenges, particularly with navigating and accessing services, accessing respite and support, and a lack of supportive employment conditions.

## Dementia-Friendly Communities

Dementia Australia works towards to the creation of dementia-friendly communities. Dementia-friendly communities are places where people living with dementia are supported to live a high quality of life with meaning, purpose and value.

They are places where people with dementia are understood, respected and supported, and confident they can contribute to community life.

Dementia progressively impacts on people's cognition, thinking, mobility, emotional and social skills. In a dementia-friendly community people will be aware of and understand dementia, people with dementia will feel included and involved, and they will have choice and control over their day to day lives.<sup>6</sup>

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<sup>6</sup> Dementia Australia (2014) [A Guide to Becoming a Dementia-Friendly Community](#).

Dementia Australia's research has found that people living with dementia and their carers are significantly more lonely than other members of the general public. People living with dementia want our communities to be more dementia-friendly, and to them to continue to live well and to be involved in the activities they enjoyed before diagnosis.<sup>7</sup>

We need to enable innovative solutions which embed dementia-friendly design, community inclusion and access to transport and supports. Inclusion and accessible communities for people living with dementia and their carers means infrastructure and built design which facilitates community engagement, accessible transport, suitable housing, and access to community, health and wellbeing services.

People living with dementia can experience their surroundings as confusing, disorienting or disabling. There are a range of design strategies that can be implemented to improve accessibility for people living with dementia. Good design should provide essential prompts for wayfinding, maximise accessibility and reduce risks. Dementia-friendly inclusion strategies need to include the physical environment, such as signage, lighting and colours, and access to convenient transport.<sup>8</sup>

More information about dementia-friendly communities is available at <https://www.dementiafriendly.org.au>.

## Emergencies

An important aspect of emergency management is to ensure that police and other first responders are trained in dementia and supporting people with a cognitive disability. Dementia education improves the ability of first responders to ensure the safety of people living with dementia in emergency situations.

It is also important that during emergencies, service models for people living with dementia are flexible. The wellbeing and mental health of people living with dementia can be affected by social exclusion, isolation and loneliness.

Carers and family members are vital contributors to quality care for people living with dementia, as they best understand their loved one and advocate for their needs.

It is critical that families and communities can continue to engage with people living with dementia to remain socially connected during times of emergency and this should be factored into emergency planning.

## Restrictive Practices

We note that it would be beneficial to assess how restrictive practice are overseen under the Act where they relate to people with a disability accessing services outside of the National Disability Insurance Scheme. For example, people with disability who are subject to restrictive practices in the mental health, health and aged care systems.

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<sup>7</sup> Dementia Australia (2019) [Creating Dementia-Friendly Communities – Community Toolkit](#).

<sup>8</sup> Dementia Australia (2019) [Creating Dementia-Friendly Communities – Community Toolkit](#).

As previously noted, dementia is a disability which affects people of all ages. People living with dementia access services from disability, health, aged care and community sectors.

Many people living with dementia experience changed behaviours as their dementia progresses. Changed behaviour needs to be understood as a response to the person's environment and a form of communication about an unmet need. This unmet need might be physical, psychological or emotional. Interventions should target the causes of the behaviour, rather than the resultant behaviour itself.<sup>9</sup>

Despite consistent evidence of their limited efficacy and a high associated risk of adverse effects, psychotropic medications are still widely inappropriately prescribed for people living with dementia.

Dementia Australia strongly supports minimising the use of chemical restraint in people living with dementia, as well as inappropriate use of other restrictive practices. People living with dementia have the right to freedom of movement, independence and autonomy while being safe and free from harm.

With respect to the Disability Inclusion Act, it would be beneficial to outline how the role of Senior Authorising Officer and the functions of the Act will interface with other regulatory systems including the Aged Care Quality and Safety Commission.

