



**dementia
australia™**

**The House of Representatives
Standing Committee on Social
Policy and Legal Affairs inquiry
into homelessness in Australia**

Dementia Australia

12 June 2020

About Dementia Australia

Dementia Australia (formerly known as Alzheimer's Australia) is the peak, non-profit organisation for people with dementia and their families and carers. We represent the more than 459,000 Australians living with dementia and the estimated 1.6 million Australians involved in their care.

Dementia Australia works with people of all ages impacted by dementia, all governments, and other key stakeholders to ensure that people with all forms of dementia, their families and carers are appropriately supported – at work, at home (including residential aged care) or in their local community.

Our close engagement with individuals and communities means that we can advocate for those impacted by dementia and we are also well placed to provide input on policy matters, identify service gaps and draw on our expertise to collaborate with a wide range of stakeholders, including researchers, technology experts and providers.

In addition to advocating for the needs of people of all ages living with all types of dementia, and for their families and carers, Dementia Australia provides support services, education and information aimed at addressing the gaps in mainstream services.

Dementia Australia is a member of Alzheimer's Disease International, the umbrella organisation of dementia associations around the world.

Introduction

Dementia Australia welcomes the opportunity to respond to the House of Representatives Standing Committee on Social Policy and Legal Affairs inquiry into homelessness in Australia. Our submission addresses a number of issues concerning dementia and cognitive impairment among people who experience or are at risk of experiencing homelessness, and those who care for them, to bring awareness to this especially vulnerable group and to advise on how to most effectively respond to their needs.

This submission will specifically focus on Term of Reference 6 – f and g - *“support and services for people at particular risk of homelessness, including: f. people aged 55 or older; g. people living with disability.”*

About dementia

Dementia is the term used to describe the symptoms of a large group of neurocognitive diseases which cause a progressive decline in a person’s functioning. Symptoms can include memory loss as well as 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. It is a terminal condition and there is currently no cure. It is the leading cause of death of women in Australia, the second leading cause of death in this country and is predicted to become the leading cause of death within the next five years.¹ Although more common in older people, dementia is not a natural part of ageing, and can affect people in their 50s, 40s, and even their 30s.²

It is estimated that there are more than 459,000 Australians living with dementia in 2020 and an estimated 1.6 million people involved in their care. Without a significant medical breakthrough, there will be almost 1.1 million people living with dementia by 2058.³

About homelessness

Dementia Australia recognises that homelessness encompasses various situations and can affect anyone at any point in their lives.

According to the Australian Bureau of Statistics (ABS), 2016 census, homelessness encompasses those living in:

- Severely crowded dwellings, enumerated at 51,088
- Supported accommodation for the homeless, enumerated at 21,235
- Living in boarding houses, enumerated at 17,503
- Living in improvised dwellings, tents or sleep-out, enumerated at 8,200.⁴

¹ Australian Bureau of Statistics (2018) Causes of Death, Australia, 2017 (cat. no. 3303.0).

² There are also some rare forms of childhood dementia, including Sanfilippo Syndrome, Niemann Pick Type C Disease and others.

³ Dementia Australia (2018) Dementia Prevalence Data 2018-2058, commissioned research undertaken by The National Centre for Social and Economic Modelling [NATSEM], University of Canberra.

⁴ Australian Bureau of Statistics (2016) Census of Population and Housing: Estimating homelessness. Online source.

Although, the exact numbers of people living with dementia who are homeless or at risk of homelessness are not able to be precisely determined, it is important to note that the homeless population in Australia is not a homogenous group and that there is gender, age and ethnic diversity as well as diversity in the symptoms of dementia. The ABS 2016 census recorded that those who were born overseas and arrived in Australia in the last five years accounted for as high as 15% (17,749 persons) of all persons who were homeless.⁵ Additionally, according to the Australian Housing and Urban Research Institute, Aboriginal and Torres Strait Island peoples represent 1 in 5 (22%) of homeless Australians.⁶

Prevalence of dementia in the homeless population

Despite the limited data about the exact numbers of homeless people with dementia, evidence of poor health outcomes point to the rates of cognitive impairment being higher in this group 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 persons living with dementia and those who care for them.

According to the 2016 census, 116,427 people Australia-wide were categorized as being homeless (up from 102,439 persons in 2011).⁷ Based on broader prevalence rates in the general population, it is likely that at least 10% of this population – more than 11,642 people – have some form of cognitive impairment.

These estimates are likely to be very conservative: a survey of homelessness service providers undertaken for the Alzheimer's Australia (South Australia) Service Access Liaison Officer (SALO) project in 2016⁸ indicated that more than 60% of people connecting to these services presented with a type of cognitive impairment.

This submission aims to contribute to a better understanding of the experiences and needs of people living with dementia who may be experiencing homelessness.

