

# HOMELESSNESS AND DEMENTIA



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# CONTENTS

Executive Summary	2
Background and Methodology	4
Dementia in Australia	4
Methodology	5
Consultation Findings	6
Dementia awareness and knowledge among homelessness services	6
Homelessness awareness and knowledge among dementia, health and aged care services	8
Assessment and diagnosis, and lack of accurate prevalence data	9
Use of cognitive screening tests in the homeless population	10
Access to dementia pathways and services	12
Access to appropriate aged care accommodation and services	13
Vulnerability of homeless people with cognitive impairment	14
Summary of feedback from the SA Homelessness and Dementia Advisory Group	14
Literature review: Homelessness and dementia	15
Homelessness in Australia	15
Risk factors and impact of homelessness	15
The health of homeless people in Australia	16
Prevalence of cognitive impairment and dementia in the homeless population	17
Heightened risk factors for dementia in the homeless population	17
Issues in service delivery for homeless people with dementia	19
The current service response to homelessness and dementia	23
The Alzheimer’s Australia Service Access Liaison Officer (SALO) homeless projects	23
The Younger Onset Dementia Key Worker (YODKW) Program	25
Dementia Training Study Centres (DTSCs)	25
Specialist aged care services	26
Conclusion	28
References	31
Methodology	36

# EXECUTIVE SUMMARY

There are significant numbers of people in the homeless population with cognitive impairment, including dementia. Yet little is known about this population or their needs. This discussion paper aims to begin to address these knowledge gaps, and provides information which could help improve services and outcomes for people with dementia who are homeless.

The 2011 Census data indicates that there are over 105,000 homeless people in Australia; and it is likely that at least 10% of this population – more than 10,500 people – have cognitive impairment, with the percentage being much higher for older homeless people. These estimates are likely to be very conservative: a survey of homelessness service providers undertaken for this project indicated that more than 60% of people connecting to these services present with a cognitive impairment of some sort.

This discussion paper is based on the work of the Alzheimer's Australia (South Australia) Service Access Liaison Officer (SALO) project, funded by the Australian Government under the Service Development Pathways Project. It is based on extensive consultations with homelessness service providers and other informants in South Australia, and with other relevant projects across Australia; and also draws on a review of relevant literature. The findings of this project align with those of another recent project on dementia and homelessness undertaken by Alzheimer's Australia Victoria.

The literature review and consultations undertaken for this project confirm that there are significant rates of dementia in the homeless population: perhaps 10% in the overall homeless population, with much higher rates amongst older homeless people.

There is potential to develop a greater level of shared knowledge and understanding between homelessness sector workers, and workers in the dementia, health, and aged care sectors. There is also great potential value in homelessness sector workers developing an improved awareness and understanding of cognitive impairment and dementia. Similarly, it would be beneficial for workers in the dementia, health, and aged care sectors to better understand homelessness, and the complex service and care needs of homeless people with dementia. Education and training across these sectors, and improved collaboration and partnership across sectors, has the potential to improve the services offered to homeless people with dementia.

Homeless people are not routinely assessed for cognitive impairment and dementia. Cognitive impairment and dementia among homeless people often co-exist with, are compounded by, and are difficult to distinguish from, other issues such as mental health problems, traumatic brain injury, and substance abuse. Improved and consistent methods of cognitive assessment for the homeless population could help service providers to better understand the needs of homeless people with dementia, and target services better to meet those needs.

This discussion paper explores housing and care options for homeless people with dementia, who suffer from multiple layers of disadvantage, including a lack of access to aged care services due to financial barriers. There are some positive examples of successful initiatives in the delivery of appropriate housing and care services for this population, which may provide useful models for broader implementation.

One such example is Alzheimer's Australia's Younger Onset Dementia Key Worker Program. This is an important initiative in meeting the needs of people with younger onset dementia, who can "fall through the cracks" between the aged care and disability services sectors. With the implementation of this program, referrals from homelessness service providers for younger homeless people have become an important and valid option.

This project also found there is support for service providers working with homeless people to take a health promotion and risk reduction approach, focusing on addressing potentially modifiable dementia risk factors.

This discussion paper aims to contribute to a better understanding of the experiences and needs of homeless people with dementia. Alzheimer's Australia trusts that this paper will make a useful contribution to the level of knowledge and discussion of these issues, and will assist policy makers and service providers in the delivery of programs and services aimed at meeting this needs of homeless people with dementia.

# BACKGROUND AND METHODOLOGY

## Dementia in Australia

Dementia is a complex chronic condition caused by one or more of a large number of illnesses affecting the brain. It is a terminal and devastating condition that robs people of their abilities and memories (Mitchell et al, 2009). It is cloaked in stigma and misunderstanding (George, 2010), isolates people with dementia and their carers from social networks (Blay and Peluso, 2010), and carries significant social and economic consequences (AIHW, 2012).

The care and support of people with dementia is one of the largest healthcare challenges facing Australia. It is estimated that there are now more than 350,000 Australians living with dementia and over a million people involved in their care; and that by 2050 there will be nearly 900,000 people with dementia (AIHW, 2012).

Dementia has an enormous impact on the health and aged care system, with the cost of dementia to these sectors calculated to be at least \$4.9 billion per annum (AIHW, 2012). Dementia also has a profound social impact. People with dementia experience stigma and social isolation (Alzheimer's Australia, 2014), and family carers often find it difficult to balance work, life and caring responsibilities (Brooks et al, 2015). Dementia has a major impact upon the quality of life and health of the person living with dementia and their family and carers (AIHW, 2012).

Dementia results in a progressive decline in brain function and impacts a range of domains including memory, language, judgement, comprehension, thinking and learning (WHO, 2006). The progression of dementia differs from person to person and will depend on a number of factors including physical health, health behaviours, the type of dementia diagnosed, and the social supports available to the

person with dementia (AIHW, 2012; Lipton and Marshall, 2013). The cognitive decline associated with dementia inevitably impacts upon the person's capacity to carry out activities associated with self-care, often resulting in the person requiring full-time care (AIHW, 2012; ADI, 2009).

While the risk of dementia increases with age, there are 25,100 Australians with dementia who are under the age of 65. This number is expected to increase to 36,800 by 2050 (AIHW, 2012). There are many causes of younger onset dementia, with the most common being Alzheimer's disease, stroke, and frontotemporal dementia. Due to their younger age, many people with younger onset dementia "fall between the cracks" of the aged care system and the disability system. This group appears to be highly represented amongst the homeless population.

Overall, there are significant numbers of people with cognitive impairment and dementia in the homeless population, yet little is known about this population or their needs. This discussion paper aims to begin to address this knowledge gap, and provide information that could be helpful in shaping future programs to meet the needs of homeless people with dementia.

## Methodology

This report has been developed as an outcome of a Homelessness and Dementia project undertaken through the Alzheimer's Australia (South Australia) Service Delivery Pathways Project (SDPP). Key information sources include:

- A survey of South Australian front-line homelessness services, connecting with 54 contacts across multiple agencies and organisations in South Australia.
- Input from a Homelessness and Dementia Advisory Group (HDAG) comprising participants willing to assist the project further.
- Consultations with a range of government and non-government advisory and advocacy bodies such as Housing SA, Shelter SA, Health Consumers Alliance SA, Central Adelaide and Hills Medicare Local and the Assistance with Care and Housing for the Aged (ACHA).
- Input elicited from a working partnership with Hutt Street Centre, a front-line homelessness service in eastern Adelaide.
- Consultations with Alzheimer's Australia's SDPP projects and similar work undertaken by Alzheimer's Australia across states and territories; as well as with representatives of Alzheimer's Australia's Younger Onset Dementia Key Worker Program.
- A brief review of relevant literature, as well as information drawn from a more comprehensive literature review undertaken in 2015 for the Victoria/Tasmania Dementia Training Study Centre (Chenco, 2015).

Further information regarding the methodology is contained in the Appendix to this report.

The body of this report outlines key issues and themes emerging from the consultations and literature review, and summarises the current service response to homelessness and dementia in Australia. Extensive verbatim quotes from the consultation process are provided, to illustrate the key issues.

