

Review of Australia's Disability Strategy

Dementia Australia Submission August 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.

The Dementia Australia Policy team can be contacted at policyteam@dementia.org.au.

Dementia across the lifespan

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 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 2054.¹

Dementia is major public health concern and a leading cause of disease burden among Australians aged 65 and over.² It is the second leading cause of death for Australians and the

¹ Dementia Australia (2024) [Dementia in Australia 2024-2054](#).

² Australian Institute of Health and Welfare (2024) [Dementia in Australia](#).

leading cause of death for women.³ In 2023, there were an equivalent of 15 people with dementia per 1,000 Australians.⁴

Although more common in older people, dementia is not a natural part of ageing. In 2024, it is estimated there are almost 29,000 people living with dementia who are younger than the age of 65. This is projected to increase to almost 41,000 by 2054.⁵

It is now also recognised that dementia affects children, teenagers and young people, with more than 100 rare genetic conditions causing childhood dementia. One in every 2,900 babies is born with a condition that causes childhood dementia. Sadly, half of all children with dementia die by the age of just 10 years old.⁶

Dementia and Australia's Disability Strategy

Dementia Australia appreciates the opportunity to provide feedback to the review of Australia's Disability Strategy. In this submission, we address how the Strategy can be made more effective for people living with dementia of all ages.

Key to these recommendations is understanding that dementia is a cognitive, neurodegenerative disability and is not a normal part of ageing. This is critical to ensuring that people living with dementia of all ages have full realisation of their human rights and full inclusion in the community.

Implementation of Australia's Disability Strategy could be improved by consideration of dementia and other progressive neurological conditions across all outcome areas, and the engagement of people living with dementia in governance and oversight. This would ensure that the Strategy is responsive to the needs of this overlooked cohort in disability policy settings and promote their social inclusion.

All of the outcome areas of the Strategy are relevant to people living with dementia, as are principles of non-discrimination, inclusion, respect for autonomy and independence, accessibility, equality and preservation of identity. Challenges for people living with dementia are often amplified for First Nations people, culturally and linguistically diverse people, and those living in regional or rural areas.

Employment and financial security

Community misunderstanding of dementia as a condition of older age leaves many employers unprepared to support employees who develop dementia during their working life. Lack of employer awareness of dementia as a disability is a significant challenge for people living with dementia who wish to remain employed.

The intersection of employment law and discrimination law is complex, and individuals who receive and declare a diagnosis of dementia whilst employed are likely to be an uncommon scenario for many employers who may not be aware that dementia is not just an illness but should be considered a disability. Dementia Australia has heard numerous stories where

³ Australian Institute of Health and Welfare (2024) [Dementia in Australia](#).

⁴ Australian Institute of Health and Welfare (2024) [Dementia in Australia](#).

⁵ Dementia Australia (2024) [Dementia Facts and Figures](#).

⁶ Childhood Dementia Initiative (2024) [Childhood dementia facts and statistics](#).

failure by employers to offer reasonable adjustments or redeployment could be seen as a breach of the disability discrimination act 1992. This in turn has a significant financial and psychological impact on people living with dementia who are not of retirement age, have families to support and mortgages or other housing costs.

It is important that the Strategy includes initiatives to support people living with dementia and other neurodegenerative conditions to maintain employment, including employer education, training and inclusive policies for accessing leave and flexible working arrangements.

Inclusive homes and communities

Most people with dementia live in the community, rather than in residential care facilities. They are active participants in their families and communities.

However, people living with dementia experience a wide range of barriers and challenges to inclusion across the community. We need to support people with cognitive and neurological disabilities to live, participate and be included in their own communities. This includes accessible homes, buildings and community environments that sustain autonomy, support meaningful connection and promote social engagement.

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.

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.⁷

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 can provide essential prompts for

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

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.⁸

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.⁹ The Strategy should include initiatives to build dementia-friendly communities and support people living with dementia to remain in their communities as their symptoms progress.

Safety, rights and justice

For people living with dementia, it is critical that supported decision-making approaches are embedded into health, aged care, disability and government services.

The 2008 United Nations Convention on the Rights of Persons with Disabilities represents an important recognition of the rights of people with dementia or cognitive impairment to make decisions about all aspects of their lives. With no Australian 'gold standard' for assessment of legal capacity, people living with dementia are vulnerable to unconscious bias or presumptions about competency.

It is often assumed that a diagnosis of dementia means a lack of decision-making capacity. But this is not the case. Decision-making capacity in people living with dementia can fluctuate and is situation specific. Fatigue, medication, delirium, illness or sundowning can all impact the person.

Capacity is neither a person's level of cognition, nor their physical function. A person with dementia may be unable to perform a certain task, but they can still make meaningful decisions about whether they want assistance performing that task.

While we are currently seeing a positive shift towards use of supported decision-making with people with cognitive or neurodegenerative disability, there remains significant reform effort required to advance a human rights approach to capacity and decision-making. It is relevant to embed this approach across health, aged care, disability and government services, including education and training about cognition, capacity and autonomy.

Personal and community support

An estimated 67% of people with dementia live in the community.¹⁰ This will likely increase as more Australians choose to live at home as they age.¹¹ There is an evolving community expectation that regardless of the care setting, people living with dementia should be able to receive quality care delivered by a skilled workforce which supports their wellbeing.

Younger people living with dementia are often caught between the disability and aged care services system. While the disability system is not well designed to provide support to people

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

⁹ Dementia Australia (2014) [A Guide to Becoming a Dementia-Friendly Community](#).

