



Canberra Age-Friendly City Plan 2025-35

Dementia Australia Submission

June 2024

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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.

The physical and cognitive changes associated with dementia will vary for each individual and require a responsive approach to every aspect of dementia care and support, including involvement in decision-making.

In 2024, it is estimated there are more than 421,000 people living with all forms of dementia in Australia. This figure is projected to increase to more than 812,500 by 2054.¹ In the Australian Capital Territory (ACT) it is estimated that almost 5,900 people living with all forms of dementia. This figure is projected to increase to almost 12,300 by 2054.²

More than 1.6 million people in Australia are involved in the care of someone living with dementia.³ Dementia is 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.⁴

¹ Dementia Australia (2023) Dementia Prevalence Data 2024-2054, commissioned research undertaken by the Australian Institute of Health and Welfare instead of Australian Institute of Health and Welfare (2022) Dementia in Australia, AIHW, Australian Government.

² Dementia Australia (2023) Dementia Prevalence Data 2024-2054, commissioned research undertaken by the Australian Institute of Health and Welfare instead of Australian Institute of Health and Welfare (2022) Dementia in Australia, AIHW, Australian Government.

³ Based on Dementia Australia's analysis of the following publications - Department of Health and Aged Care, 2020 Aged Care Workforce Census Report, 2020, p. 6; Australian Institute of Health and Welfare (2022) Dementia in Australia, AIHW, Australian Government.

⁴ Australian Institute of Health and Welfare (2022) Dementia in Australia, AIHW, Australian Government.

Introduction

Dementia Australia welcomes the opportunity to provide input into the Canberra Age-Friendly City Plan 2025-2035. This submission is informed by feedback from our Dementia Advocates as well as Dementia Australia staff experiences. Dementia Advocates are people living with dementia, carers and former carers who are involved across all aspects of the organisation including media opportunities, systemic advocacy, research, service development, and learning and education products.

“In the general operation of the community an awareness of the impact of dementia on the individual will be, in my view, a major asset to any community, attempting to maintain/improve quality-of-life across the aged care cohort.” Carer

Health

We acknowledge and support the ACT Government's health initiatives supporting people living with dementia, including the Re-envisioning Older Person's Mental Health and Wellbeing in the ACT Strategy 2022-2026, the ACT Health Services Plan 2022-2030, identifying a site for dementia village, and the ACT Seniors Grants Program, which collectively focus on promoting mental health, reducing hospital stays, enhancing dementia care, and supporting overall health and wellbeing through various community programs and activities.

Dementia is major public health concern and a leading cause of disease burden among Australians aged 65 and over.⁵

Dementia has broad social impacts, including being a key factor in the demand for primary health care and aged care services. People with dementia use more primary health care services than the general population, have a higher rate of hospital admissions than others with similar illnesses, and experience longer and more frequent admissions and readmissions.⁶ Additionally, Dementia Advocates in the ACT have reported long wait times to see specialists. Hospitalisation in people living with dementia is associated with high economic costs, with health care expenditure for people with moderate to severe dementia double that of people without dementia.⁷

Around half of people living in permanent residential aged care have dementia, and this is associated with need for high levels of care and higher funding levels.⁸

⁵ Australian Institute of Health and Welfare (2024) Dementia in Australia.

⁶ Livingston et.al. (2020) Dementia prevention, intervention, and care: 2020 Report of the Lancet Commission, Vol 396, Issue 10248.

⁷ Livingston et.al. (2020) Dementia prevention, intervention, and care: 2020 Report of the Lancet Commission, Vol 396, Issue 10248.

⁸ Australian Institute of Health and Welfare (2024) Dementia in Australia.

Caring for someone living with dementia also impacts on family members such as spouses or children, contributing to decreased economic participation and increasing the use of health services by carers.⁹

A 2020 Lancet Review identified twelve evidence-based modifiable risk factors for dementia. These are lower education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes, low social contact, excessive alcohol consumption, traumatic brain injury and air pollution. Together these risk factors are thought to account for around 40% of dementia cases globally.¹⁰

The impact of repeated traumatic brain injury on brain health is also increasingly under scrutiny in Australia. Increased exposure to repeated traumatic brain injury increases the risk neurodegenerative disease in later life.