# CONSULTATION FINDINGS

As noted above, consultations for this project were undertaken with homelessness service providers in South Australia, including through the SA Homelessness and Dementia Advisory Group; government and non-government bodies in South Australia; and Alzheimer's Australia SDPP projects and other relevant projects across Australia. Key issues emerging from the consultations are outlined below.

## **Dementia awareness and knowledge among homelessness services**

The consultations held in SA as well as experience from the implementation of the SDPP Projects indicates that across states, homelessness sector workers generally had some knowledge of dementia, but the depth and scope of understanding was very varied. Few sector workers were aware of the prevalence of dementia across the Australian population, of the many types of dementia, and that dementia presents in many ways that do not necessarily include immediate short-term memory loss. Alzheimer's disease was by far the most well-known of the dementias. Not all agency workers had made the connection between an ageing homeless community and increased risk for dementia.

Consultations indicated that there generally appeared to be good knowledge of alcohol-related brain injury amongst homelessness sector workers, but they still had questions around alcohol-related dementia and other dementias affecting executive functioning. Some homelessness workers felt unable to distinguish potential signs of dementia from co-existing mental health presentations. While acknowledging that the homeless population is an ageing community, where homelessness workers suspected dementia, it was largely considered to be a result of traumatic or alcohol related brain injury, rather than due to other known causes and types of dementia. Homelessness sector workers felt that there were gaps in their dementia knowledge and they would be assisted by receiving further information.

Sector workers were particularly keen to know at what point a brain injury due to alcohol becomes a dementia. Some homelessness sector workers noted that many clients have poor memories, are often confused, lack an ability to self-manage, are unable to make decisions, and have behaviours which fall outside accepted social boundaries. However, they did not necessarily consider them to potentially have dementia, and as such many clients have never been formally cognitively assessed.

In addition, the role focus of homelessness sector workers may lie elsewhere, for example many work in areas such as youth homelessness, family support, or domestic violence, so have limited direct experience with dementia.

Consultations confirmed that many homelessness sector workers recognise that further dementia education would be beneficial. Homelessness sector workers felt they specifically lacked understanding around dementia associated behaviours; and reported a need to gain knowledge on types of dementia, signs and symptoms, dementia services, communication, activities, and changed behaviours.

Greater dementia awareness across homelessness services was identified in all Alzheimer's Australia SDPP homelessness projects as key to improving access to dementia services. Strategies identified to increased dementia awareness across homelessness services included access to updated information, courses and training; engagement with the homelessness networks through community organisations and local municipalities; online learning; and online surveys. With regard to education and

**Box 1: Knowledge gaps - Comments made by homelessness sector workers to SA Homelessness and Dementia Advisory Group**

*"Are there more types of dementia than Alzheimer's?"*

*"I have heard of HIV dementia, which is interesting as HIV rates are increasing across Australia and is seen in homelessness, and I think other conditions would also contribute."*

*"We go a lot on our gut feeling but it would be good to have better skills to make a judgement on what we see."*

*"I don't always know whether someone has a cognitive impairment that is suggestive of a dementia or if it is a brain injury or mental health condition."*

*"I did have a client that was placed in a residential nursing home because of dementia."*

*"We are seeing many older people who are homeless so I think we really need to think about how we look at their cognition and be able to recognise when they need to be referred on."*

*"It would be great to partner with Alzheimer's Australia. We could run a monthly memory health clinic here so more people can understand dementia and to think about happens to their brain".*

*"We don't know enough about the different types of dementia to second guess if a person should be assessed or not unless it is an obvious Alzheimer's."*

*"Some training would be good. And tips regarding terminology may help us."*

*"I have never thought that Alzheimer's Australia would be able assist our client group."*

*"I suspect that there would be many who should have a dementia diagnosis but who don't, and probably never will."*

*"I would estimate that more than half of our clients present with some of the signs that need to be assessed for dementia."*

*"So many of our clients have a cognitive impairment. Very few would have a specific diagnosis."*

*"We see lots of clients who have what we think is alcohol dementia but they don't have a formal diagnosis and they can be quite young."*

*"We don't have too many very old people in our service so don't see much Alzheimer's but we do see many people with memory loss and other cognitive issues."*

*"We do have an area on our assessment form that allows for comment on cognition, this should give us an idea of how many of our clients have a cognitive problem."*

*"The problem is that we see quite a lot of clients who present poorly in their cognition but who will not see a doctor about it. This is why they do not get a diagnosis until they are hospitalised or have some other significant event happen."*

*"We have access to medical professionals who can help towards assessment but I don't think the numbers of homeless people who have cognitive impairment or dementia are correlated across the state."*

training, it was recognised that for sector relevance, dementia in the context of homelessness may require a different education and training approach and content, as compared with dementia seen in the general population.

The consultations indicated that knowledge sharing between homelessness and dementia services would help bridge some gaps in shaping services for homeless people with cognitive impairment.

Each of the Alzheimer's Australia SDPP homelessness projects has found enthusiasm among homelessness services and day centres who wish to embrace greater knowledge and awareness of dementia, to better understand the cognitive issues and dementia risk factors that impact their clients, based on a desire to provide them with the best possible support and service options.

### **Homelessness awareness and knowledge among dementia, health and aged care services**

Consultation with dementia services indicated a limited understanding around the definition of homelessness. This contributes to poor understanding of the prevalence of dementia in homelessness and of the importance of shaping services to meet the needs of homeless people living with dementia. All Alzheimer's Australia SDPP projects recognised dementia service delivery for homeless people as a challenge, due to the multiple barriers, pre-judgments and assumptions related to homelessness, and the person's capacity to link to, and engage with, support services.

It is apparent that there is scope to improve understanding of homelessness challenges across all dementia and health care service delivery settings, including hospitals, specialists, and memory clinics. The ongoing development of the Dementia Training Programs provide an opportunity to address these gaps.

## Assessment and diagnosis, and issues relating to prevalence data

South Australian homelessness service providers have commented that they believe more than 60% of people connecting to their services present with a cognitive impairment of some sort. This suggests that there may be significant numbers of homeless people who require cognitive evaluation, many of whom may have undiagnosed cognitive impairment including dementia. By better understanding the prevalence of dementia in homelessness, the important first steps in meeting the needs of homeless people with dementia may be taken.

Whilst communication with homelessness agency workers confirms that a high number of clients present with apparent cognitive impairment, few individuals were known to have been formally assessed for dementia, though several agencies reported that they would refer clients to mental health services if dementia was suspected.

Working with medical and other services to assess for cognitive impairment may not be of immediate priority for homelessness sector case workers who need to focus on issues seen as having greater urgency. Some agency workers reported that overriding issues included preventing rooflessness, dealing with domestic violence, suicidal tendencies, aggression, safety, or other areas of acute need, all of which were prioritised ahead of cognition. An Alzheimer's Australia Victoria project also identified co-morbidities and malnutrition as further compounding the complexities of assessment. All of these factors may account for a lack of cognitive acknowledgement during client assessment. Indeed, some case workers suggested that they continually and cyclically work across crisis management. Other case workers thought that memory loss and confusion was a general feature of ageing, or that they regarded this as a benign norm seen in homelessness. Most saw their time, energy and funding exhausted towards more immediate issues.

Informants in the consultations expressed a need for greater service recognition of the poor or non-existent informal supports that a homeless person typically has. This means that subtle changes in cognition associated with the onset of dementia may not be noticed or acted upon in a timely manner. Homelessness service providers are sometimes the only people who may observe cognitive changes over time. However, due to the general lack of dementia awareness and knowledge amongst homelessness sector workers, it is quite possible that initial changes in a person's cognition may be missed or misunderstood.

Additionally, cognitive concerns can be overshadowed by mental health issues or other illness, hidden by those in unhealthy relationships, or not identified in those reluctant to engage with case workers.

Some homelessness sector workers also expressed concern that assessment and diagnosis could increase stigma and marginalisation. Whilst Alzheimer's Australia and other dementia services have gone a long way in de-stigmatising dementia in the community, this effort has largely bypassed homeless people. Some homelessness sector workers suggested that by cognitively screening a homeless person, the findings may cause further marginalisation and labelling, or increase a sense of hopelessness. Consequently, not all agency workers felt comfortable discussing memory concerns or dementia with their clients.

