



Final Report

Housing priorities of people with dementia: security, continuity and support

authored by

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ACRONYMS

ACAP	Aged Care Assessment Program
ACAT	Aged Care Assessment Team
ACHA	Assistance with Care and Housing for the Aged
AD	Alzheimer's disease
AHURI	Australian Housing and Urban Research Institute Limited
AIHW	Australian Institute of Health and Welfare
CALD	Culturally and Linguistically Diverse
CDC	Consumer Directed Care
CDR	Clinical Dementia Rating
CHSP	Commonwealth Home Support Program
DFCS	Department of Family and Community Services, NSW Government
DHHS	Department of Health and Human Services, Tasmanian Government
FaCSIA	Australian Government Department of Families, Community Services and Indigenous Affairs
HACC	Commonwealth Home and Community Care Program
NDIS	National Disability Insurance Scheme
NGO	Non-Government Organisation
NSECHR	National Statement on Ethical Conduct in Human Research
PwD ¹	People Living with Dementia
SA	South Australia
SDAC	Survey of Disability, Ageing and Carers
SDWGRS	Scottish Dementia Working Group Research Sub-group
SHA	State Housing Authority
SP	Service Provider
UK	United Kingdom
USA	United States of America

¹ Please note, that while this acronym is commonly used to refer to People with Disabilities, it is also used in a range of contexts to refer to people living with dementia. See, for example, <http://aspe.hhs.gov/daltcp/napa/acronyms.shtml#P>. Moreover, we have chosen to use this acronym for consistency with this project's earlier Positioning Paper.

EXECUTIVE SUMMARY

Overview

Over the past decade, dementia has gained prominence as a key health, aged care and social policy challenge. Dementia is predicted to become the leading cause of disability in Australia by 2016. Recent data analysis estimates that 298 000 Australians had dementia in 2011, with the number of people with dementia expected to reach almost 400 000 by 2020 (AIHW 2012, p.ix). Like other first world nations, Australia's population is ageing due to the combined effects of longevity and decreased fertility. Consequently prevalence of dementia is projected to increase into the future. AIHW (2012, p.ix) data indicates that the total direct health and aged care system expenditure on people with dementia in Australia in 2009–10 was at least \$4.9 billion, of which about \$2 billion was directly attributable to dementia.

Dementia is an incurable syndrome that impacts on higher cognitive functions, behavioural and psychological traits, and physical function. It is terminal, but with varied trajectories of decline. While there is a comprehensive literature around managing dementia, to date, insights into the role of housing in supporting people living with dementia (PwD) and the planning and coordination of health and housing services has been limited. This project on the future housing and support needs of PwD begins to address this gap. The research has been structured around five major research questions:

1. What is known about the links between housing and care provision for people with dementia?
2. What are the current and projected living arrangements and housing pathways of people with 'mild, 'moderate' and 'severe' dementia in Australia?
3. To what extent are existing community care programs able to adequately support people with dementia effectively across a range of home settings, particularly those in low cost and insecure housing situations?
4. How do people's initial housing circumstances impact on their housing and care pathways, including their transition into residential care?
5. What policy responses and measures could better support practitioners, housing providers and family carers to respond effectively to the future housing and support needs of people with dementia?

The research team relied on a mixed-method approach to answer these questions. In relation to the first two questions, the team undertook a comprehensive literature and policy review, as well as secondary data analysis of ABS and AIHW data. The results of this analysis were previously reported in a Positioning Paper (Gabriel et al. 2014).

In relation to Research Questions 3, 4 and 5, the research team conducted interviews with relevant stakeholders across two study sites—South Australia (SA) and Tasmania. The research team consulted with 44 housing and community care service providers across 18 agencies between May and October 2014. The results of this analysis are reported in Chapter 3.

The research team also consulted with PwD and their family carers. The team obtained insight into 12 people's experiences of living with dementia between August and December 2014. People's level of participation in the interview process varied. While in some instances PwD were able to actively participate and respond to questions, at other times the person with dementia was present but did not participate significantly. Four carers provided insight into their parent/partner's experience without their family member present. The results of this analysis are reported in Chapter 4.

Stakeholder consultation: key findings

The stakeholder consultation, which forms the basis of Chapters 3 and 4, provides insight into the role of housing and support services in enabling PwD and their carers to retain quality of life. While many issues were canvassed in this wide-reaching and exploratory study, there were three recurring themes raised throughout the consultation. These include: the importance of secure housing, which over time has become a familiar and comforting home, in enabling PwD to maintain quality of life; the importance of continuity in both the home environment and the care received in the home in reducing anxiety; and the importance of comprehensive home-based care and community support (including innovative respite services) in enabling people to retain independence and dignity as they experience decline in their cognitive function.

