



Draft ACT Disability Health Strategy 2023-2033

Dementia Australia Submission

Dementia Australia

Dementia Australia is the source of trusted information, education and services for the estimated 400,000 Australians living with dementia, and the more than 1.5 million people involved in their care. We advocate for positive change and support vital research.

We are here to support people impacted by dementia, and to enable them to live as well as possible. Founded by carers more than 40 years ago, today we are the national peak body for people living with dementia, their families and carers.

We involve people impacted by dementia and their experiences in our activities and decision-making, to make sure we are representative of the diverse range of dementia experiences. We amplify the voices of people impacted by dementia through advocating and sharing stories to help inform and inspire others.

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

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 2058.¹

In February this year, 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 women². In 2023, it is estimated there are more than 5,650 people living with all forms of dementia in the ACT. This figure is projected to increase to almost 13,000 by 2058³.

There are an estimated 400 people living with younger onset dementia in the ACT, which is dementia diagnosed before the age of 65. Without a medical breakthrough, the number of people living with younger onset dementia is expected to increase to an estimated 780 people by 2058⁴.

Dementia is a disability

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 across the lifespan including in childhood - there are approximately 2,300 Australian children living with dementia⁵.

Community awareness of dementia as a disability is limited. People living with dementia regularly experience stigma and discrimination and may be denied their human rights. The cognitive and other changes that are associated with the condition are often 'invisible' or under-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 dementia⁶.

¹ [Dementia in Australia](#)

² [Dementia in Australia, Summary, Impact](#)

³ [Dementia in Australia](#)

⁴ [Younger Onset Dementia in Australia](#)

⁵ [Childhood Dementia](#)

⁶ [Dismantling Dementia Discrimination](#)

Cognitive disability is an umbrella term that can broadly be conceptualised as difficulties with memory and thinking that arise from intellectual disability, dementia, brain injury, autism, neurological disorders, fetal alcohol spectrum disorder, learning disorders or mild cognitive impairment. People with cognitive disability may have challenges with remembering, learning, concentrating, decision-making, attention, communication and problem-solving, among other difficulties⁷.

Dementia Australia suggests that the ACT Disability Health Plan 2023-2033 make specific reference to cognitive disability and include strategies relevant to the outcomes and experiences of people with a cognitive disability in the ACT health system. We suggest that cognitive disability should be included in the priority population list and that an Action Plan for cognitive disability be developed.

Focus area 1 – health information and literacy

Better community awareness of dementia is an important health literacy strategy in the ACT and would have several important outcomes:

- Reducing the risk of dementia through promotion of brain health.
- Improving community recognition of signs and symptoms of dementia.
- Reducing stigma and building dementia-friendly communities.
- Increasing advanced care planning for people diagnosed with dementia.
- Supporting health workforce development to:
 - increase early diagnosis of dementia
 - improve capacity in communication and supported decision-making
 - connect people living with dementia and carers to appropriate services and support pathways.

Supported decision-making enables people with cognitive disabilities to make decisions about their own health and care, with appropriate assistance. It recognises the importance of making decisions with, rather than for, a person.

⁷ **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.**

The supported decision-making model recognises that for someone living with dementia, decision-making capacity can change day to day. A variety of psychological, physical and environmental factors can influence someone's capacity to engage in decision-making. Both supported and substitute decision-making can be appropriate in different contexts. More information can be found in Dementia Australia's Policy Position Paper: **Supported Decision Making**.

The health workforce needs capacity to implement appropriate decision-making models, working closely with the person living with dementia and their families and carers. It is important that health professionals can understand a person's decision-making capacity at different times, and work inclusively with the person living with dementia.

This relies on the health workforce having good knowledge of the types and presentations of dementia and well-developed skills in communicating with people with cognitive disability. It means implementing a truly person-centred approach where the individual is empowered, and their personal choices enacted.

Dementia Australia understands that in previous discussion about mental health reforms in the ACT, it was suggested that a register of enacted Enduring Powers of Attorney be created. This has not eventuated but may be a useful approach to explore further.