Consultations helped identify the challenges to assessment and diagnosis from a homeless person's perspective. It was thought that homeless people may experience denial, suspicion, fear and increased anxiety if requested to visit a consultant or memory clinic. Without the usual family supports afforded to most people, or community assistance in place, physical attendance at consultations also presents great challenges in the homeless population.

Challenges may include basic transport needs,

difficulties in self-advocating, in managing ongoing appointments, medical directives, investigatory testing or pharmaceutical instruction. Indeed, the nature of dementia itself compromises a person's ability to manage these things, even without the additional challenges of homelessness.

The availability of specialist referral services was also identified as an issue. Whilst many South Australian agency workers relied upon mental health or direct GP pathways to manage their cognitive referrals, this did vary from state to state. Alternative referral options such as the MICAH Projects health services in homelessness in Queensland and the Cognitive, Dementia and Memory Service (CDAMS) in Victoria widened choice for case workers. CDAMS provides a diagnostic service and operates across various Victorian metropolitan and country areas. It is a model of service identified as an access point for homelessness services seeking cognition assessments for clients; however, waiting times for CDAMS can be considerable.

### Use of cognitive screening tests in the homeless population

Cognitive tests are used to measure and evaluate cognitive, or 'thinking', functions such as memory, concentration, visual-spatial awareness, problem solving, counting and language skills. Cognitive tests are vital in the diagnosis of dementia and are often used to differentiate between types of dementia. They can also be used to assess mood and may help diagnose depression, which can cause symptoms similar to those of dementia.

There are several cognitive tests available such as the Mini-Mental State Examination (MMSE) which is commonly used. Consultations indicated concern that these general cognitive tests lack sensitivity for use in homelessness. This was a consistent comment made by homelessness case workers who pointed to the inappropriateness or

non-relevance of the questions within the MMSE test. Many case workers raised concerns for clients who were under the influence of alcohol or other drugs and who had repeatedly been turned down for a cognitive assessment because of this. Other concerns included that most cognitive tools were not appropriate for non-Alzheimer type dementias such as alcohol dementia, or deficits arising from traumatic brain injury.

To better understand the role of cognitive screening tools in homelessness, information was sought from GPs, nurses and occupational therapists working in the sector. Most GPs used the MMSE or the General Practitioner Assessment of Cognition (GPCOG) to assess cognition, but concerns were expressed regarding their suitability in homelessness.

Occupational therapists mainly referred to the Montreal Cognitive Assessment (MOCA). Through their role, occupational therapists appeared to place greater value in witnessing a person's functional capacity within their own environment, which sometimes prompted the use of MOCA. However, it was also identified that this screening tool equally relied upon a person's educational ability, albeit less so than the MMSE, and that it lacked cultural diversity required for comprehensive useability in homelessness.

The consultations identified the importance of having an appropriate cognitive screening tool for people who are homeless. This was regarded as an important step towards obtaining a diagnosis. There was strong support for a screening tool which addresses the low levels of educational attainment and high cultural diversity seen in homelessness. Similarly, workers felt that there needs to be a way to assess cognition in people who were unlikely to cease regular and consistent alcohol consumption or other drug use.

There are cognitive screening tools which may have appropriate use within homelessness. The Rowland Universal Dementia Assessment Screening tool



**Box 2: Cognitive assessment - Comments made by homelessness sector workers to SA Homelessness and Dementia Advisory Group**

*"I took a client to see a memory specialist once who asked him questions that he was never going to be able to answer, such as what month is it? Who is the Prime Minister? The appointment went downhill after that and the client refused to go back again."*

*"We would refer to mental health if we thought someone had dementia, especially to the older people's mental health services, but lots of our clients are under 65 years of age too and then we have a problem."*

*"Clients are refused cognitive assessments because they are not sober."*

*"Until we have an outreach access, able to undertake assessments first thing in the morning before people turn to alcohol or other drugs, then we will always face the same dialogue from health professionals, come back when the client is able to soberly comply."*

*"In my role as the Occupational Therapist I do use a cognitive assessment with my clients. It's important; and this may be the best way of assessing any progression."*

*"We would take someone to a GP who works in homelessness services but I'm not sure how they would monitor memory loss unless the client was compliant in attending ongoing appointments there."*

*"If a client has a crisis or is admitted to a hospital that is where they most likely would be assessed for dementia and this can affect their discharge destination."*

*"Our clients wouldn't go to a memory clinic. We are lucky if they see a GP for their diabetes or other urgent condition."*

*"For clients who live in our accommodation we have a visiting doctor who gets to know them well. This would be our point of referral if we have any concerns."*

*"I have had clients turned down from a cognitive assessment because they are constantly intoxicated. But this is their baseline."*

*"Can we get GPs and consultants to better understand the difficulties that homeless people have and why there are additional problems obtaining a cognitive assessment?"*

*"We need outreach cognitive screening from homelessness day centres."*

(RUDAS) was developed to overcome limitations seen across other screening tools in the areas of education, language and cultural background, and this tool along with the Kimberley Indigenous Cognitive assessment (KICA) for Indigenous Australians, have been under discussion in South Australia as potentially useful cognitive assessment tools for the homeless population.

### Access to dementia pathways and services

Consultations indicated a strong acknowledgment, across multiple homelessness agencies that potentially large numbers of clients present with a cognitive impairment. Equally acknowledged are the significant challenges experienced when trying to support homeless persons towards mainstream dementia pathways. Without a simple, meaningful way to screen a person's cognition at the point of assessment, homeless people who may have dementia can fall through gaps in dementia services.

There are a variety of reasons why people experiencing homelessness fail to access dementia assessment pathways. Poor health literacy and an inability to self-refer and self-advocate means that people often rely upon homelessness services to fill those gaps on their behalf. As noted above, many homelessness sector workers have indicated that they lack adequate knowledge of signs and symptoms of dementia making it difficult to recognise the disease. Workers also experienced difficulties in distinguishing cognitive impairments from either mental health issues or from acquired, non-progressive brain injuries. Also, having mental health issues or acquired, non-progressive brain injuries does not preclude dementia or vice versa. As a result, many sector workers refer cognitive concerns to mental health services.

The consultation process identified homelessness agency frustration in trying to support a person towards accessing a cognitive pathway. For example, many homeless people do not have a regular GP, or may be reluctant to see any GP, so fail to be referred on. In addition, some health professionals may fail to understand, appreciate and consider the complex needs of the homeless person. Equally, conversations with homelessness sector GPs identified that it can be challenging to follow up a homeless person with cognitive impairment, due to appointment and medication noncompliance issues. It was commented that dementia service providers were somewhat inflexible and unable to accommodate the challenges of homelessness; for example, access to some Alzheimer's Australia services and supports may depend on a formal diagnosis, which very few homeless people have.

Homelessness agencies felt that there was a need for improved understanding amongst dementia service providers and health service providers of homelessness challenges. This indicates that in the same way that there could be benefit from homelessness sector workers receiving education and training on cognitive impairment and dementia, so too there could be benefit from dementia and health service providers receiving education and training on homelessness.

Consultations suggested that the response to the needs of homeless people with dementia would be greatly assisted by meeting agency requests for outreach screening tools, and by making referral systems more simple and ensuring appropriateness within the context of homelessness. This would include priority responses from a referred dementia service, to address the challenges of transiency, precariousness and immediate lack of family support and advocacy.

## Access to appropriate aged care accommodation and services

Dementia is a progressive illness and homeless people living with dementia will require aged care services over time. While there is no intention that being homeless should preclude a person from accessing residential aged care, this can be the ultimate effect of eligibility restrictions. On the other hand, housing and accommodation services for homeless people are often delivered by non-government organisation such as Anglicare, Common Ground, Unity Housing and others. Eligibility criteria vary between organisations, with some having rigid eligibility requirements which can exclude people who present with highly complex cognitive issues and who have changed behaviours. Wintringham Aged Care in Victoria argue that “our clients are ‘aged and homeless’ rather than ‘homeless and aged’ and therefore should be part of mainstream aged care funding programs”. This definition is important when accessing service options through aged care or homelessness funding streams.