Housing security

Among stakeholders, there is growing recognition of the advantages of enabling PwD to remain in a familiar environment. A key element in achieving this continuity is housing security.

Our consultation with service providers and carers highlighted the advantages of owning your own home and having access to housing wealth for families coping with the challenges and stress of dementia. People who own their own home are able to readily make appropriate home modifications to support their changing needs. They are also potentially able to afford extra home-based care and support if it is required as their condition progresses. In other circumstances, people who own their own home and who are able to access wealth are potentially able to seek alternative, more appropriate housing options within the housing market that can better support their needs.

People living in public rental housing share in common with home owners high levels of housing security. However, the process of obtaining suitable home modifications and/or accessing alternative, more appropriate housing options is more complex and more constrained. While service providers noted that there was capacity to move tenants to more appropriate housing options, the availability of better designed housing and/or service-integrated housing was limited. Further, the possibility of tenants accessing extra home-based care and support as their condition progresses is less feasible due to financial constraints.

In contrast, housing security was a significant concern for PwD who are living in private rental and/or marginal housing situations, such as caravan parks and boarding houses. The major concerns raised by service providers were the PwDs' capacity to maintain the tenancy due to: problems with maintaining the residence, confusion about lease arrangements and rental payments, and problems with affording increasing rent and utility bills. They also noted that marginal housing situations such as caravan parks and boarding houses were problematic for managing personal care and accessing home-based support.

Service providers emphasised the importance of inter-agency collaboration and the need for ongoing case management to ensure that people with complex needs at risk of homelessness were able to continue to access the supports they required. Service providers also raised the problem of the lack of appropriate, affordable housing options for people who have complex needs and who are marginally housed. Without this, there can be a push towards transition into residential care.

Service providers noted that an expansion of brain health initiatives among the homelessness population and the introduction of outreach cognitive screening would address current delays in people living in marginal and precarious housing situations receiving diagnosis and support. Across the two case sites examined, there was greater evidence of collaboration underway in South Australia, compared with Tasmania.

PwD talked about their strong attachment to their home and neighbourhood, as well as happy memories from the past. Housing security was a critical issue for PwD and their carers. It was

tied to people's sense of wellbeing and quality of life. The home is a place where PwD feel at ease and they can function well. PwD and their carers organise the home to compensate for loss of short term memory. Importantly, the home is often a repository of longer term memories. In contrast, the idea of change and moving home was a source of frustration and anxiety for many.

Continuity in housing environment and home-based support

Stakeholders emphasised the importance of continuity in terms of the home environment and also continuity in terms of available supports and care. Continuity was viewed as critical in enabling people experiencing memory loss to maintain quality of life and in reducing anxiety and stress.

Home modification was viewed as a critical component of enabling PwD to remain in their homes and to retain quality of life. Service providers were critical of current housing design, which focuses on aesthetics above function for older people including those with mobility and cognitive issues. Service providers emphasised the value of timely access to home modification. This did not always occur due to lack of education, lack of resources and waiting lists. They noted that modifications for PwD are most effective when they are tailored to the specific needs of the individual. This is a challenge for public and community housing providers who are operating with constrained and declining budgets.

Service providers also highlighted current challenges with accessing appropriate levels of home-based support. They noted that there was a need to work with families and try to establish a good, working partnership. In situations where people are living alone, it is a challenge to provide adequate levels of care as their condition progresses. They identified gaps in service provision including the need for regular prompts to take medication, limited service access over the weekend, and shortfalls in adequate respite care. Service providers also cited examples of discriminatory practices that impact on people's capacity to age in place within retirement village developments. There is a need for further research into barriers to ageing in place for PwD in retirement village settings.

Family carers observed that any potential changes can be distressing for care-recipients: changes in care staff, changes in care routines, and conversations about moving house or into residential care. Family carers wanted care-recipients to remain at home in an environment that is familiar to them and which makes them feel good for as long as possible. However, children who were carers and in separate dwellings also expressed concerns about their parents' safety and capacity to manage alone. Many of the carers had made modifications to the bathroom to support care-recipients' independence with showering and toileting. Carers played an important role in making minor changes to the home environment to help the PwD to orientate themselves around the home and to reduce the risk of accidents.

Providing continuity in the housing and support environment was recognised as problematic for particular groups in the community. Consultation highlighted that there are specific issues around communication and dementia in CALD communities and consequently that there is a need for specialised support services. In addition, service providers highlighted the challenges associated with supporting PwD who live in rural and regional areas to age in place. Major issues included a lack of diverse and appropriate community services that can reduce social isolation, the costs involved in delivering care in the home in regional locations, and the additional requirements of travel to access community and health services.