Health of people experiencing homelessness and risks of dementia

Compared with the general population, people experiencing homelessness tend to have poorer health outcomes, exacerbated by poor access and underutilisation of health services and poor nutrition.^{9 10} Those who are in a cycle of long-term homelessness and rough sleeping are at higher risk of developing dementia, premature ageing and typically have

www.abs.gov.au/AUSSTATS/abs@.nsf/allprimarymainfeatures/ED457E1CF56EA15ECA257A7500148DB3?opendocument

⁵ Australian Bureau of Statistics (2016) Census of Population and Housing: Estimating homelessness. Online source.

www.abs.gov.au/AUSSTATS/abs@.nsf/allprimarymainfeatures/ED457E1CF56EA15ECA257A7500148DB3?opendocument

⁶ Australian Housing and Urban Research Institute (2019) An effective homelessness services system for older Australians. Online source. www.ahuri.edu.au/data/assets/pdf_file/0022/47371/AHURI-Final-Report-322-An-effective-homelessness-services-system-for-older-Australians.pdf.

⁷ Australian Bureau of Statistics (2016) Census of Population and Housing: Estimating homelessness. Online source.

<https://www.abs.gov.au/AUSSTATS/abs@.nsf/allprimarymainfeatures/ED457E1CF56EA15ECA257A7500148DB3?opendocument>

⁸ Alzheimer's Australia South Australia (2016). *Homelessness and Dementia*.

⁹ Department of Social Services (2008). *Which way home? A new approach to homelessness*.

¹⁰ Chin C, Sullivan K, Wilson S (2011). A 'snap shot' of the health of homeless people in inner Sydney: St Vincent's Hospital. *Australian Health Review*, 35(1): 52.

other complex healthcare needs.¹¹ Among these complex health issues are poor mental health,¹² self-harm, suicide risks, and injuries associated with violence, such as head injuries. Research indicates that compared with the public, homeless people were 13 times more likely to have experienced violence.¹³

Moreover, people who experience homelessness face a range of physical long-term health problems. These include dental health, respiratory tract diseases, skin infections, diabetes, hypertension, liver disease, musculoskeletal disorders and communicable diseases such as human immunodeficiency virus (HIV). These mental and physical illnesses can contribute to increased risks of dementia.^{14 15 16}

Risk of homelessness for people living with dementia and their carers

Dementia Australia has heard from many people with a lived experience of dementia who have shared their personal stories about the increased risk of homelessness after a dementia diagnosis.

The key issues involve changes to employment and often loss of jobs for both the person with dementia and those who care for them. In many cases, it is a spouse or child who cares for the person with dementia and that requires a reduction in work or study. It can lead to them losing current work and limiting other employment opportunities. As such, household income decreases and people can be forced into vulnerable situations, particularly if they are renting or already experiencing low socioeconomic status. This coupled with stress and pressure to pay bills and maintain quality of life can have devastating consequences for people and increase their risk of homelessness.

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

“It was very hard, I had no access to supports.” – Former carer

For people living with dementia, their families and carers, there can be a lack of opportunities in the housing market and little to no support from landlords. This can mean people are forced to relocate homes into areas that are more affordable, but then lack the services and supports necessary to meet their needs. Specifically, the stress associated with financial and housing instability can 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

¹¹ Australian Institute of Health and Welfare (2015). *Australia’s health 2012*. Available from: www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=10737422169.

¹² St Vincent’s Mental Health Service and Craze Lateral Solutions (2005). *Homelessness and mental health linkages: review of national and international literature*.

¹³ The Australian Institute of Criminology (2008). *Homeless people: their risk of victimisation*.

¹⁴ Australian Institute of Health and Welfare (2015). *Australia’s health 2012*. Available from: www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=10737422169.

¹⁵ Anderson D (2008). ‘The homeless population’. In: Ivanov L, Blue C, eds. *Public health nursing: policy, politics and practice*. 1st edition, p. 574.

¹⁶ Hwang S (2001). ‘Homelessness and health’. *Canadian Medical Association Journal*; 164(2): 229- 233.

“In rental accommodation, you’re at the mercy of the landlords – your choice and power is taken away from you.” – Former carer

One of the key concerns raised by people with a lived experience of dementia is that housing is seen as a commodity, when it needs to be viewed as a basic human right.

“Basic housing is not a privilege, it’s a human right.” – Former carer

There needs to be an exploration of reasonable housing for reasonable living to ensure the safety and wellbeing of people living with dementia, their families and carers, particularly those who are already socioeconomically vulnerable. Due to the nature of dementia, maintaining regular employment can be challenging and due the responsibilities placed on family and carers to care for the person, their employment opportunities can also be compromised. There needs to be consideration of this and means testing implemented to support people living with dementia, their families and carers and ensure they do not end up being homeless because the system does not support them.

Particularly since COVID-19, we are seeing an increase in financial challenges and negative impacts to carer’s wellbeing. A survey of 471 family and friend carers conducted by the Caring Fairly campaign has revealed that, while the coronavirus and its consequences have impacted negatively on many Australians, carers of people with disability, mental illness, chronic illness and the frail aged have faced a very high level of challenges to their finances and wellbeing. The survey, which was conducted over two weeks in April and May, 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-19¹⁷

“I cannot sleep because I am concerned about money, going over and over numbers to make sure I can cover everything and hold it all together. I also feel stressed because I now have no help or support at home and feel like I am pulled in many directions.” – Carer

Recommendation 1:

The Federal government, in partnership with State and Territory governments need to consider a Human Rights based approach to affordable housing to avoid people living with dementia and their carers slipping into homelessness.

