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australia™**

Dementia Australia's response to the Parliament of Victoria's Inquiry into Homelessness in Victoria

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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 Parliament of Victoria's inquiry into the state of homelessness in Victoria. Our submission addresses a number of issues concerning dementia and cognitive impairment among people who experience or are at risk of experiencing homelessness, to bring awareness to this especially vulnerable group and to advise on how to most effectively respond to their needs.

“The one thing that’s been constant in Australia is you can access nothing if you don’t have an address, you can’t have a bank account, you can’t get Centrelink (Social Security) you can’t even get ID, so you pray like hell you don’t get sick, as you can’t access anything without health care cards, ID or Medicare card, even if you have all that, I literally couldn’t afford to get a home in any aged care facility because I couldn’t afford the near average half a million dollars it costs to even get into one.” - Person living with dementia

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 it 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 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

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.

- Living in improvised dwellings, tents or sleep-out, enumerated at 8,200.⁴

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.

According to the 2016 census, over 24,000 Victorians and 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 Alzheimer's Australia (South Australia) Service Access Liaison Officer (SALO) project in [2016],⁸ 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

⁴ Australian Bureau of Statistics. Census of Population and Housing: Estimating homelessness, 2016. Online source. www.abs.gov.au/AUSSTATS/abs@.nsf/allprimarymainfeatures/ED457E1CF56EA15ECA257A7500148DB3?opendocument

⁵ Ibid

⁶ Australian Housing and Urban Research Institute. An effective homelessness services system for older Australians, Nov 2019. 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. Census of Population and Housing: Estimating homelessness, 2016. Online source. 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 A further study revealed that, in Melbourne, over 30% of the 4,000 people surveyed had experienced mental illness, with 15% experiencing mental health issues prior to becoming homeless.¹⁴

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.^{15 16 17}

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 rooflessness, dealing with domestic violence, suicidal tendencies, aggression, safety, or other areas of acute need, take precedence over referring for formal cognitive assessment

¹¹ Australian Institute of Health and Welfare (AIHW) (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 Johnson G, Chamberlain C (2009). *Are the homeless mentally ill?* Available from: http://apo.org.au/files/Resource/rmit_are-thehomeless-mentally-ill_2009.pdf

¹⁵ Australian Institute of Health and Welfare (AIHW) (2015). *Australia's health 2012*. Available from: www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=10737422169.

¹⁶ Anderson D (2008). 'The homeless population'. In: Ivanov L, Blue C, eds. *Public health nursing: policy, politics and practice*. 1st edition, p. 574.

¹⁷ Hwang S (2001). Homelessness and health'. *Canadian Medical Association Journal*; 164(2): 229- 233.

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 experiencing homelessness. Consequently, not all homelessness service workers feel comfortable discussing memory concerns or dementia with people experiencing such matters.

Recommendation 1

The Victorian government should ensure that all workers engaged in supporting people experiencing homelessness receive dementia-specific education to facilitate detection, timely diagnosis and management. Education should include content on dementia signs and symptoms, communication styles, activities and changing behaviours, as well as referral pathways to key dementia services.

Homelessness awareness among health, disability and aged care services

Consultations by 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 suited to 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 2

Improve awareness and understanding of homelessness across all health care, disability and aged care service, including hospitals and specialists.

Recommendation 3

Fund the development of resources for people living with dementia experiencing homelessness in Victoria.

¹⁸ National Ageing Research Institute (2015). Focus group interviews conducted at Wintringham aged care services.

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*.

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.

Feedback from focus groups carried out by the National Ageing Research Institute (NARI) in Victoria, for example, reflected the lack of awareness among homeless persons of what services such as Cognitive, Dementia and Memory Services (CDMAS) or Dementia Australia can offer. Their reduced ability to self-refer and self-advocate 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, often result in homeless people attending emergency departments when in crisis rather than proactively accessing services that support them to maintain their independence.

Recommendation 4

Build dementia service pathways into Victoria's homelessness and rough sleeping action plan, especially in Part Four of the plan – An effective and responsive homelessness service system.

Recommendation 5

Ensure that Towards Home emergency response packages for those sleeping rough across inner Melbourne incorporate the needs of people with dementia who are experiencing homelessness (e.g. by ensuring that living arrangements are dementia-friendly and considering dementia while delivering on the Homes for Victorians plan).

Recommendation 6

The Victorian Government adopts the Report on Government Services 2020, Homeless Services performance indicators to assess homelessness services in Victoria 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 2019, there were an estimated 27,250 people with younger onset dementia in Australia, of which almost 6,900 people live in Victoria. The number of people with younger onset dementia in Victoria is expected to almost double to an estimated 12,700 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 hampered if an individual has diverse needs, and the experience of homelessness further compounds this accessibility.

Recommendation 7

The Victorian government collaborates with the National Disability Insurance Scheme Agency (NDIA) when it comes to provision of appropriate living arrangement for homeless persons with younger onset dementia.

A need for specialist dementia and homelessness services

People with dementia experiencing homelessness will have better support and care outcomes, if they have access to specialist services that are well designed to support their needs. One example of this specialist service model is Wintringham Specialist Aged Care service.

The Wintringham Specialist Aged Care service provides an example of an innovative and responsive aged care service for older people who are experiencing homelessness, amongst which are people with dementia. They offer a suite of services, some of which are full care accommodation, outreach services, and independent housing for older people and support with managing their Commonwealth home care packages.

Established in 1989, Wintringham is a Victorian-based not-for-profit welfare company specialising in the housing and care of older people who are homeless or vulnerable to homelessness. It is based on principles of justice, and their approach is towards dignified and respectful support that include working with frail aged and people with dementia.

Models like the Wintringham's integrated suite of services ensures that people who are homeless are more likely to break the homelessness cycle, receive targeted services that help them build capacity to manage their health conditions (including dementia) and access a wider range of care and support.

Recommendation 8:

Ongoing government funding to support the provision of specialist aged care services for older homeless persons with dementia. The Victorian government to explore joint funding opportunities with the Australian government, of innovative pilots and projects like the Wintringham service to ensure the needs of people with dementia experiencing homelessness are addressed.

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

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

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 way to meeting the needs of this vulnerable group.

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