Comprehensive home-based and community support

Service providers noted that in the past dementia was heavily stigmatised and a diagnosis of dementia was often made in late stages. Diagnosis was therefore often associated with significant and rapid decline in cognitive function and a pathway to residential care, but this situation is changing. Increased awareness of dementia and increased access to diagnostic

services has seen earlier diagnoses of dementia. However, service providers highlighted that there remained scope for increasing awareness of the importance of early diagnosis in order to access appropriate support and maintain quality of life.

Service providers noted that there was a need for increased awareness about dementia and the pathways to assessment within the social housing and homelessness sector. This is important in enabling service providers to respond appropriately to complex situations where mental health issues, memory loss and a dementia condition may be present. It is also important in achieving inter-agency collaboration and enabling PwD to access appropriate, stable housing and support services in a timely way.

It was recognised by housing providers that structural changes in the public housing sector were impacting on the capacity of staff to provide adequate duty of care towards older tenants. This was a concern in Tasmania where recent structural changes had resulted in State Housing Authority (SHA) staff having reduced knowledge of and engagement with tenants. SA has also experienced some rationalisation of services, however, participants were optimistic that tenancy support would be targeted towards those in need, including older tenants.

Service providers observed that the home-based care landscape was also changing with the introduction of Consumer Directed Care (CDC). In general, participants recognised the value of enabling clients and carers to be involved in developing a tailored package of services that might best support the individual person's circumstances and meet their personal care needs. However, participants also noted that the issue of choice was problematic for PwD. While a carer would be able to advocate for their care-recipient, a person living alone would need access to an advocate or would rely on trusted service providers to assist with this process. Participants were also concerned that in an environment that encourages competition between service providers and a focus on discrete service activities, some of the things that are less tangible and not easily calculated, such as building trust and rapport between clients, carers and service providers, might disappear. In particular, participants noted that CDC was problematic for vulnerable people living in marginal housing situations.

Carers valued any home-based support they could access to reduce their care burden. However, they saw gaps in the range of services offered. They wanted help with: transport, the preparation of nutritious meals in the home, podiatry services, and a more comprehensive home-based service to manage medication and health needs. Carers were also concerned about being able to readily access information about their options. They felt that they were not being provided with an overview of the range of home-based support services available. When they asked for information, they were referred to online content, pamphlets and/or telephone numbers, but what they wanted was face-to-face, human support. This was important as they were time poor and they were struggling to absorb information during a time of emotional upheaval.

Service providers and carers emphasised the growing need for innovative respite services. Accessing respite was viewed as critical to stimulating the PwD, managing high care burdens, and making transitions to residential care easier by familiarising the PwD with this environment gradually over time. In SA, the carers interviewed had been able to tap into peer support from other carers and regular respite services that offered their care-recipients meaningful activities and satisfying experiences outside the home. Both peer support and regular respite services had played a significant role in enabling carers to cope with their demands of supporting someone with dementia. Carers observed that PwD who live in the community need access to meaningful activities.

A key issue raised by service providers was the specific needs of people under 65 years with early onset dementia. Participants were concerned about the lack of appropriate housing options for people under 65 years, difficulties accessing home-based support services, and the lack of relevant community activities. Currently, people with early onset dementia are not

recognised as clients of disability or aged care services. They were hopeful that the National Disability Insurance Scheme (NDIS) might be able to address this situation.

Finally, in relation to delivering comprehensive home-based and community support, there is a growing need for affordable and accessible housing options for low-income older Australians. Participants noted that service-integrated housing options for PwD, in particular those who have experienced housing and financial insecurity throughout their life, are limited.

Policy directions

The project has highlighted a range of areas for policy reform and innovation. These include the need to increase community awareness and address discrimination; expand advocacy and case management services to support people in marginal housing situations; build knowledge of the experience of living in the community with dementia and/or memory loss, and build pathways to support among housing providers; review the impact of social housing policy reforms on tenants with dementia; expand affordable, service-integrated housing; and expand and innovate respite services.

Build community awareness and address discrimination

There is a need to continue the positive work undertaken by Alzheimer's Australia to raise community awareness about dementia and address discrimination towards people with memory loss. This awareness-raising, particularly in relation to living well with dementia, is important in increasing early diagnoses of dementia, which is essential in accessing support and can improve health outcomes for the PwD. More awareness of the potential for elder abuse is also required.

Discrimination towards people with dementia can occur across a range of housing settings. However, our consultation highlighted that, currently, home modifications are less likely to occur in private rental. A community campaign may build understanding among landlords about the importance of housing security, as well as minor modifications to a home in enabling PwD to live with dignity and retain independence in the community. Service providers also observed that some residential villages exclude people with a diagnosis of dementia. The need to provide education about living well in the community with dementia entails being able to age in place without fear of losing one's home.