¹⁰ AIHW (2024) [Dementia in Australia, Prevalence of Dementia](#).

¹¹ AIHW (2024) [Dementia in Australia, Community Based Aged Care](#).

with neurodegenerative conditions, the aged care system also does not serve younger people well.

The Strategy should include initiatives to develop the capacity of the disability and aged care systems to deliver high quality, person-centred supports that are easily accessible and responsive to rapidly changing needs.

Carers also deserve support, including respite, counselling and education. Carers make an invaluable contribution to families, communities and the economy, and must be recognised as a critical component of personal and community supports for people living with dementia.

There are also important issues to consider for children with dementia. There are currently an estimated 2,300 children living with dementia across Australia. Their quality of life could be significantly improved by better understanding of childhood dementia within the disability support system, especially the nature of degenerative diseases¹².

Health and wellbeing

Early diagnosis of dementia allows people to plan ahead, access treatment, connect with psychosocial support and take part in activities designed to slow progression of symptoms. However, systemic issues remain in relation to obtaining an early and accurate diagnosis and appropriate post-diagnostic care and support. There are long wait times for referral to specialist services and unclear support pathways.

Comprehensive education of GPs and other health professionals is an ongoing imperative. Appropriately skilled GPs are critical to ensuring the health and wellbeing of people living with dementia. People living with dementia should be connected to coordinated, dementia-friendly services that meet their changing needs, including end of life care.

The Strategy should include initiatives to promote early diagnosis and improve coordination of post-diagnostic support.

Education and learning

Research from the Childhood Dementia Initiative has shown that children living with dementia are often excluded from essential services and that the education system does not cater well for their unique needs.¹³ All children with a disability have a right to education and the Strategy should include initiatives to develop better capability in the education system to support children living with dementia to access education that meets their individual needs.

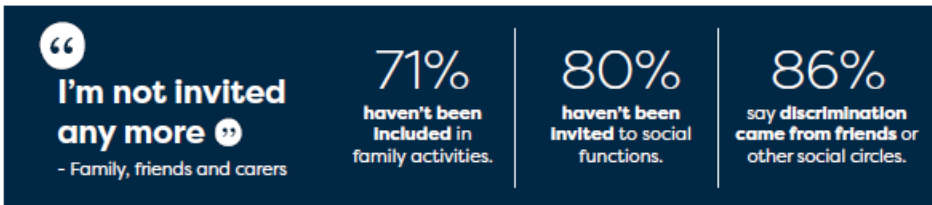
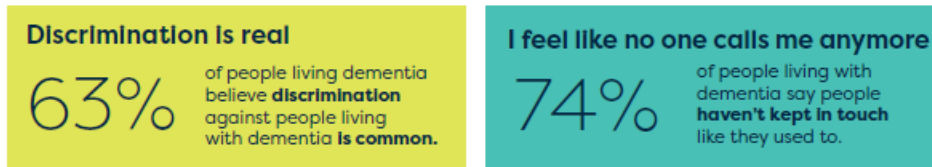
Community attitudes

Tackling stigma and discrimination is a defining objective for people living with dementia. 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.

¹² Childhood Dementia Initiative (2023) [Childhood dementia and the National Disability Insurance Scheme](#).

¹³ Childhood Dementia Initiative (2024) Childhood Dementia: Family

All statistics are based on 5,767 survey respondents.



Your words affect me



Discrimination affects the breadth of public and social life, affecting emotional wellbeing and mental health, finances, employment and access to health care. People living with dementia have told us that they have a wide range of discrimination, stigma, hardship and denial of rights, experiences of harassment, abuse or assault, and that these experiences have a profound impact on their lives. The Strategy must include initiatives to promote awareness and understanding of dementia, break down stigma and tackle discrimination.

Recommendations

- 1) Increase government accountability by extending ADS data to include visibility on the experiences of people with neurodegenerative and cognitive disabilities. Ensure that this data is monitored and the impact of strategies evaluated over the course of the Strategy.
- 2) Include people living with dementia in the governance and oversight mechanisms for the Strategy.
- 3) Within the new Inclusive Homes and Communities Targeted Action Plan, include an action for all state and territories to implement the National Construction Code Living Housing Design Standards as soon as practicable.

- 4) Within the new Safety, Rights and Justice Targeted Action Plan, include actions to expand the use of a supported decision-making model across health, disability, aged care and government service settings.
- 5) Within the new Community Attitudes Targeted Action Plan, include initiatives to address stigma and discrimination against people living with dementia and promote community understanding of the condition.
- 6) Within the priority topics under each Outcome area, adopt the following goals:
 - a. Under employment and financial security, strategies to support people with neurodegenerative conditions to maintain employment.
 - b. Under inclusive homes and communities, strategies to build dementia-friendly communities and support people living with dementia to remain in their communities as their symptoms progress.
 - c. Under safety, rights and justice, initiatives to embed supported decision-making approaches into health, disability and government services for people with cognitive disabilities.
 - d. Under personal and community support, initiatives to:
 - i. develop the capacity of the disability and aged care systems to deliver high quality, person-centred supports that are easily accessible and responsive to rapidly changing needs.
 - ii. Develop better capability in the disability system to support children living with dementia.
 - e. Under health and wellbeing, include initiatives to promote early diagnosis of dementia and improve coordination of post-diagnostic support.
 - f. Under education and learning, initiatives to develop better capability in the education system to support children living with dementia to access education that meets their individual needs.
 - g. Under community attitudes, initiatives to promote awareness and understanding of dementia, break down stigma and tackle discrimination.