Consultations through this project indicated that some agency workers felt it imperative to accommodate a client, usually in hostels or boarding houses, irrespective of any cognitive need. However, it was acknowledged that for clients who required intense support around cognition and behaviours, their needs soon exceeded the scope of the facility, which could then no longer accommodate them. This can place cognitively impaired homeless people at risk of multiple, failed, short-term accommodation arrangements.

The consultations also revealed that there are limited aged care accommodation options for people living homeless who have challenging behaviours due to cognitive impairment or dementia. Furthermore, tensions exist between aged care services and disability services when supporting younger homeless people who have intense and complex cognitive needs. People aged under

### Box 3: Challenges - Comments made by homelessness sector workers to SA Homelessness and Dementia Advisory Group

*“Our clients are the biggest challenge for other services to manage.”*

*“There is always talk about a person’s cognitive baseline’, but I think it must be recognised that for some individuals, their baseline cognition is, for them, permanently under the influence of alcohol and they shouldn’t be discounted because of it.”*

*“What would be the benefit of someone having a diagnosis? Isn’t it just another label?”*

*“There is so much inflexibility in the system, and in who can get what”*

*“Waiting times to see specialists are problematic for some of our clients. We don’t know where they will be in 3 months’ time.”*

*“It’s very hard when service providers don’t understand the person’s background and the story behind them and why they are homeless and why they can’t access supports like other people can”*

*“It’s hard for someone to have to rely on services, and then those services may be not offering the best solutions”*

*“Our clients often forget to turn up for appointments”*

*“If you can only get a service by having a diagnosis of dementia then many deserving homeless people in need will miss out.”*

*“Access to health services, such as clinics, should be equitable – but in reality, they are not.”*

65 with Younger Onset Dementia are unable to access aged care services, and have even more limited options in terms of receiving an appropriate service. A particular case identified was of a person with Korsakoff's Syndrome, under 65 years, who consistently fell between the gaps of aged care and disability services, each reluctant to allow access until the other service had exhausted their resources.

### **Vulnerability of homeless people with cognitive impairment**

Consultations identified that additional challenges arise for people with cognitive impairment who are living in close proximity to others, for example in lower cost shared living environments, state housing unit complexes and supported accommodation facilities. People can be placed into crowded living circumstances and environments with others with whom they have little commonality of culture, interests, values or beliefs. The behaviours and habits of having people who are strangers, living in shared spaces, may place a cognitively vulnerable person at risk of abuse or resentment.

It was commented that the greatest challenge lies with the most vulnerable of homeless people, for example Aboriginal clients and those with disabilities or who have other significant needs such as mental illness. Migrant and refugee clients, especially those exposed to prior traumatic experiences would also be included in this group.

### **Summary of feedback from the SA Homelessness and Dementia Advisory Group**

Key feedback from the SA Homelessness and Dementia Advisory Group included:

- There are service gaps for assessment, referral, and associated support management for clients where a dementia is suspected.
- There can be difficulty in separating behaviours associated with mental health illness or acquired brain injuries from those associated with a dementia. This is particularly hard for outreach workers, and can cause confusion with regard to forward referrals.
- Homeless people are highly unlikely to attend ongoing cognitive appointments with formal memory clinics sited in hospitals or specialist clinics without considerable assistance.
- A health promotion and risk reduction approach focusing on potentially modifiable dementia risk factors in homelessness, and fostering a greater understanding of brain health, would be beneficial.
- There would be value in dementia services better understanding the difficulties and complexities associated with homelessness. This could help to improve dementia assessment and diagnosis rates in the homeless population.
- There would be value in improved dementia services and pathways for homeless people who are in their 30s, 40s and 50s.
- Training within the homelessness sector relevant to dementia in homelessness settings would be beneficial.

# LITERATURE REVIEW: HOMELESSNESS AND DEMENTIA

## Homelessness in Australia

The number of homeless people in Australia is increasing. In 2011, the Australian Bureau of Statistics (ABS) estimated that 105,237 people were homeless, an increase of over 15,000 people since 2006. This is the most recent estimate based on Census data. Nearly three quarters of the increase in homelessness estimates between 2006 and 2011 was accounted for by people born overseas (ABS, 2012a).

According to the ABS, a person is considered homeless if they do not have suitable accommodation alternatives and their current living arrangement is:

- In a dwelling that is inadequate, or
- Has no tenure or a short tenure that is non extendable, or
- Does not allow them to have control of, and access to space for social relations.

This includes people who are residing in impoverished dwellings or tents, those who sleep out, those living in supported accommodation for the homeless, people staying temporarily in other households, in boarding houses or other temporary lodgings, or in severely overcrowded dwellings. These figures do not include the nearly 75,000 people who were living in some form of marginal housing and who may have been at increased risk of homelessness (ABS, 2012b).

Aboriginal and Torres Strait Islander peoples accounted for 25% (26,744) of all persons defined as homeless in 2011, well above their representation in the overall population. These numbers may in fact underestimate the actual number of Aboriginal and Torres Strait Islander peoples who were homeless, due to under counting of Aboriginal and Torres Strait Islander peoples in the 2011 Census. Those residing in severely overcrowded dwellings accounted for 75% of the Aboriginal and Torres Strait Islander homeless population, while 12% were residing in supported accommodation and 6% were living in improvised housing, tents or sleeping out (ABS, 2012a).

ABS figures indicate that 14,851 people aged 55 and over were homeless on Census night in 2011. This is approximately one out of seven people counted as experiencing homelessness in Australia, or around 14%. Yet people over 55 comprised only 7% of clients accessing specialist homelessness services in 2014-15. Homelessness Australia notes that "This is partly due to service system design, but also indicates that there is a lack of beds for older Australians within the homelessness service system." (Homelessness Australia, 2016)

## Risk factors and impact of homelessness

The causes of homelessness are varied and complex (ABS, 2012a). There are a number of risk factors which often work collectively to increase a person's risk of homelessness. Socio-economic issues, social exclusion and individual issues all play a role in homelessness. These include but are not limited to:

- Unemployment/problems with employment
- Family violence
- Intergenerational poverty
- Severe overcrowding/unaffordable housing/lack of public housing
- Mental illness
- Exiting state or prison care
- Financial or legal crisis/issues
- Problem gambling
- Drug and alcohol abuse
- Other events that result in further social and economic exclusion. (Homelessness Australia, 2013a; DSS, 2008)

Homelessness is often experienced in cycles through different types of marginal housing rather than a single episode of living without conventional housing. This cycle often repeats and serves to

further marginalise the individual. The trauma associated with homelessness further strains relationships and negatively impacts upon the individual's mental and emotional health; which makes obtaining or maintaining employment, keeping a tenancy, and completing education even more difficult (DSS, 2008).

Homelessness has a significant impact upon individuals, families and communities. For the individual, homelessness causes considerable instability and often results in the person leaving behind important relationships and connections. The ability to participate in education, employment, family and community becomes problematic, serving to exclude the individual from mainstream life. Homelessness may also trigger negative health outcomes for the person such as substance abuse, depression, poor nutrition, or mental health issues (Homelessness Australia, 2013a; DSS 2008).

## The health of homeless people in Australia

People experiencing homelessness have poorer health outcomes than the general population and experience a range of physical and mental health problems (DSS, 2008; Chin et al, 2011). In Australia, comprehensive national data regarding the health and health care needs of people experiencing homelessness is lacking. A range of information sources, however, indicates that those experiencing homelessness have highly complex health care needs and underutilise health services (AIHW, 2015).

There are higher rates of a range of health issues in those experiencing homelessness including self-harm and suicide, injuries associated with violence, poor dental health, respiratory tract diseases, skin infections, diabetes, hypertension, liver disease, musculoskeletal disorders and communicable diseases such as human immunodeficiency virus

(HIV). These health issues are further complicated as diseases are generally identified at an advanced stage rather than at a preventable or primary stage (Chin et al 2011; AIHW, 2015; Anderson, 2008; Hwang, 2001).

