



National Housing and Homelessness Plan Consultation

Dementia Australia Submission

19 October 2023

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

Introduction

Dementia Australia welcomes the opportunity to provide this submission to the National Housing and Homelessness Plan consultation. This submission seeks to raise awareness of the issues related to the experiences of people living with dementia who are, or are at risk of being, homeless.

People experiencing homelessness often face higher rates of substance abuse, mental health issues, social isolation, and traumatic brain injury (TBI), which are known risk factors for dementia.¹ Given this, it is important that the National Housing and Homelessness Plan specifically addresses the needs of those with dementia and establishes clear, accessible pathways to support, ensuring that this vulnerable population receives the comprehensive care and stable housing essential for their well-being.

Considering the complex challenges faced by individuals with dementia who are experiencing or at risk of homelessness, Dementia Australia's ongoing work in capacity building, focuses on building capacity of community organisations to support people experiencing homelessness, enhancing dementia knowledge and awareness and establishing referral pathways to Dementia Australia. The goal is to strengthen referral processes and to equip Dementia Australia staff with the necessary skills and knowledge to direct those experiencing homelessness to appropriate services and supports. If successful, there are plans to extend this pilot to other states and territories. We are open to engaging in further discussions about our ongoing efforts and would be pleased to provide additional information regarding this capacity-building work to inform The Plan, should there be interest.

¹ Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., ... & Mukadam, N. (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *The Lancet*, 396(10248), 413-446.

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 2058.² 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.³

The term younger onset dementia is used to describe any form of dementia diagnosed in people under the age of 65. Although less common in younger people, dementia can be diagnosed in people in their 50s, 40s and even in their 30s. In 2023 there were an estimated 28,650 people with younger onset dementia, expected to rise to 42,400 people by 2058.⁴ People with younger onset dementia can experience significant psycho-social stressors, not only due to the nature of disease, but because of its impact on work/employment, family, friends and the prospective changes to living arrangements. As evident from the Royal Commission into Aged Care Quality and Safety and the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, age-appropriate accommodation and care for people with younger onset dementia is currently limited and access is further hindered if an individual has complex needs.

Dementia in the homeless population

There is limited data on the exact numbers of homeless people with dementia, yet evidence of poor health outcomes point to the rates of cognitive impairment being higher in this cohort than in the general population. This poses challenges for the healthcare and social services workforce to meet the demands of identifying and providing appropriate care and support for homeless people living with dementia and those who support them.

According to the 2021 Census, 122,494 people Australia-wide were categorised as being homeless (up from 116,427 persons in 2016).⁵ A survey of homelessness service providers

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

³ AIHW (2023) Dementia in Australia, Summary, Impact <https://www.aihw.gov.au/reports/dementia/dementia-inaus/contents/summary>

⁴ AIHW (2022) Dementia in Australia

⁵ ABS (2021) Estimating Homelessness: Census

undertaken for then Alzheimer’s Australia (South Australia) Service Access Liaison Officer (SALO) project in 2016 indicated that more than 60% of people connecting to these services presented with a type of cognitive impairment.⁶

Additionally, people experiencing homelessness are at especially high risk of traumatic brain injury (TBI).⁷ TBI results from an impact to the head and its severity can range along a continuum from mild (a brief change in mental status or consciousness) to severe (extended loss of consciousness, prolonged amnesia, or death). The impact can be direct, as in a forceful blow, or indirect, as in a whiplash. Increased exposure to repeated TBI increases the risk of neurodegenerative disease in later life. International research findings have established strong circumstantial evidence for a causal link between repeated TBI and the neurodegenerative condition known as Chronic Traumatic Encephalopathy (CTE).⁹ One meta-analysis of 22 studies shows an average of 53.1% of individuals experiencing homelessness had at least one TBI of any severity indicating a higher risk of CTE.¹⁰ The high incidence of TBI among those experiencing homelessness suggests that this population is at an increased risk of dementia. This necessitates targeted interventions and support systems within the National Housing and Homelessness Plan to ensure that those at risk or currently facing homelessness receive adequate healthcare, housing support, and other services.