Community awareness raising might also provide additional opportunities for more peer support groups to be established for carers who are supporting PwD in the community. This can address problems of information barriers and fragmented services and can provide carers with much-needed emotional and practical support.

Advocacy and case management

There is a growing need for advocacy for PwD in the community. This is important for people living in precarious and marginal housing situations, as well as PwD who are living alone and who do not have family support. With a shift towards Consumer Directed Care (CDC), there may also be an increased demand for an independent advocate to support PwD to navigate a complex and fragmented health care system and to make decisions regarding home-based support and future residential care. Currently, there are state-based disparities in the costs of appointing a Public Trustee to people whose decision-making is impaired because of cognitive issues.

While case management is currently available to PwD who are experiencing financial and housing insecurity, this requires substantially more funding to enable providers to manage cases over a longer period of time and to facilitate effective inter-agency collaboration.

Build knowledge of the experience of living in the community with dementia and pathways to support among housing providers

There is a need for education about brain health and dementia service support pathways within the social housing and homelessness sector. This is important in enabling service providers to respond appropriately to complex situations where mental health issues, and/or dementia may be present. It is also important in achieving inter-agency collaboration and enabling PwD to access appropriate, stable housing and support services in a timely way.

An expansion of brain health initiatives among the homelessness population and the introduction of outreach cognitive screening would address current delays in people living in marginal and precarious housing situations receiving diagnosis and support.

Review the impact of social housing policy reforms on tenants living with dementia

There is a need for adequate and sustainable funding for SHAs and/or community organisations to enable housing providers to take on a duty of care role in relation to tenants who are experiencing dementia.

There is a need to address uncertainty about the role of SHAs in delivering an appropriate living environment for tenants with dementia and supporting tenants to access home-based support services. A comparison of best practice across the states and territories has the potential to reduce disparities and improve service delivery.

Any future reforms to the social housing sector need to review the impact of such reforms on tenants living with dementia. For example, reforms that further contribute to both declining tenant engagement and declining organisational knowledge about tenant needs reduce the capacity of housing providers to provide duty of care towards tenants living with dementia.

Expand affordable, service-integrated housing

The study has highlighted the importance of secure and stable housing for enabling PwD to live well in the community. It is also important that the house is relatively easy to maintain and is designed with accessibility issues in mind. Much of Australia's housing stock does not perform well on either of these measures. Across the board, there is a growing need for new housing options that are designed with accessibility in mind and access to onsite-services.

Service-integrated housing options for PwD, in particular those who have experienced housing and financial insecurity throughout their life, are limited. The gold standard in Australia is specialist housing provider, Wintringham Specialist Home Care².

There is also a need for additional housing options and support services for people with early onset dementia who are under 65 years of age.

Expand and innovate respite services

There is growing demand for a range of innovative respite services to ensure that family carers of PwD living in the community can cope and can continue to provide care. There is also growing demand for community services that offer PwD a chance to participate in meaningful and stimulating activities. Respite might entail regular activities outside the home and/or home visits so that the carer can leave the PwD at home safely, overnight and weekend stays, and/or extended stays. Accessing respite was viewed as critical to stimulating the PwD, managing high care burdens, and making transitions to residential care easier by familiarising the PwD with this environment gradually over time.

Finally, the report concludes by identifying potential future research directions. In order to enhance our understanding of the housing and support needs of older Australians, there is a need for further insight into: the economic context in which housing decisions by older people

² See: <http://www.wintringham.org.au/>

are made; supply-constraints in relation to new service-integrated housing models; the effectiveness of different housing models to support people to age in place; the costs to individuals of managing health and housing needs in later life, and the impact of care decisions on housing and financial stress; the specific housing and support needs of people under 65 who are living with dementia; and culturally-appropriate research in partnership with Indigenous communities about the housing and support needs of Indigenous PwD in urban, regional and remote areas.

1 INTRODUCTION

1.1 Research and policy significance

Over the past decade, dementia has gained prominence as a key health, aged care and social policy challenge. Dementia is predicted to become the leading cause of disability in Australia by 2016. Recent data analysis estimates that 298 000 Australians had dementia in 2011, with the number of people with dementia expected to reach almost 400 000 by 2020 (AIHW 2012, p.ix). Like other first world nations, Australia's population is ageing due to the combined effects of longevity and decreased fertility. Consequently prevalence of dementia is projected to increase into the future. AIHW (2012, p.ix) data indicates that the total direct health and aged care system expenditure on people with dementia in Australia in 2009–10 was at least \$4.9 billion, of which about \$2 billion was directly attributable to dementia.