Research has identified an increasingly strong causal link between repeated traumatic brain injury and chronic traumatic encephalopathy, a type of preventable dementia which progressively affects brain function. There are several different population groups at risk of chronic traumatic encephalopathy, including contact and collision sports participants, domestic and family violence survivors and military personnel. CTE is a preventable form of dementia.¹¹

The Lancet Review called for ambitious prevention activity to mitigate the risk of dementia over the life course. Both public health programs and individually tailored interventions are required. Preventive health approaches should address high-risk population groups, aiming to increase social, cognitive and physical activity and vascular health.¹²

Employment and financial security

The ACT Government has developed initiatives for employment and financial security, including supporting flexible work and employment opportunities in the ACT Public Service, strengthened age discrimination laws, enhancing the ACT Seniors Card Program, energy efficiency programs, and comprehensive cost of living support, which collectively help improve the quality of life for older Canberrans, including those living with dementia and carers.

Dementia and employment

Too often, a diagnosis of dementia brings about the end of employment. Frequently, people are instructed by their medical practitioners to retire and begin planning for end of life.

⁹ Livingston et.al. (2020) Dementia prevention, intervention, and care: 2020 Report of the Lancet Commission, Vol 396, Issue 10248.

¹⁰ Livingston et.al. (2020) Dementia prevention, intervention, and care: 2020 Report of the Lancet Commission, Vol 396, Issue 10248.

¹¹ Concussion and CTE Coalition (2024) Concussion and Chronic Traumatic Encephalopathy in Australia.

¹² Livingston et.al. (2020) Dementia prevention, intervention, and care: 2020 Report of the Lancet Commission, Vol 396, Issue 10248.

Dementia advocate and 2017 South Australian of the Year, Kate Swaffer described this as 'prescribed disengagement':

"One has to ask the question: Why is it that one day I was studying a tertiary degree, working full time, volunteering, raising a family and running a household with my husband, and the next day, told to give it all up, to give up life as I knew it, and start 'living' for the time I had left? This prescribed disengagement sets up a chain reaction of defeat and fear, which negatively impacts a person's ability to be positive, resilient and proactive. Dementia is the only disease or condition and the only terminal illness that I know of where patients are told to go home and give up their pre-diagnosis lives, rather than to 'fight for their lives'."

There are many factors that contribute to medical practitioners declaring a person with dementia unfit for work. As there is no 'gold standard' assessment for legal capacity in Australia, people living with dementia can be vulnerable to their practitioner's unconscious bias or assumptions about competency. The terminal prognosis of dementia and the limited treatments available can instil a pessimistic view of what it means to live with dementia. Well-intentioned advice to get 'their affairs in order' and prepare for the end of life disempowers people with dementia and reinforces a culture that focuses on a person's deficits rather than what they can still achieve.

"Medical advice was – literally, at the point of diagnosis – gracefully retire while you still can. Then, from my long-time GP, a few days later: unfit to work from now till the time of my death." Person with dementia

This deficit-driven attitude can then spill over into all aspects of a person with dementia's life. Unlike many other disabilities, people with dementia are rarely offered rehabilitation or recovery-based services. People with dementia report that workplaces are unable or unwilling to offer alternate duties or reasonable adjustments that would support their continued employment. When some people reveal their dementia status to their employer, their employment is rapidly terminated.

"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

"With a dementia diagnosis and the nature of the job, there was no alternative to retirement that was ever offered or considered." Person with dementia

The stigma associated with dementia leads many people with dementia who experience discrimination to avoid confrontation and withdraw from employment from that point on.

"When I informed the 'powers that be' that I might have a disability it was five months before I received a response of any kind. By which time I had formed the opinion that any chance of receiving any support to continue working was unrealistic and unlikely to happen in my lifetime. Hence, I took the opportunity to 'leave' rather than battle on." Person with dementia

“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

A ‘one size fits all’ workplace adjustment strategy is unlikely to be adequate for dementia. A bespoke response, developed in partnership with the individual living with dementia and their employer, is more likely to lead to longer workforce participation. Employers could be supported through this process with information on how to create an accessible and inclusive workplace for people living with dementia.

Some recommendations for improving work conditions from people living with dementia include:

- Focussing on abilities rather than disabilities in the workplace
- Recognising that with earlier diagnosis people can remain in employment longer
- Educating employers on dementia as a disability
- Ensuring that there is a safe environment for people with dementia to work
- Supporting people living with dementia to remain in work and promoting continued employment, with the NDIS being the primary source of this support
- Respectfully handling the termination of employees in the event they must medically retire

Work and care

The employment of carers of people with dementia is precarious, as balancing work and caring responsibilities presents considerable challenges. Carers, often family members, provide essential support for daily living activities and decision-making related to treatment and care. The economic value of informal care was estimated at \$77.9 billion in 2020, with lost earnings from reduced or relinquished employment valued at \$15.2 billion, according to a Deloitte Access Economics report.¹³ As Australia's population ages and the average retirement age increases, supporting working-age people with dementia and their carers will become a critical employment issue.