Risk of homelessness for people living with dementia

Some people living with dementia may face a heightened risk of homelessness post-diagnosis, primarily due to employment changes and job loss affecting both themselves and their carers. Often, carers—usually spouses or children—must reduce work or study hours, leading to decreased household income and increased vulnerability, especially for renters or those in low socioeconomic brackets. This financial strain, paired with the stress of maintaining living standards, can escalate the risk of homelessness.

“If I had stable housing, the situation wouldn’t have been so severe.” – Former carer

People with dementia, their families, and carers often face limited housing options and inadequate support from landlords, forcing them into more affordable but underserved areas. This relocation, coupled with financial and housing instability, may accelerate cognitive decline.

“The stress and pressure of affording rent and having to move multiple times impacted mum’s dementia – her mental and cognitive health declined.” – Former carer

There’s an urgent need to explore affordable housing solutions that safeguard the wellbeing of those with dementia and their carers, especially from socioeconomically disadvantaged

⁶ Alzheimer’s Australia South Australia (2016). Homelessness and Dementia.

⁷ Young JT, et al. Traumatic brain injury and homelessness: from prevalence to prevention

⁸ Stubbs JL, Thornton AE, Sevick JM, Silverberg ND, Barr AM, Honer WG, Panenka WJ. (2021) Traumatic brain injury in homeless and marginally housed individuals: a systematic review and meta-analysis.

⁹ Nowinski, C. J. et al. (2022) Applying the Bradford Hill Criteria for Causation to Repetitive Head Impacts and Chronic Traumatic Encephalopathy.

¹⁰ Stubbs JL, Thornton AE, Sevick JM, Silverberg ND, Barr AM, Honer WG, Panenka WJ. (2021) Traumatic brain injury in homeless and marginally housed individuals: a systematic review and meta-analysis

backgrounds. Implementing means-tested support is crucial to prevent homelessness among these individuals, as the financial and emotional toll on carers has surged since COVID-19, evidenced by the Caring Fairly campaign's survey highlighting the significant challenges faced by numerous Australian carers. The survey, which was conducted over two weeks in April and May 2020, reveals that:

- 42% have lost some/all of their regular income since the COVID-19 outbreak.
- 40% say that they've had to work fewer hours because of the need to provide extra support to the person they care for, whereas about half that number have had to work fewer hours because their employers initiated a reduction in work hours.
- 12% reported losing their job since COVID-19¹¹

The National Housing and Homelessness plan should include a human rights-based strategy for affordable housing to prevent individuals living with dementia and their carers from becoming at increased risk of homelessness.

Dementia awareness and diagnosis among homelessness services

Early signs of dementia are often identified by family members, carers or friends, prompting initial assessments by GPs. People experiencing homelessness, however, are often socially isolated and encounter people who are unfamiliar to them, their personality or their medical history. This lack of support may mean that the subtle changes and early signs of dementia are difficult to identify.

In the case of people who are experiencing homelessness and developing symptoms of dementia, diagnosis can be further complicated, even if they access a local service regularly. There can be compounding issues of substance abuse and intoxication that may mask the symptoms of dementia. The symptoms of dementia can also be confused with the symptoms of mental illness. Many homelessness sector workers report that, although their training focuses to some degree on mental health, they lack adequate knowledge on the early signs and symptoms of dementia, making it difficult to recognise the disease or distinguish between dementia and mental health symptoms or other neurocognitive issues (such as acquired brain injuries).

Moreover, welfare service workers often report that overriding issues of preventing homelessness, dealing with domestic violence, suicidal tendencies, aggression, safety, or other areas of acute need, take precedence over referring for formal cognitive assessment services.¹² Some individuals experiencing homelessness (or health workers) have expressed concerns that a dementia diagnosis may carry further risks of marginalisation, labelling, stigma and discrimination against a person struggling with homelessness. Consequently, not all homelessness service workers feel comfortable discussing memory concerns or dementia with people.¹³

¹¹ Caring Fairly (2020) COVID-19 Carer Survey Summary of Results.

¹² National Ageing Research Institute (2015). Focus group interviews conducted at Wintringham aged care services.

¹³ National Ageing Research Institute (2015). Focus group interviews conducted at Wintringham aged care services.