The high prevalence of mental health issues is also well documented in this population (St Vincent's and Craze, 2005). Research conducted in Melbourne with over 4,000 homeless people found that over 30% of the sample had a life time experience of mental illness with 15% of the sample experiencing mental health issues prior to becoming homeless (Johnson and Chamberlain, 2009). Similarly, high rates of mental health issues were reported in a major study conducted in Sydney, with 75% of the sample of 210 homeless people reporting mental health problems, and many participants reporting more than one mental health issue (Hodder et al, 1998).

There are a range of barriers that homeless people encounter in receiving treatment and care. These barriers include delays by the individual in seeking care, non-adherence to treatment or therapy, long waiting times, inflexible scheduling by service providers, inadequate or inappropriate services, and complex admission criteria. These barriers often result in homeless people attending emergency departments when in crisis. The difficult circumstances faced by people experiencing homelessness need to be better understood by health services, and current service delivery models to be changed if the care needs of the homeless population are to be addressed (Chin et al, 2011; Weiland, 2009).

## Prevalence of cognitive impairment and dementia in the homeless population

There is limited information available regarding the prevalence of cognitive impairment and dementia in the homeless population (Chenco, 2015). A handful of studies conducted in Australia and internationally have provided some insight into the impact of cognitive impairment and dementia in this population.

Research exploring the prevalence of cognitive impairment among a cohort of homeless men and women in several hostels in inner Sydney found that 10% of people experiencing homelessness had cognitive impairment, constituting a nearly sixfold increase in prevalence over the general Australian population. Age was the only significant predictor of cognitive impairment. Fifty five per cent of subjects with a cognitive impairment had schizophrenia, while thirty three per cent had an alcohol disorder (Buhrich et al, 2000).

Another study conducted in Sydney explored cognitive impairment in the elderly homeless population. 105 homeless participants were screened with 70 (66.7%) showing evidence of cognitive impairment, and 79 (75.2%) reporting mental health problems. People with cognitive impairment reported higher rates of mental health problems (Rogoz et al, 2008).

An American study which looked at 90 homeless men found possible cognitive impairment in 80% of the sample. The study observes that “many homeless people seek treatment at social service agencies in crisis, with complex problems, chaotic lifestyle and little social support. Their presenting problems can be so pressing that more subtle issues, such as mild or moderate cognitive problems, are often ignored.” The study concluded that “these findings suggest that the homeless men in this study had considerable assessment and treatment needs that were not being met by most of the health and social services offered to them” (Solliday-McRoy et al, 2004).

## Heightened risk factors for dementia in the homeless population

Spence, Stevens and Parks (2004) note that homelessness is associated with multiple adversities that might impact upon brain function, and that most studies indicate a considerable burden of cognitive dysfunction among homeless people. The authors asked “whether such cognitive impairment is in any way specific to the homeless or whether it is similarly prevalent among other at-risk groups (e.g. people living in poverty)”. The authors found that that too little research existed to provide conclusive comment, and suggested that medical questions on cognition risk pertinent to homelessness warranted further study. They noted that “given the number of homeless adults living in the world, it is surprising that so few studies have examined their cognition” (Spence et al 2004).

A later study by Backer and Howard (2007) noted that cognitive impairments arise from a number of sources – including schizophrenia, substance abuse, traumatic, or acquired brain injury, progressive neurological disorders and developmental disabilities – and that for many homeless people, their impairments may come from more than one source. Each of these factors increases the risk for developing dementia, and sits alongside other commonly recognised cognitive risks such as diabetes, premature ageing, thiamine deficiency, HIV, depression and social isolation, all of which are disproportionately correlated with homelessness.

Some key risk factors for dementia which are heightened amongst people who are homeless, are outlined below

### Physical health problems

Homelessness is associated with particular health problems that may increase the risk for dementia. For example, diabetes mellitus is a prevalent diagnosis among homeless people (Lloyd et al, 2012), and population studies suggest that type II

diabetes, on average, doubles the risk of developing dementia compared with people who do not have the condition (Alzheimer's Australia, 2015d).

Similarly, HIV rates are higher among the homeless population than in the general population (Donohoe, 2004). Whilst the introduction of new retroviral therapies has positively impacted HIV affected life expectancy, the effects of ageing are significant, and HIV associated neurological disorder (HAND) persists (Cysique et al, 2012).

### **Mental health problems**

People experiencing homelessness have higher rates of mental illnesses than the average person. Depression, bipolar disorder, schizophrenia, anxiety disorder and alcohol dependence have all been found to be significant and independent risk factors for late-life dementia after adjusting for diabetes, heart disease, cerebrovascular disease and smoking risk factors (Zilkens et al, 2014).

Recent Australian media has reported on an increase in Australian veterans experiencing homelessness with a high association of post-traumatic stress disorder (Hall, 2014). A study by Yaffe et al (2010) suggests that veterans with post-traumatic stress disorder (PTSD) are at a nearly two-fold higher risk of developing dementia than those without PTSD. The link between PTSD and dementia in younger veterans has been the subject of other studies, and further research in this area has been suggested (Meyer and Schuyler, 2014).

### **Head injury**

There are many causes of acquired brain injury (ABI) which refers to any type of brain damage that occurs after birth. Research indicates that approximately 50% of homelessness service users (58% of homeless men and 42% of homeless women) have a history of traumatic brain injury (Rota-Bartelink, 2010).

The association between head injury and homelessness was the focus of a 2014 study looking

at 111 homeless men aged 27 to 81 years old who were recruited from a Toronto men's shelter. The study found that 45 per cent of these men had experienced a traumatic brain injury, and of these, 70 per cent were injured during childhood or teenage years, and 87 per cent experienced an injury before becoming homeless. The study noted that in men under age 40, falls from drug/alcohol blackouts were the most common cause of traumatic brain injury while assault was the most common in men over 40 years old (Topolovec-Vranic et al 2014).

Cations et al (2015) have identified traumatic brain injury, along with cardiovascular illness, psychiatric illness, heavy alcohol use, and estrogen-related factors, as potential risk factors for younger onset dementia; with a dose-response relationship found between cumulative and/or increasing severity of exposure and risk for younger onset dementia. Similarly, a study of clients aged 50 years and over attending drug and alcohol services found that 40% had been injured in a fall in the last 12 months (Lintzeris et al, 2015).

Topolovec-Vranic et al (2014) found that mental illness was more prevalent among homeless men with a traumatic brain injury than among homeless men without such injury, suggesting an interaction between acquired brain injury and mental health problems in some cases.

### **Alcohol consumption**

The causes of ABI include brain damage caused by chronic abuse of alcohol. It has been established that "the incidence of alcohol abuse among the homeless population is considerably higher than in the general population and many older homeless people present with long-term, well entrenched patterns of drinking, a history of multiple failed attempts at sobriety and, very often, varying degrees of alcohol related brain injury" (Rota-Bartelink, 2012). Alzheimer's Australia recognises chronic alcohol consumption as a risk factor for dementia which may arise from the direct toxic effect of alcohol

on the brain cells. The lack of thiamine, resulting from coexisting poor nutrition is an additional and contributing factor (Alzheimer's Australia, 2015b).

A review by Ridley et al (2013) found that neuropathological and imaging studies suggest that excessive and prolonged use of alcohol may lead to structural and functional damage that is permanent in nature; however there is debate about the relative contributions of the direct toxic effect of alcohol, and the impact of thiamine deficiency, to lasting damage. The authors found that epidemiological studies suggest that individuals with alcohol-related dementia typically have a younger age of onset than those with other forms of dementia, are more likely to be male, and often are socially isolated.

### Issues in service delivery for homeless people with dementia

There can be significant challenges in meeting the needs of homeless people with dementia, which may vary from person to person and area to area. Some of the key challenges documented in the literature are outlined below.

#### Assessment, diagnosis, and referral

The challenges of cognitive screening in the homeless population are documented by Backer and Howard (2007) who state that "people in shelters are infrequently assessed for cognitive impairments. Even when they are, they are often only treated for other conditions such as severe and persistent mental illness or substance abuse. For people on the streets, the ability to assess cognitive impairments may be compromised by more temporary conditions such as inebriation or recent drug use."