There are different demands on carers depending on their age, and the age of the person that they are caring for. Carers supporting someone with younger onset dementia (diagnosed before the age of 65) are in a different stage of life, still in the workforce with financial obligations and other active care commitments such as children or elderly parents. The care recipient may have been the primary source of income, causing financial difficulties. The experience of dementia is also likely to be different, with the person living with younger onset dementia more likely to be active and experience greater frustration with loneliness, boredom and loss of income, independence, and self-esteem. There are likely to be less respite options available to families. On the other hand, carers for older people with dementia are more likely to have their own health issues, and their loved one is more likely to be frail or have comorbid health issues.

Across the board, carers are likely to experience a financial impact from their caring role. Caring is a full-time role, and paid employment is often significantly affected to the point that

¹³ Deloitte Access Economics (2020) The value of informal care in 2020.

many carers must withdraw from paid employment entirely. Their own physical and mental health is often affected as carers strive to meet the needs of their loved one.

'Had to give up paid work completely as the caring role was 24/7.' Carer

"I had to quit my teaching job completely. I then worked in customer service, starting full-time, and gradually decreasing. Then had to resign from that to become a full-time carer." Carer

A range of measures could be implemented to support informal carers in their critical role in the care and support economy.

- There needs to be more respite available for carers and families, and this needs to be accessible and regularly available. Caring can be exhausting, and carers need time out.
- Services need to be easier to access and navigate, with significantly reduced administrative complexity. A central access point for carers would be beneficial.
- Carers need access to training or education and support groups are also helpful.
- Carers need better financial and income support.
- A system which supports carers well helps to enable people with dementia to remain living at home when they choose to.
- Carers need access to flexible working arrangements including extra leave.

The National Carers Survey indicated that the services needed most by carers for people with dementia were planned respite and emergency respite. The need for these services was higher for carers of people with dementia than for other carers. The survey also highlighted that a large proportion of carers are not asked about their needs as a carer by GPs and other health services.¹⁴

"They need money. They need skills, they need training, they need backup, they need to be able to put in place a standby team." Person living with dementia

Dementia Australia advocates for enhanced dementia education for employers. Recommendations include promoting inclusive policies for leave and flexible working arrangements to support continued workforce participation for individuals with dementia and their carers.

"Acknowledge the extensive work informal carers undertake and remunerate accordingly. It's a road to poverty for so many of us and we lose our health along the way." Carer

Housing

We acknowledge and support the ACT Government's ongoing initiatives, including implementing the ACT Housing Strategy; the Housing Options Advisory Service that aids older Canberrans with retirement planning, downsizing, and accessing supports; the

¹⁴ Carers NSW (2022): 2022 National Carer Survey. Unpublished dataset. Carers NSW: North Sydney.

Affordable Rental Scheme targeting older people on low incomes; mortgage relief and rates assistance to help eligible older people stay in their homes; dedicated public housing for Aboriginal and Torres Strait Islander people designed in collaboration with their Elected Body; and the Tenant Participation Grants (TPG) that support participation in activities for physical, social, and personal development.

“Our common goal is the person living with dementia maintains a good quality of life and confidence to maintain their independence for as long as possible. Small (and big) changes around our homes, wherever that may be will achieve this...One thing I have in the back of my mind, is that there aren’t many purpose-built disability homes built let alone those which incorporate accessible dementia principles.” – Carer

Dementia-enabling environment principles are frequently incorporated into the construction or modification of residential aged care facilities. However, as people with dementia increasingly wish to remain in their own homes and avoid transitioning to residential aged care, the availability of dementia-enabling housing stock, including social housing, within the broader community is critical. Housing that is dementia-enabling provides a safer and engaging environment for people living with dementia. It can facilitate participation in daily activities and foster independence. Dementia-enabling housing also supports carers, who can be reassured knowing their loved one is safe.

Dementia-enabling housing is especially important for people with dementia who live alone. A home environment that supports their independence, while offering safeguards against risk, is essential. Assistive technology has a considerable role to play. For example, sensor lights and automated cut-off sensors for taps, gas and ovens.

“When you make modifications, you need to think past current need and tailor it for future need. It’s not going to get any better. Dementia is a progressive disease. So, if you think you need it now, you probably need it twice as much in 12 months’ time.” – Person living with dementia

Australia’s existing housing stock is rarely dementia-enabling. Often, as dementia symptoms progress, people living with dementia, their families and carers are compelled to modify or renovate their home to ensure that it is fit for purpose. Significant changes to bathrooms and kitchens are common - additions such as grab rails, altering shower recesses, and refitting tiles and floors to create contrast between walls, benches and household items.