Homelessness awareness among health, disability and aged care services

Consultations by then Alzheimer's Australia (South Australia) in 2016 found that there was limited knowledge and understanding of homelessness among dementia service providers, contributing to poorer service provision for people experiencing homelessness.¹⁴ Mainstream services have been described by persons experiencing homelessness to be uninviting, sterile environments that do not cater for people experiencing housing stress and rough sleeping. People who are homeless also report feeling anxiety about receiving prejudiced treatment that further precludes them from seeking and engaging with support services. Additionally, the general cognitive tests available are always unsuitable and lack sensitivity for use in the homeless population. They are not tailored to individuals with lower levels of education, or appropriate for people with cultural and linguistic diversity. The challenging circumstances faced by people experiencing homelessness need to be better understood by mainstream health services, and current service delivery models need to be changed if the care needs of the homeless population are to be appropriately met.^{15 16}

Below are considerations for inclusion in the National Plan:

- Dementia-specific education for workers engaged in supporting people experiencing homelessness receive. This is to facilitate detection, timely diagnosis and management. Education should include content on dementia signs and symptoms, communication styles, activities, changing behaviours, and referral pathways to key dementia services.
- Working collaboratively to improve awareness and understanding of homelessness across all health care, disability and aged care services, including hospitals and specialists.

Access to dementia services and supports for persons experiencing homelessness.

People living with dementia who experience homelessness may not seek care because they lack insight into their condition or because of the challenges they may face in navigating and accessing services. There is a diminished ability to self-refer and self-advocate which means that they often rely upon outreach homelessness services to fill those gaps on their behalf. Moreover, there can be excessive wait times for a homeless person to gain a diagnosis of dementia and access support services. Barriers like long waiting times, inflexible scheduling by service providers, inadequate or inappropriate services and complex admission criteria,

¹⁴ Alzheimer's Australia South Australia (2016). Homelessness and dementia.

¹⁵ Chin C, Sullivan K, Wilson S (2011). 'A "snapshot" of the health of homeless people in inner Sydney: St Vincent's Hospital'. *Australian Health Review*, 35(1): 52.

¹⁶ Weiland T (2009). Health services for the homeless: a need for flexible, person-centred and multidisciplinary services that focus on engagement.

often result in homeless people attending emergency departments when in crisis rather than proactively accessing services that support them to maintain their independence.¹⁷

Below are considerations for inclusion in the National Plan:

- Service pathways into homelessness policies, strategies and action plans, especially in relation to delivering an effective and responsive homelessness service system.
- Developing, in partnership with Dementia Australia, resources specifically aimed at assisting people living with dementia who are experiencing homelessness.

Dementia-enabling housing

“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

¹⁷ Alzheimer’s Australia South Australia (2016). Homelessness and dementia.

Disability Insurance Scheme (NDIS), and there is some capacity for home modifications in aged care home care packages, however this is underutilised.¹⁸ 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. If there was a regulation for new housing to be accessible and dementia-enabling, this would benefit many.

Including dementia-enabling principles in a minimum accessibility standard for housing would help ensure that new housing stock is designed with the needs of people living with dementia in mind. It would go some way to limiting the need for expensive and disruptive modifications, renovations or moves in future, and assist people living with dementia, their families and carers to avoid additional challenges.

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. Further information about dementia enabling environment principles is available through Dementia Training Australia at

<https://dta.com.au/resources/environmental-design-resources/>

Below are considerations for inclusion in the National Plan:

- Collaborating with housing organisations to create homes designed with dementia-enabling features.
- Encouraging and establishing dementia-friendly communities where individuals with dementia are recognised, respected, and actively included.

Conclusion

Our submission has highlighted opportunities for enhancing dementia awareness within homelessness services, while also tailoring mainstream health, disability, and ageing services to better serve those experiencing homelessness. More consistent workforce training in recognising dementia, as well as a multi-level coordinated approach which clearly outlines access pathways for homeless people of any age, will make a significant difference to those impacted by dementia. Additionally, the National Housing and Homelessness Plan must prioritise the integration of dementia-enabling housing principles in new constructions and existing housing modifications. This would ensure safe, supportive, and familiar environments that encourage independence for individuals with dementia and provide respite and assurance for their carers, thereby creating a more inclusive and sustainable housing landscape for all Australians.

Dementia Australia welcomes further opportunities to discuss any matters raised in this submission.

¹⁸ Stewart Brown (2020) Home Care Provider Survey Analysis of Data Collected, April 2020, Department of Health