The study by Solliday-McRoy et al (2004) into the neurological functioning of homeless men highlighted that staff at a homelessness shelter "long had concerns about some of

the men's cognitive abilities"; but the authors found no comprehensive data regarding the neuropsychological functioning of homeless men that could be used to inform the intake and assessment procedures and the psychoeducational and supportive programming that would be most helpful to these people.

#### Appropriate, accessible services

Homeless people face significant barriers in accessing both mainstream services and specialist homelessness services. A report from the Australian Housing and Urban Research Institute states that "given the complexity and diversity of need across the homeless population, access points must incorporate high quality assessment and referral processes to enable an adequate response to be provided" (Black and Gronda, 2011).

Clapton et al point out that because of the complexity of their needs, homeless people with impaired capacity are likely to have contact with an array of service providers such as hospitals, courts, emergency services and even prisons, however "because interventions are tenuous and often only episodic due to systems issues such as restrictive support program guidelines, structural constraints and individual attributes, people with impaired capacity are consistently described as 'falling through the gaps' and experience various forms of precariousness exacerbated by poverty, chronic illness and social isolation" (Clapton et al 2012).

Lipmann (2009) identifies a disconnect between older homeless people and care services. The author notes that elderly, frail homeless people lack the resilience needed to self-advocate towards positive relationships between themselves and care services. Indeed Lipmann notes "Before any relationship with an older homeless person can begin, the person needs to feel that he or she can trust you. Relationships start over a shared smoke, a footy story, or a joke about someone else. Only later it is sometimes possible to tackle housing or health

issues.” Lipmann highlights the specialist nature of working with older homeless people, and the need for “a strong outreach support model funded by the Commonwealth and State programs” (Lipmann 2009).

People who are living with long term homelessness age more quickly and often have a reluctance to engage with services (Rota-Bartelink, 2012). This premature ageing is recognised as a consequence of living with disadvantage and as such, homeless people aged 55 years may require access to aged care services. However, Homelessness Australia has noted that there are barriers to homeless people accessing the aged care system, including difficulties in meeting fees. Homelessness Australia concludes that “priority needs to be directed towards funding models of aged care, specifically for older people with histories of housing insecurity and homelessness” (Homelessness Australia, 2016).

The geographical location of a homeless person with dementia can impact on access to services. Not only are there state and territory service provider differences, there are variations in the services available between rural and remote, regional and metropolitan areas within each state and territory. The White Paper ‘The Road Home: A National Approach to Reducing Homelessness’, produced by the Department of Families, Housing, Community Services and Indigenous Affairs (2008), indicated that homelessness is greater in rural and remote areas. However, there is frequently less service availability in these areas.

Chenco’s recent review of the literature confirms that providing access to services including housing, health, and aged care for older homeless people with multiple complex problems is challenging. However, many studies have found that providing appropriate outreach services to older homeless people can be effective, provided the services are based on a multidisciplinary team approach, in which skilled and specialised health professionals engage with

this population and build trust over time. Chenco notes the importance of seamless service delivery through effective co-ordination between aged care, health, and housing; and concludes that “Ultimately, the best model for care of older homeless people is a one stop service that provides prevention, outreach, assessment and evaluation, all types of housing including crisis, transitional, community and residential, and support services such as mental health, addiction, etc; assistance with all aspects of daily living and continuity of care” (Chenco, 2015).

### **Knowledge and skills in the homelessness sector**

A recent review confirmed the importance of health professionals being able to locate, engage, screen and assess homeless people with cognitive impairment, and found that staff need to be skilled in liaising with, and coordinating services, sharing information, program delivery and program management. The review found that specialist knowledge and skills are required not only to provide the best care, but also to manage some of the risks to staff and their clients associated with dealing with the myriad of acute and chronic illnesses that older homeless people are at risk of, or live with. However, the review found that there was a distinct lack of information in relation to cognitive impairment and the needs of the staff working with homeless persons with dementia, and recommended that further research in this area is warranted (Chenco, 2015).

### **Lack of self-management skills**

Homeless people with cognitive impairment have limited capacity to self-manage their needs, and this could be better recognised in both homelessness and dementia services. Unless there is focus on supporting this population, their complex needs can be largely ignored, and people are ill-equipped to access treatment or follow through on referrals. Clapton et al (2012) state that there is “a need for services to connect with people to help them navigate through the service system at crucial points

otherwise vulnerable clients would get lost. For some clients, a name and agency number were not enough – concerns were raised that clients become isolated and for a whole range of reasons may not have the capacity to access follow up support themselves” (Clapton et al, 2012).

### **Behavioural issues**

Challenges exist for dementia services in supporting antisocial, aggressive or disruptive individuals. This includes people affected by alcohol or other substances. Backer and Howard (2007) surmise that if hostility is evident then a person’s ability to access a service is compromised and potentially they may end up in the criminal justice system. Homeless people are faced with differing approaches from GP’s, with some prepared to bulk bill and others not (Clapton 2012), and from service providers who may have restrictions around eligibility criteria such as age, behaviours or in what service they can provide. Essentially, a person has to fit with a service rather than the service fitting with them (Zilkens et al, 2014).

### **Box 4: Service Gaps - Comments to SA Homelessness and Dementia Advisory Group**

*“I’d like a clear flow chart or something to refer to so we know who to speak to and where to connect clients to services.”*

*“There isn’t a particular system for referral that I can think of. Finding appropriate services to assist with assessment would be helpful.”*

*“It would be so good if we could pick up a phone and ask for someone to come out to screen a client for memory loss and who can then work with their doctor and us together.”*

*“A list of homelessness friendly GPs that can assist with assessment with clients would be good.”*

*“Referral options are complicated as mental health services i.e. Mental Health Triage would most likely not be able to assist with an assessment due to ‘not a threat to themselves or to the community’.”*

*“It’s no good talking about hospital or specialist clinics until they become accepting of our clients.”*

*“Are mental health services the right place to make referrals to? I don’t know.”*

*“Information help sheets that are applicable to our sector would be important.”*

*“It is hard to think about how we would assist someone to get a dementia diagnosis.”*

*“I have thought about referring my client to a doctor but he would not visit a hospital or memory clinic. It doesn’t work for him.”*

*“Our clients may say one thing but do another. They are not always reliable so it is hard to get them to agree to visit a clinic or hospital service.”*

*“We need a way to connect assessments with clients in their environment.”*

*“Most sector workers would not have time to think too long about a person’s cognition – and I’m not sure how long a GP will have once they have looked at all the other health problems.”*



# THE CURRENT SERVICE RESPONSE TO HOMELESSNESS AND DEMENTIA

The service response to homelessness and dementia would benefit from a collective and coordinated, national approach which clearly defines and outlines access pathways for homeless people of any age, towards timely dementia assessment, service and support. Some positive current initiatives are outlined below.

## The Alzheimer's Australia Service Delivery Pathways Projects

Commencing late 2010, Alzheimer's Australia Service Access Liaison Officer (SALO) roles, funded by the Australian Government through the Service Development Pathways Project (SDPP), aim to improve access to dementia services for specific needs groups and to improve Alzheimer's Australia's capacity to further develop diverse, flexible and responsive services (Stevens et al, 2011). Groups targeted through the SDPP projects include Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse communities, people who identify as lesbian, gay, bisexual, transgender, or intersex (LGBTI), people who are homeless, and people living alone. The SDPP projects work to build capacity and develop partnerships across sectors; and to advocate and educate towards an increased understanding of dementia across a particular community.

The SDPP homelessness projects work to improve understanding of service needs and access to services for homeless people with dementia; raise awareness of homelessness and dementia across all sectors, including aged care services; and identify where barriers in service access exists and influence strategy and pathway development. In Victoria, the homelessness folio currently sits with the Diversity Officer under different funding arrangements, although with similar goals and outcomes to the Service Access Liaison projects.