Dementia is an incurable syndrome that impacts on higher cognitive functions, behavioural and psychological traits, and physical function. It is terminal, but with varied trajectories of decline. It is:

... associated with more than 100 different diseases that are characterised by the impairment of brain functions, including language, memory, perception, personality and cognitive skills. (AIHW 2012, p.2)

The most common types of dementia are Alzheimer disease, vascular dementia, dementia with Lewy bodies, and fronto-temporal dementia.

Dementia impacts on three levels:

1. Cognitive impairment—memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement.
2. Behavioural and psychological symptoms—anxiety, phobias, depression, paranoia, delusion, wandering, disruption, agitation, inappropriate dressing/undressing, repetitive behaviour, physical and verbal aggression, resistance to personal care assistance, inappropriate sexual behaviour.
3. Functional limitations—walking, using the telephone, finding their way, handling money, personal care, eating, drinking, continence (AIHW 2007).

Typically, dementia causes a gradual deterioration in a person's cognitive capacity and, as the severity of the condition worsens, people become increasingly dependent on carers to assist with many aspects of daily living. The course of dementia is described in three stages 'mild', 'moderate' and 'severe' (see Table 1 below).

In Australia, a substantial proportion of PwD live in the community; an estimated 70 per cent of all PwD, and this is expected to grow over the coming decades. However, as PwD experience progressive decline in their cognitive capacity, the option of remaining in their home becomes problematic (Karmel et al. 2012). People with late-stage dementia typically move into residential care accommodation in order to access more intensive support. It is anticipated that as the population ages there will be an increasing demand for limited residential care beds, and as a consequence an increasing number of PwD will be residing in the community for longer periods than has occurred previously. This raises concerns about the quality, accessibility and safety of housing in which people live, the security of the PwD's financial and housing situation, and the capacity for PwD and their families to access appropriate levels of support and care within the home.

In relation to policy development, A *National Framework for Action on Dementia* was established in 2006 to improve cooperation and coordination of health care responses across different levels of government (NSW Department of Health 2006). More recently, the Australian Government released its aged care reform package entitled *Living Longer, Living Better*

(Department of Health 2012), which included additional funding for dementia-related programs and services. Informed by the Productivity Commission's inquiry into *Caring for Older Australians* (2011), this funding was directed towards improving quality of care for PwD living in the community and in residential care facilities (AIHW 2012, p.7). The Australian Government's new policy framework, *Healthy Life, Better Ageing* (Liberal Party of Australia 2013) continues to identify dementia as a key national health priority.

A major shift in recent Aged Care policy is the introduction of Consumer Directed Care (CDC) (Productivity Commission 2011, p.xxviii). Consumer Directed Care introduces greater flexibility and choice in the provision and delivery of housing and health care. It aims to give older Australians greater choice regarding the types of care services they receive and the delivery of those services. Users are provided with information about the costs of particular services and they can opt for particular services and service providers. From 1 July 2015, all Commonwealth Home Care Packages will offer CDC³.

³ See: <http://www.myagedcare.gov.au/aged-care-services/home-care-packages>.

Table 1: Prevalence by severity of dementia [adapted from Morris (1993) and AIHW (2007)]

Score	Mild—CDR 1	Moderate—CDR 2	Severe—CDR 3
Memory	Moderate memory loss interferes with everyday activities—more marked for recent events.	Severe memory loss, only highly learned material retained.	Severe loss—only fragments of memory remain.
Orientation	Moderate difficulty with time relationship, orientated for place at examination.	Severe difficulty with time relationships, usually disorientated in time, often to place.	Orientated to person only.
Judgement & problem solving	Moderate difficulty in handling problems, social judgement usually maintained.	Severely impaired in handling problems and impaired social judgement.	Unable to make judgements or solve problems.
Community affairs	Unable to function independently, but appears normal to casual inspection.	No pretence of independent function outside of the home, but well enough to be taken to functions.	Appears too ill to be taken out.
Home & hobbies	Mild impairment of function at home, will abandon more difficult chores/hobbies.	Only simple chores are preserved, very restricted interests.	No significant function in home.
Personal care	Needs prompting for personal care.	Requires assistance in dressing, hygiene.	Needs much help with all personal care, frequent incontinence.
Overall dependence	Still able to undertake daily activities but significant impact	Independent living is not possible without assistance	Permanent supervision and assistance required
Prevalence Barendregt & Bonneux 1998 prevalence study	Estimated prevalence—55% of all PwD in Australia.	Estimated prevalence—30% of all PwD in Australia.	Estimated prevalence—15% of all PwD in Australia.
ABS SADC 2004 mapped against CDR	93% of PwD living in community.	4.5% of PwD living in community.	2.3% of PwD living in community.