Recommendation 2:

The Federal government needs to continue to support people living with dementia and their carers with Job Seeker and Job Keeper payments.

¹⁷ Caring Fairly (2020) COVID-19 Carer Survey Summary of Results. Available from: <http://www.caringfairly.org.au/sites/default/files/2020-05/Caring%20Fairly%20COVID19%20survey%20results%20%281%29.pdf>

Dementia awareness and diagnosis among homelessness services

Early signs of dementia are often identified by family members, carers or friends, prompting assessments by primary care physicians. People experiencing homelessness, however, are often socially isolated and may only come into contact with people who may not be familiar 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 or diagnose.

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: homelessness sector workers often come across clients who have poor memories, are confused, lack the ability to self-manage their health, are unable to make decisions or exhibit disruptive or unstable behaviours. There are often 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, while 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). It is also important to note that mental health issues or acquired, non-progressive brain injuries do not preclude dementia or vice versa.

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.¹⁸ 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 struggling with these matters.

Recommendation 3

The Federal government needs to work with State and Territory governments and community organisations to ensure that all workers engaged in supporting people experiencing homelessness receive dementia-specific education. 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.

¹⁸ 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 2016¹⁹ found that there was limited knowledge and understanding of homelessness among dementia service providers, contributing to poorer service provision for people experiencing homelessness.

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 often report feeling anxiety about receiving prejudiced treatment that further precludes them from seeking and engaging with support services.

Moreover, the general cognitive tests available are 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.^{20 21}

Recommendation 4

Federal, State and Territory governments need to work collaboratively to improve awareness and understanding of homelessness across all health care, disability and aged care services, including hospitals and specialists.

Recommendation 5

Federal government (in collaboration with Dementia Australia) need to develop resources for people living with dementia experiencing homelessness in Australia.

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 reduced ability to self-refer and self-advocate which means that these vulnerable persons 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,

¹⁹ Alzheimer's Australia South Australia (2016). *Homelessness and dementia*. See also: www.dementia.org.au/files/NATIONAL/documents/homelessness-and-dementia.pdf.

²⁰ Chin C, Sullivan K, Wilson S (2011). 'A "snap shot" of the health of homeless people in inner Sydney: St Vincent's Hospital'. *Australian Health Review*, 35(1): 52.

²¹ 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.

Recommendation 6

Federal government needs to build dementia service pathways into any homelessness policies, strategies and action plans, especially in relation to delivering an effective and responsive homelessness service system.

Recommendation 7

Federal Government needs to work with State and Territory governments to adopt the Report on Government Services 2020, Homeless Services performance indicators to assess homelessness services in each state or territory with consideration of people with dementia. These include: access of special needs groups to homelessness services; unmet demand for homelessness services; addressing client needs; client satisfaction; achieving quality standards; cost per day of support; economic participation; and achievement of sustained housing.

Younger onset dementia and access to appropriate disability accommodation and services

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 2020, there were an estimated 27,800 people with younger onset dementia, expected to rise to 29,350 people by 2028 and 41,250 people by 2058.²²

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 Aged Care Quality and Safety, and the Disability Royal Commissions, age-appropriate accommodation and care for people with younger onset dementia is currently limited and access is further hindered if an individual has diverse needs, and the experience of homelessness further compounds this accessibility.

Recommendation 8

Federal Government needs to collaborate with the National Disability Insurance Agency (NDIA) when it comes to provision of appropriate living arrangement for homeless persons with younger onset dementia.

Conclusion

People living with dementia and experiencing homelessness face significant social and health challenges. Despite the higher than average risk factors for developing dementia, the

²² 3 Dementia Australia (2018). Dementia Prevalence Data 2018-2058, commissioned research undertaken by NATSEM, University of Canberra.

condition is often missed and usually poorly managed among people who are homeless or at risk of homelessness.

People living with dementia, their families and carers are also at increased risk of homelessness due to changes to employment and financial status, and this is a matter of importance for government action. This includes working collaboratively with state and territory governments and property owners to improve understanding and support for people impacted by dementia.

There are opportunities to improve the awareness of dementia in homelessness services as well as cater to the needs of people experiencing homelessness in more mainstream health, disability and ageing services. More consistent workforce training in recognising dementia, as well as a multi-level coordinated approach which clearly defines and outlines access pathways for homeless people of any age, will make a significant difference to those impacted by dementia.

There are also opportunities for developing shared knowledge, and understanding between homelessness sector workers, dementia-specific services, and the broader health, disability and aged care sectors. This collaborative approach can create a holistic approach to meeting the needs of this vulnerable group.

Dementia Australia welcomes further opportunities to discuss any key matters raised in this submission with relevant Government departments.