Projects were designed to suit their particular demographic, geographic, organisational and service system context, and to develop and implement clear and credible strategies for achieving the objective of increased access to services.

An external evaluation of the projects (Stevens et al, 2011) outlines that across the projects, three clusters of strategies have been used to increase access:

- Building knowledge – by identifying factors that reduce access to dementia services for specific groups and options for increasing access.
- Addressing demand side issues – by raising awareness and knowledge of the signs of dementia and the importance of early diagnosis, raising awareness and knowledge of the availability of services and how they can be accessed, and changing negative attitudes of people with dementia and carers towards services.
- Addressing supply side issues – by changing the way dementia services are provided to make them more appropriate, providing more individualised responses to consumers' particular and changing needs, identifying and addressing gaps in services, and developing integrated service systems and referral pathways.

At present, several of the Alzheimer's Australia SDPP projects include a focus on homelessness and dementia. Key recent initiatives have included:

- The Queensland project has worked to establish partnerships and linkages with homelessness organisations, and develop an understanding of how services can best meet the needs of people experiencing or at risk of homelessness. Work is being undertaken to build service knowledge around dementia, through training and networking sessions and resource packs covering the symptoms and behaviours associated with dementia, and how dementia impacts people who are homeless. The project

is laying the foundations for improved sharing of knowledge between Alzheimer's Australia and the homelessness sector around reducing the risk for dementia, the importance of an early diagnosis, and the development of pathways for support for homeless people with a dementia diagnosis. The homelessness sector will have the capacity to support 'at risk' people who are homeless to reduce their risk, recognise the symptoms of dementia and know where and how to refer clients when there is a concern. The health sector will have a greater understanding of the issues facing people who are homeless. This will result in better outcomes for homeless people, through improved healthcare, risk reduction and more accessible supports and services.

- Alzheimer's Australia NSW has been working to develop and implement train-the-trainer approaches and resources that build capacity of service providers to deliver quality service responses to consumers with special needs who have dementia or at risk of developing dementia. As part of this, educational seminars on ageing, homelessness, and dementia have been delivered to the homelessness and housing and aged care sectors; and a range of awareness-raising activities and events have been undertaken.
- With the support of the Ian Potter Foundation and Gandel Philanthropy, Alzheimer's Australia Victoria undertook a Dementia and Homelessness project in 2015-16, aimed at building the capacity and knowledge of dementia in staff supporting people who are homeless or at risk of homelessness. Education was delivered to a broad range of stakeholders across the state, with more than 300 attendees receiving tailored education and resources.
- The South Australian project has continued to have an ongoing focus on homelessness building on the consultations as documented in this report, and has been working to identify

and address the access and equity issues of homeless people in relation to the provision of quality dementia care, support and services. Positive outcomes have been achieved through building capacity in the homelessness sector, and through the provision of direct support and education to people who are homeless, people who have an increased risk for dementia or who have a dementia diagnosis and are at risk of homelessness. Alzheimer's Australia SA has also been able to engage with homeless consumers through a Brain Health Clinic, providing information about dementia, screening for memory loss, and making further referrals as required. The project's Dementia Awareness and Education Program has delivered brain health and risk reduction training sessions to people at risk of homelessness. The sessions have been very positively received by consumers, with people stating that they now see how they could reduce their risk for dementia, and all stating they would apply the knowledge in practical ways, to reduce their risk.

The projects have encountered some challenges at times in engaging with homelessness agencies, including an expression from some homelessness agencies that they see various external projects come and go, without lasting benefit; an expression that the gap between the person living homeless with a cognitive impairment and access to the specialist services needed would be insurmountable; a lack of staff time to engage with the project in an ongoing capacity; and staff movement within and out of the homelessness sector.

## The Younger Onset Dementia Key Worker (YODKW) Program

Alzheimer's Australia's YODKW Program is a critical initiative in meeting the needs of people with younger onset dementia, who often "fall through the cracks" between the aged care and disability services sectors. With the implementation of this program, referrals from homelessness service providers for younger homeless people have become an important and valid option.

Under this program, the Key Worker acts as a primary point of contact for providing information, support, counselling, and advice. The program aims to effectively engage people with services that are appropriate to their individual needs. Eligibility includes being under 65 years on first contact to the program; and includes all forms of dementia, including a person with symptoms of dementia that have not yet been diagnosed. With regard to this last criterion, Key Workers will be important in assisting access towards a diagnosis. The YODKW Program provides the core Alzheimer's Australia service for those living homeless with a dementia, who are under 65 years of age. The program is important in demonstrating effective approaches to homelessness and dementia, as Key Workers co-ordinate service access across disability services, aged care services and homelessness services. However, experience suggests that challenges remain, including in some cases a lack of appropriate and flexible services to which to refer clients with dementia; and a need for specialised knowledge and skills to work effectively with this population.

A few case studies are presented on page 27 to illustrate the impact of the program on addressing the housing needs of people with younger onset dementia.

## Dementia Training Study Centres (DTSCs)

In early 2016 the Australian Government announced the next phase in a new national approach to programs and services supporting people with dementia and their carers. Under this new approach the Government has announced Dementia Training Programs that will deliver a streamlined dementia education program. The Dementia Training Program's will consolidate the Dementia Training Study Centres and the Dementia Care Essentials program. The new Program's will be delivered by a consortium, led by the University of Wollongong, which brings together the expertise of Australia's leading dementia educators and trainers, to build on the experience they have gained in operating the Dementia Training Study Centres and the Dementia Care Essentials program for the last nine years and developing the world's premier health care Massive Open Online Course (MOOC).

This collaborative and national approach to dementia training will ensure that the next generation of dementia training is based on the most up to date, evidence based best practice, delivered in a coordinated, nationally consistent way. The training will be accessible to a broad range of health and aged care personnel, from personal care assistants in the community and residential care to medical specialists in hospitals.

This will ensure the very best available knowledge in dementia training is translated into best practice on the ground, so the outcomes for people with dementia and their families and carers can be improved.

## Specialist aged care services

Government has responded to the growing aged care needs of older Australians experiencing homelessness. Aged care services for older homeless people have been funded since 1993 through the Assistance with Care and Housing for the Aged (ACHA) program, a Government program that aims to provide housing and support for incapacitated, low income older people who are living in insecure housing, at risk of homelessness, or already homeless. ACHA provides service coordination to assist with both housing and with linking a person to community based supports. The program is accessed through a number of service providers such as Catholic Community Services. In addition, the Residential Aged Care Homeless Supplement better supports aged care homes that specialise in caring for people with a history of, or at risk of, homelessness; and there are services funded under the Home and Community Care Program that have enabled harder to reach older homeless populations to receive support. While not specifically for homeless people with dementia, those assisted by these initiatives will include people with dementia (Chenco, 2015).

Whilst awareness of dementia among homelessness service providers can be limited or the issue can have low priority, there are some notable exceptions, particularly in residential aged care facilities specifically for people living with disadvantage, complex issues and/or homelessness. Wintringham Specialist Aged Care services in Victoria provides a non-conventional model of service to older homeless people based upon social principles of justice, and their innovative approach is towards dignified and respectful support that includes working with frail aged and dementia. Wintringham staff have in-house training, including face to face training with an internal behaviour management consultant as well as access to online delivery of behaviour management training (NARI, 2015).

AnglicareSA Ian George Court, Adelaide, is an example of an ageing-in-place facility providing 40 beds to support disadvantaged frail aged care for those homeless or at risk of homelessness, and who are referred through the Exceptional Needs Unit of the Department of Health. Ian George Court staff have extensive knowledge in the connection between homelessness and dementia, particularly in people who are, or have been, long-term users of alcohol and who are presenting with an associated cognitive deficit. Other examples can be found such as Common Ground and the Salvation Army.

### **Case study 1: Support to meet the complex needs of an Aboriginal client with Younger Onset Dementia**

The YODKW program had a referral from a client who is Aboriginal but stated she does not wish to be identified as such on any record. She had no proof of identity and was subsequently at risk of homelessness. The Key Worker slowly built a relationship with the client and carer, who had proven to be resistant and suspicious of services as they had not worked out previously. The YOD Key Worker gained a birth certificate for client and placed her on a waitlist for housing to address the risk of homelessness. The YOD Key Worker throughout this process has been able to assist the client to trace her family history (Stolen Generation). The client now loves attending a social program which had been rejected previously without the intervention of the YOD Key Worker.