1.2 Research themes and questions

The overall aim of this project is to equip housing practitioners and policy-makers with new knowledge into the future housing and support needs of people with dementia (PwD).

The first stage of the research focused on two major research questions:

RQ1: What is known about the links between housing and care provision for PwD?

RQ2: What are the current and projected living arrangements and housing pathways of people with 'mild, 'moderate' and 'severe' dementia in Australia?

In relation to the first two questions, the team have undertaken a comprehensive literature and policy review, as well as quantitative secondary data analysis of ABS and AIHW data. The results of this analysis have previously been reported in an earlier Positioning Paper (Gabriel et al. 2014).

The second stage of the research, which we report on here, focuses on three major research questions:

RQ3: How do people's initial housing circumstances impact on their housing and care pathways, including their transition into residential care?

RQ4: To what extent are existing community care programs able to adequately support PwD effectively across a range of home settings, particularly those in low cost and insecure housing situations?

RQ5: What policy responses and measures could better support practitioners, housing providers and family carers to respond effectively to the future housing and support needs of PwD?

In relation to Research Questions 3, 4 and 5, the team have conducted interviews with relevant stakeholders including service providers, social and public housing managers, social workers, PwD and their family carers, across two study sites, South Australia and Tasmania.

1.3 Recent research on dementia and housing

The study findings reported here build on an existing body of international and national research on housing and dementia. In this section, we provide a short overview of key themes emerging from the literature review conducted as part of this study. The review has previously been detailed in the first output of the project, the Positioning Paper (see Gabriel et al. 2014). The discussion is organised around: the significance of home for PwD, home modification and neighbourhood support, PwD living in low cost and marginal housing, and housing and dementia support services for Indigenous people.

1.3.1 *Significance of home for people with dementia*

International research on dementia highlights the significant impact of housing on the quality of life for PwD living in the community (Percival 2002; Oswald & Wahl 2004; Steeman et al. 2007; Hyde 2012; National Housing Federation 2013). One of the major advantages of PwD remaining in their own home following diagnosis is that the home is a familiar environment. As PwD experience cognitive decline they typically struggle to acquire new knowledge and skills, however they often retain the ability to perform previously learned skills, which rely on repetitive motions (van Hoof et al. 2010, p.206). In addition, PwD benefit from the sense of belonging that comes from being in a long-term home and the memories that reside within the home as well as the familiar objects that surround them.

A PwD's home is critical to their quality of life (Aged and Community Services Australia 2004, p.3). PwD are more likely than others in the community to be spending a significant proportion of their time in the home. Continuing to live in their family home and share their lives with family members is of primary significance in enabling PwD to cope with the challenges of loss of

memory function. Co-resident caregivers become a critical companion in supporting PwD to continue to undertake tasks they are competent in and assisting with tasks when the PwD experiences a loss in capacity (Steeman et al. 2007, p.128). PwD require appropriately targeted resources such as social support, in-home services and home modifications in order to reduce the risk of adverse developments such as self-neglect, self-injury, depression, and exploitation by others.

While managing dementia at home is difficult for PwD, the challenges are even greater for those who live alone (Nourhashemi et al. 2005). Living alone provides a great structural potential for social isolation and PwD who live alone are also at risk of self-neglect including poor nutrition (Alzheimer's Australia 2013, p.9). PwD who live alone have fewer choices in a service system designed primarily around the needs of informal carers and may transition to residential care because of a deficiency of options. Consequently, they are also likely to be admitted to residential care at an earlier stage of the dementia trajectory than PwD who live with another person.

1.3.2 Home modification and neighbourhood support

In general, Australia's housing stock has been designed to meet the needs of young families, without regard to accommodating the needs of older people, particularly those with limited mobility. However, there are a range of design interventions that can make a difference to the wellbeing of PwD (Hyde 2012, pp.6–7). In her overview of dementia and housing, Hyde (2012) identifies the multiple cognitive deficits associated with dementia that make everyday tasks difficult for PwD. These include difficulty with short-term memory, decline in ability to plan and execute complex tasks, difficult way-finding and 'mental maps', poor safety awareness, loss of visual acuity and other sensory losses, decline in balance and mobility, and increased depression and emotional lability. Given that dementia prevalence rates increase with age, many PwD are also living with multiple health conditions, which need to be considered when adapting the home and integrating appropriate assistive technology (Lawrence & Murray 2009).