Financial support to make modifications and/or undertake renovations is limited. Some people with younger onset dementia have been able to access funding through the National Disability Insurance Scheme (NDIS), and there is some capacity for home modifications in aged care home care packages, however this is underutilised.¹⁵ Hence, adapting one’s own home to be dementia-enabling can be dependent on having significant income or savings to draw upon. There are further challenges for renters who rely on landlords to make or allow changes.

¹⁵ Stewart Brown (2020) Home Care Provider Survey Analysis of Data Collected, April 2020, Department of Health

A dementia-friendly or dementia enabling environment is one that: promotes independence and supports wellbeing; has familiar surroundings; allows easy access and wayfinding; supports meaningful tasks; supports participation in daily activities; and promotes safety, security and comfort.

Access and connection

We acknowledge and support the ACT Government's ongoing access and connection initiatives, including improved engagement and communication through targeted resources and feedback panels, consultation with older Canberrans on suburb design and urban renewal projects, the Age-Friendly Suburbs Program enhancing neighbourhood access with footpath and lighting improvements, promotion of Seniors Card benefits to encourage public transport use, and the piloting of dementia-friendly spaces and audits in government shopfronts and events.

For many people with dementia their physical environment can have a significant impact on their ability to continue to access everyday activities such as shopping, banking or using public transport. Refer to our [Toolkit for Councils](#) for dementia friendly design recommendations.

Around 70% of people living with dementia live in the community. Our communities need to support people with dementia to live, participate and be included in their own communities. 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.

Respect, inclusion and belonging

We acknowledge and support the ACT Government's ongoing respect, inclusion, and belonging initiatives, including promoting volunteering opportunities and age-friendly communication through the Age-Friendly City Plan, recognising the achievements of older Canberrans through various awards, funding social participation initiatives via the ACT Seniors Grant Program, delivering regular dementia training for staff at Access Canberra Service Centres, introducing a new complaints function to address abuse, neglect, or exploitation of vulnerable people, enacting legal protections against the abuse of older people, implementing the National Plan to Respond to Abuse of Older People, promoting inclusivity through the Capital of Equality Strategy, and supporting people with disabilities of all ages through the ACT Disability Strategy.

Following a diagnosis of dementia, people with dementia and their carers often experience stigma, loss of social engagement and connection. The rights and capabilities of the person with dementia can become eroded leading to experiences of discrimination in a wide range of settings from home, community and retail spaces to the health care sector. This in turn, impacts on their ability to fully contribute to the social, cultural and economic fabric of their communities.

Communities play a critical role in encouraging inclusivity, respecting the rights of people with dementia and facilitating access to the services, supports, activities and spaces that every Australian citizen is entitled to.

Dementia-friendly communities

In its broadest sense, a dementia-friendly community is a place in which a person with dementia is supported to live a high-quality life with meaning, purpose and value. Ultimately, a dementia-friendly community will be friendly for everyone.

People living with dementia have described their priority areas as:

1. Increasing community awareness and understanding about dementia
2. Improving access to social activities and opportunities for engagement including volunteering
3. Employment opportunities or support to remain employed
4. Access to appropriate health and care services to support them to continue to live at home for as long as possible
5. Access to affordable and convenient transportation options
6. Improved physical environments including appropriate signage, lighting and colours

“A continuing education program / awareness program in regards to Dementia sufferers is probably one of the most valuable tools to us.” Carer

There is no single, ideal model of a dementia-friendly community. No two suburbs or towns are alike, and each area will have strategic priorities and plans specific to their region that will shape how they respond to local needs. The sorts of initiatives that take priority will inevitably reflect:

- The needs or preferences identified by people living with dementia in a given community.
- The characteristics of the community itself (for instance, metropolitan; regional; range of cultures reflected; age demographic).
- The availability and nature of existing supports and services and the ways in which these could be improved or expanded.

It is essential that people living with dementia are included in the development of dementia-friendly initiatives. Dementia Australia has developed a comprehensive guide to meaningful engagement with people living with dementia, families and carers called [Half the Story](#). Meaningful engagement means seeking out, affirming, and ratifying the voices of people living with dementia, families, and carers to understand the full story.

We recommend that the ACT Government continue to support local dementia-friendly initiatives to enhance the respect, inclusion and belonging of people living with dementia.

Conclusion

Dementia Australia appreciates the ACT Government's commitment to creating an age-friendly city, as outlined in the Canberra Age-Friendly City Plan 2025-2035 and acknowledge the progress the ACT has made to date. By integrating dementia-friendly principles into various aspects of community life, from health services and employment opportunities to housing and public spaces, the ACT Government can support people living with dementia, their families, and carer. We welcome any further opportunities for consultation.