## Recommendations

In summary, we recommend that the new Disability Inclusion Act and Strategy:

- Define disability in a way that recognises cognitive and neurological disabilities.
- Include as wide a range of agencies as possible that operate in the South Australian service environment and promotes partnerships among agencies to increase access to services and supports in local communities.
- Require public service agencies to make reasonable adjustments to support employees living with dementia to remain in employment if they choose to.
- Clarify how the Act overshadows and relates to the use of restrictive practices in settings outside of the National Disability Insurance Scheme.
- Require South Australian public service agencies delivering emergency response functions to be trained in dementia and other neurological and cognitive disabilities to provide safe responses for this cohort in emergencies.
- Explicitly address the experiences of people living with dementia of all ages and include relevant inclusion strategies, such as building dementia-friendly communities across the state.
- Engage South Australian public service agencies in initiatives to develop dementia-friendly built environments. An Appendix to this submission has been included, highlighting a range of dementia-friendly design strategies.

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<sup>9</sup> <https://www.dementia.org.au/sites/default/files/2021-10/PS-Restrictive-Practices-ver1.pdf>



- Include a focus on awareness raising, community education and reducing stigma about a range of disabilities including dementia.

## Thank you

Thank you for considering our submission to the review of the South Australian Disability Inclusion Act. We have dedicated policy, consumer engagement and community development staff in South Australia and would be happy to discuss any of these issues with you in more detail.

Dementia Australia supports a network of Dementia Advocates who are people living with dementia, carers and former carers. We would be happy to assist the Department of Human Services by providing avenues for further consultation with our Advocate network in the future.

Dementia Australia has developed a comprehensive guide to meaningful engagement with people living with dementia, families and carers in consultation, called **Half the Story**. Meaningful engagement means seeking out, affirming and ratifying the voices of people living with dementia, families and carers. It is necessary to understand the full story.

Meaningful engagement requires us to remove or reduce the barriers that prevent people from participating. It requires us to work differently. Meaningful engagement respects people's dignity and human rights, recognises their knowledge and skills, amplifies their voices, and involves people in decisions that will affect their lives.

The Dementia Australia Policy team can be contacted on [\*\*policyteam@dementia.org.au\*\*](mailto:policyteam@dementia.org.au)

# Appendix 1 – Dementia-Friendly Built Design

There are many features of built design that can make the community more dementia-friendly.<sup>10</sup> These features include:

- Affordable, accessible transport.
- Conveniently located community venues.
- Public areas and parklands being clean, well-kept, and pleasant.
- Plentiful outdoor seating which is safe and well maintained.
- Undercover areas in parklands to ensure accessibility in all weather conditions.
- Footpaths being wide, level where possible, non-slip, well maintained and free of obstructions.
- Bicycle paths being separate from footpaths and pedestrian walkways.
- Adequate number of pedestrian crossings which are functional for people with different levels and types of disability, with non-slip markings, visual and audio cues and sufficient crossing times.
- Visual landmarks in place to assist with wayfinding, such as garden beds, murals, water fountains and features.
- Adequate and evenly distributed street lighting to assist those with dementia and lower visual acuity.
- Level changes are clearly marked and well lit, with handrails and non-slip, non-glare surfaces.
- Building entrances being clearly visible and obvious.
- Buildings being well-signed outside and inside, with sufficient seating and toilets, accessible elevators, ramps, railings and stairs, and non-slip floors.
- Indoor and outdoor public toilets being well-maintained, clean, accessible and adequate in number with appropriate signage.
- Bus shelters having enclosed and adequate seating.
- Street clutter including excessive signage, music, advertisements and bollards being minimal.
- Background noise being minimal with acoustic barriers such as trees, hedges and fencing in place, and grass rather than hard surfaces.
- Signs having large graphics and symbols in clear colour contrast to the background, preferably dark lettering on a light background.
- Signs having non-glare lighting and non-reflective coverings.
- Quiet space being available for someone who might be anxious or confused.

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<sup>10</sup> Dementia Australia (2019) [Creating Dementia-Friendly Communities – Community Toolkit](#).