Specific interventions that can support PwD include clarifying orientation by ensuring that destinations are clearly visible and visually distinct; installing appropriate lighting and contrast as low levels of light can create confusion; appropriate levels of auditory, olfactory and social stimulation; and personal space. These types of modifications may apply to either a private home or a residential setting. Common modifications such as the installation of grab bars, handrails, raised toilets, and ramps within existing housing stock can also make performing tasks easier, reduce accidents, and support independent living. The New South Wales Government in association with Alzheimer's Australia (Alzheimer's Australia 2011) has developed a comprehensive manual that details appropriate home modifications to support PwD to prolong independence within the home. It addresses a range of issues related to supporting PwD at home, such as neighbourhood wandering, companion pets, facilitating a calm environment and home-based activities that can engage and stimulate a person with dementia.

While the adaptation of housing can enable independence at home, other mainstream social spaces, including other people's homes, shopping malls, and recreational facilities remain inaccessible. In the UK, there is growing recognition of the need for dementia-friendly communities and 'lifetime neighbourhoods' that can support people to age in place at home (Mitchell 2012; Alzheimer's Society 2013).

1.3.3 People with dementia living in low cost and marginal housing

A key priority as the population ages is ensuring that older people have access to secure and affordable housing. The challenge of managing dementia at home in the community is compounded by problems of social and economic disadvantage and access to appropriate housing.

Existing research on the experience of older Australians highlights the role of housing wealth in supporting older households to age in place and retain quality of life. The majority of older Australians own or are buying their own home. Not only are owner-occupiers more likely to be middle to high-income households than rental households, they are also more likely to hold other forms of wealth such as savings, superannuation and shares (Yates 2012). In addition, property owners potentially have more choice in their housing situation and lifestyle as they are able to draw on the equity in their home to cope with changed circumstances (Jones et al. 2007; Wood et al. 2010).

In contrast, renters are more likely than home owners to be asset poor with little or no savings and inadequate superannuation. Among older renters, around half reside in the private rental market and the remainder reside in public housing. While the ageing population profile of public and community housing tenants has resulted in the emergence of new practice guidelines from state housing authorities and community housing providers and improved linkages between health services and housing, the issue of increasing rates of dementia has not been addressed in a systematic way. This situation contrasts with the UK where the housing sector is recognised as playing a critical role in alleviating cost burdens occurring in different parts of the care and health system (Andrews & Molyneux 2013, p.5) and housing forms a core component of a National Dementia Strategy for England (Department of Health 2009; Quince 2012).

Australia's ageing population has facilitated moderate growth and diversification of new models of housing and care directed towards supporting older people. Jones et al. (2010, pp.5–6) observe that this form of service-integrated housing is under-developed in Australia, compared with the US, the UK and Europe, particularly in terms of affordable housing options. In Australia, the public sector has only played a relatively minor role in the development of service integrated housing. Instead, a resident-funded model of financing has facilitated growth in service integrated housing through the community and private sector.

2 RESEARCH METHODS

2.1 Chapter overview

In this chapter, we provide an overview of the research methods. We begin with an explanation of the use of the terms dementia and memory loss during the consultation phase. In Section 2.3 we outline the consultation with housing and community care providers. In Section 2.4 we outline the consultation with people living with dementia (PwD) and carers in the community. Here we reflect on some of the challenges that arose with recruitment of PwD as well as the challenges with the interview process itself.

2.2 Defining dementia and memory loss

Memory loss is commonly used to describe dementia partly because an inability to recall recent events is often the first noticeable symptom of dementia and partly because it has less social stigma than the term dementia. While the terms memory loss, cognitive impairment and dementia are often used interchangeably, it is important to remember that while memory loss is frequently part of dementia, a person can have memory loss without having dementia. Similarly, cognitive decline is recognised as a key feature of dementia, but one can have cognitive decline that is not caused by dementia.

Based on advice received from previous researchers in this field, we decided to adopt the term 'memory loss' for the consultation phase of the study with both stakeholders and with people living in the community who are affected by dementia. The use of the term memory loss in preference to dementia is important for two reasons:

1. Not everyone with a diagnosis of dementia is accepting of this term. Dementia has a socially marginalised status in our society (O'Sullivan et al. 2014, pp.483–484). The term is readily associated with the final stages of the disease, and therefore there is an assumption by others that a person with dementia is without mental faculty and capacity.

Previous research (Pipon-Young et al. 2011; Robertson 2014) highlights that people with a diagnosis of dementia value engagement and conversation around their capacity and what they can do. The progressive cognitive decline of dementia is a major source of anxiety for people. In contrast, memory loss fits along a continuum, which everyone in our society experiences at some point. Most people have had the experience of misplacing their car keys or forgetting a name. This shared experience is valuable in an intimate interview setting. In our interviews, we were able to ask people how memory loss impacted on them in their daily lives and what strategies and technologies they used to remind them of important tasks such as taking medication.