### **Case Study 2: Assisting a client to transition from a High Care Residential Facility into the community**

A client newly registered with the YODKW Program was living in a high care residential facility and becoming increasingly depressed. Her family had unsuccessfully tried to assist her to move to more appropriate accommodation and finally the client left the facility and moved into the studio apartment of one of her children, who has a disability. This arrangement quickly broke down and the client was at high risk of homelessness. The Key Worker partnered with another community organisation (“Partners in Recovery”) who, together with the Key Worker, supported the client to move into her own apartment with support services in place.

### **Case Study 3: Assistance to successfully access respite care**

The YODKW Program helped a client with a history of escaping from residential respite facilities, who was discharged from a regular community based respite facility in October 2015 due to changed behaviours causing risk of harm to self and others. A family breakdown in the second part of 2015 resulted in the client becoming at risk of homelessness and in urgent need of access to suitable, affordable accommodation. The Key Worker facilitated meetings between the client, carer and respite facilities to negotiate long term respite options. The Key Worker also liaised with Commonwealth Respite and Carelink Centre to successfully access funded temporary in-home and residential respite while the carer sourced suitable accommodation and moved home for the second time in six months. The Key Worker facilitated a transition into the respite facility, which resulted in the first successful residential respite stay for the YOD client. The Key Worker continues to support the YOD client and the carer to access affordable, meaningful, long term community based in-home respite.



# CONCLUSION

The literature review and consultations undertaken for this project confirm that there are significant rates of dementia in the homeless population: perhaps 10% in the overall homeless population, with much higher rates amongst older homeless people.

There is room for improvement in developing shared knowledge and understanding between homelessness sector workers, and workers in the dementia, health, and aged care sectors, so that there can be a holistic approach to dementia in homelessness. Homelessness sector workers could develop improved awareness and understanding of cognitive impairment and dementia, while workers in the dementia, health, and aged care sectors could better understand homelessness and the service and care needs of homeless people with dementia.

Education and training across sectors, and improved collaboration and partnership across sectors, has the potential to improve the services offered to homeless people with dementia. The new Dementia Training Programs also provide an opportunity to address the current gaps across knowledge and awareness in service delivery. The Dementia Training

Programs aim to provide a nationally streamlined approach to the design, development and outcomes from dementia programmes and services, and offer another platform through which the needs of homeless people with dementia can be met.

It is clear that homeless people are not routinely assessed for cognitive impairment and dementia, and that these issues often co-exist with, are compounded by, and are difficult to distinguish from, other issues such as mental health problems, traumatic brain injury, and substance abuse issues. Improved and consistent methods of cognitive assessment would be very helpful.

As discussed earlier, Alzheimer's Australia operates The Hutt Street Centre Brain Health in South Australia that is currently funded by the Commonwealth through the Service Delivery Pathways Project. This model has evidence that demonstrates its capacity to effectively act as a mechanism for initial assessment and a pathway to comprehensive assessment and access to support and services. This SA model could be scaled to provide a national service for people who are

homeless or at risk of homelessness - delivering initial cognitive assessment, support, information and referral pathway for people who have signs of dementia or who are worried about their memory.

Improved assessment and diagnosis would help in referring homeless people with dementia to housing and care services. There are positive initiatives occurring in the delivery of appropriate housing and care services for this population, and broader uptake of positive initiatives could be considered.

The consultations for this project also identified that there may be value in a health promotion and risk reduction approach focusing on potentially modifiable dementia risk factors for homeless people.

These conclusions align with relevant sections of the National Framework for Action on Dementia 2015-2019, signed by the Australian Government and all State/Territory Governments. Priorities in the National Framework include timely diagnosis of dementia, and access to quality care and support after diagnosis, and on an ongoing basis. The National Framework also recognises that diverse needs groups have particular service needs and preferences which must be addressed, and this applies to diverse groups of homeless people with dementia.

The conclusions of this project also support the intent of the National Partnership Agreement on Homelessness 2015-2017, which was also signed by the Australian Government and all State/Territory Governments. This agreement aims to support and reform service delivery in the homelessness sector, so that: fewer people become homeless; fewer people become homeless more than once; people at risk of experiencing homelessness will maintain or improve connections with their families and communities, and maintain or improve their education, training, or employment participation; people at risk of or experiencing homelessness will be supported by quality services, with improved access to stable accommodation; and the response

for those at risk of or experiencing homelessness is integrated, holistic, and in line with best practice. The Agreement specifically discusses the needs for support services and accommodation to assist older people who are homeless or at risk of homelessness.

This discussion paper has set out information from consultations and from relevant literature, with the aim of contributing to a better understanding of the experiences and needs of homeless people with dementia. This information may be useful in assisting policy makers and service providers to shape and target programs and services aimed at meeting this needs of this population.



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# METHODOLOGY

This report was developed as an outcome of a Homelessness and Dementia project undertaken through the Alzheimer's Australia (South Australia) Service Delivery Pathways Project (SDPP). In 2013 a needs survey was undertaken with South Australian front-line homelessness services, with the purpose of identifying, through a gap analysis, issues impacting on homeless people with dementia including their access to dementia services. The project connected with 54 contacts across multiple agencies and organisations in South Australia.

The survey consisted of a set of questions mostly elicited through face to face discussion, which were then subjected to evaluation and a gap analysis. Questions were specifically designed to relate to homelessness agency knowledge of dementia, to prevalence of dementia, to known barriers and gaps in service, along with any recommendations.

## **Questions put to agencies were:**

- 1) What is your understanding of dementia in homelessness?
- 2) Do you have clients who have a diagnosis of dementia? If so, how many?
- 3) Where do you see barriers in obtaining an early dementia assessment or diagnosis for clients?
- 4) What would be your recommendations to better support agency workers working with people who have a cognitive impairment or dementia?
- 5) What would be your recommendations to better support homeless people who have a cognitive impairment or dementia?
- 6) What other comments do you have on homelessness and dementia?

A Homelessness and Dementia Advisory Group (HDAG) was established, comprising South Australia Homelessness and Dementia survey participants willing to assist the project further. This was largely an email contactable group, instrumental in offering an ongoing source of information, opinion and review on homelessness and dementia, over 2013-14.

The project also consulted with government and non-government advisory and advocacy bodies such as Housing SA, Shelter SA, Health Consumers Alliance SA, Central Adelaide and Hills Medicare Local and the Assistance with Care and Housing for the Aged (ACHA) program. Ongoing contact with homelessness service providers continued with attendances at multi-agency roundtables meetings, internal agency meetings and homelessness community forums.

In addition, the project established a working partnership with Hutt Street Centre, a front-line homelessness service in eastern Adelaide. This initiative provided a visible point of contact for the aged homelessness team and other Hutt Street Centre staff to identify and initiate appropriate referrals back to Alzheimer's Australia South Australia's range of services. The partnership objectives included interaction with visiting professionals who come to the day centre (Royal District Nursing Service, GP services and allied health services) with the purpose of raising the profile of Alzheimer's Australia in homelessness and dementia, disseminating information on cognitive impairment, and working with other service providers to improve outcomes for homeless people with cognitive impairment.

In developing this discussion paper, consultations were also undertaken with Alzheimer's Australia's SDPP projects and similar work undertaken by Alzheimer's Australia across states and territories; as well as with representatives of Alzheimer's Australia's Younger Onset Dementia Key Worker Program. In addition, a brief review of relevant literature was undertaken, to provide the context for the consultations. It should be noted that separately to this project, a more comprehensive literature review on dementia and homelessness was undertaken in 2015 for the Victoria/Tasmania Dementia Training Study Centre, which also informs this report (Chenco, 2015).



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Visit the Alzheimer's Australia website  
for comprehensive information about  
dementia, care information, education, training  
and other services offered by member organisations.

**Or for information and advice contact the  
National Dementia Helpline on**

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