Lastly, we note that recent research has highlighted the importance of embedding a rights-based approach into care systems. Dementia care can involve complicated clinical and ethical issues in relation to decisions about treatment, care and quality of life. A formal, human rights approach is linked to improved access to services and the provision of good quality care for people living with dementia and their carers⁸.

⁸ Butchard, S and Kinderman, P. (2019). 'Human Rights, Dementia, and Identity', European Psychologist, 24(2), p.16

Focus area 2 – service access, design and delivery

The interface of health, disability and aged care sectors is complex. Navigating this interface can be difficult for people living with dementia. Finding information, understanding systems, and accessing services can be challenging.

Dementia Australia's services team in the ACT have found that many people living with dementia are not accessing services that are available, because there is limited awareness of what supports exist.

A crucial issue is that staffing is not in place within either the hospital system or GP practices, to link people effectively to services. There is a need for greater guidance for people living with dementia and their carers, and increased workforce capacity to make supportive referrals. Information needs to be tailored, simplified and delivered well.

We note also that universal design should include the creation of dementia-friendly environments. For further information, we recommend the following resources:

- [**How to design dementia-friendly care environments**](#)
- [**Caring for someone with dementia: changes in communication**](#)
- [**Dementia Australia Help Sheets**](#)

Focus area 3 – emergency planning, preparedness and management

An important aspect of emergency management is to ensure that police and other first responders are trained in dementia and 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.

Focus area 4 – workforce

A skilled, dementia-capable health workforce will make a tangible difference to the lives of people living with dementia in the ACT. The Dementia Australia services team in the ACT have found that limited health workforce capacity to diagnose dementia and refer for support is a major barrier.

Stigma plays a role, influencing the willingness of primary health professionals to diagnose dementia. The flow on effect is that people with dementia are not referred for appropriate support and miss out on the services they need.

This is an issue for all people with dementia but has been more acute for younger people with dementia aged under 65. The referral pathways for younger people seeking dementia assessment in the ACT are not clear, with delayed diagnosis often the result. Many GPs do not appear to be familiar with the services offered by the Memory Assessment Service or Geriatric Clinic and referrals can be limited for younger people.

Lack of access to specialist support has also meant that there are not always holistic management plans in place for people living with dementia, with clinical care relying overly on medication.

Dementia Australia understands that GPs are time-poor and have limited capacity for longer consultations. We recommend that supportive approaches be implemented in GP clinics to improve capacity for dementia care. These could include practice managers or practice nurses being educated in dementia assessment and referral pathways, to support people to connect to services and navigate aged and disability care systems.

Similarly in the hospital environment, there are difficulties in planning for discharge of people with dementia into suitable environments. People living with dementia are often discharged without the right supports in place. There are not enough staff in hospitals resourced to undertake the planning and care coordination required.

For example, services for short term bridging support between hospital and home exist but are not always being accessed. A twelve-week post-hospital support program can be accessed with referral from the hospital, but many people are not referred as there is not sufficient resourcing for care coordination.

Under pressure with tight timeframes, carers have been told to find support themselves, and may not be able to find the most appropriate services. As well as the stress this places on carers, it results in other impacts such as carers having to take time off work.

It can also mean that discharge is delayed, with people living with dementia remaining in hospital longer than is necessary.

Focus area 5 – data and research

When finalising the ACT Disability Health Plan 2023-2033, Dementia Australia recommends that a clear implementation and communication approach be articulated. Health care users will need to understand how the Plan will be used, how it will support them in their right to quality health care and what the complaints mechanisms are.

It is important to understand how the Plan will be implemented and monitored in all parts of the health sector, including in private practice and the engagement of primary health care professionals.

All communication about the Plan needs to be appropriate for people with cognitive disability. Dementia Australia has a range of resources available to assist the development of resources for people living with dementia, available at our website dementia.org.au. This includes our guide to meaningful consultation with people living with dementia, **Half the Story** and the **Dementia Language Guidelines**.

Thank you for considering our submission on the draft ACT Disability Health Plan 2023-2033. We are grateful to have the opportunity to highlight areas where the capability of the health system can be improved to deliver high quality health care to people living with dementia. We would be happy to provide any further information you may need.