2. There are many people living in the community who are experiencing memory loss that impacts significantly on their daily life and yet they have no formal diagnosis of dementia. From the housing service providers' perspective, they engage clients with a spectrum of mental health issues, cognitive impairment and memory loss, some of whom may have dementia. The boundaries of each of these conditions are not clearly delineated and service providers respond to self-reported experiences, behaviours and symptoms in the absence of explicit diagnoses. These clients are also a range of ages, including people with early onset dementia and younger people who may have impairment due to ongoing alcohol and drug use or an acquired brain injury. A key issue emerging in this consultation phase of the project was the lack of appropriate housing options and community support services for young people who are experiencing cognitive impairment, dementia and memory loss.

2.3 Consultation with housing and community care providers

The project team conducted individual and group interviews with housing managers, social workers and community care providers in two case sites, Tasmania and South Australia (SA).

They sought to consult with at least 15 service providers in each state in order to gain an understanding of the range of issues associated with supporting people with dementia to maintain quality of life in the community and the challenges associated with supporting people who live in marginal and low-cost housing situations. The reason for selecting these two case sites is that Tasmania and SA have the highest proportion of people aged 65 years and over (17.3% of the population in Tasmania and 16.7% in SA in June 2013) of all states and territories.

The project team consulted with 44 representatives from housing and community care agencies and services between May and October 2014 (Table 2 below). These contacts were identified through promotion of the project in a range of forums, through existing networks and through suggestions provided by participants who work in the housing and community care sector. In Tasmania, the research team interviewed 24 service providers across 10 agencies. In SA, the research team interviewed 20 service providers across eight agencies.

Table 2: List of participating housing and community care providers

Agency	Number of participants
Housing Tasmania—Policy	3
Housing Tasmania—Tenancy management	3
Community Based Support (Community organisation providing respite services and home modifications)	1
Advocacy Tasmania	4
Alzheimer's Australia—Tas and SA	8
DHHS - Assessment and Case Management Services, Community Dementia Service, Community Options	3
Centacare Homelessness and Tenancy Support	2
Migrant Resource Centre	2
Common Ground—Hobart and SA	2
Anglicare	2
ECH	4
Housing SA	3
ACH	1
Domiciliary Care	5
Repat Hospital	1
Total participants	44

For housing providers, the interview focused on: awareness and availability of services to support people with dementia in the community; awareness of tenants with dementia; capacity to liaise with health and support services; if relevant, direct experience of assisting people with dementia; capacity to identify signs of dementia; need for education and training around dementia; impact of dementia on tenancy; impact of housing and household situation on transition to residential care; and views on potential policy reforms (see Appendix 1).

For community care providers, the interview focused on: the major challenges associated with delivering home-based care and support for people with dementia/memory loss, particularly those in marginal housing situations; impact of recent reforms, including change in Home Care packages, the introduction of Consumer Directed Care (CDC) and the National Disability Insurance Scheme (NDIS); extent of communication and liaison between housing and community care providers; impact of housing and household situation on transition to

residential care; challenges in providing home-based care to CALD people with dementia/memory loss; and views on potential policy reforms (see Appendix 2).

The interviews were transcribed and analysed using NVivo. Framework analysis was used to organise and interpret the data (Ritchie & Spencer 1994; Srivastava & Thomson 2009). Framework analysis is widely used in social policy research. It is typically used to manage a range of qualitative datasets with the explicit intention of describing and interpreting what is happening in a particular setting. Framework analysis involves a five-step process: familiarisation, identifying a thematic framework, indexing, charting, and mapping and interpretation. While the researcher identifies themes prior to commencing fieldwork, the framework is refined in subsequent stages of analysis.

In this study, the first-round of analysis focused on identifying established themes (as outlined above) and new themes raised by participants, such as elder abuse and brain health awareness in the community. The second-round of analysis entailed looking for correspondence between themes and identifying the dimensions of three major themes: housing security, continuity of housing and support, and support and care needs within the home. In the final stage of framework analysis (i.e. mapping and interpretation), the researcher examines the data for valid associations and explanations, as well as identification of potential strategies and recommendations. Based on our consultation with service providers, people with dementia and family carers, we identified current policy gaps and scope for policy innovation in relation to housing.

2.4 Consultation with people living with dementia and family carers

2.4.1 Recruiting people living with dementia and family carers

The project team sought to conduct interviews directly with people with mild to moderate dementia in order to gain a better understanding of people's experiences of living in the community with dementia. Despite their cognitive impairment, people with mild to moderate dementia can retain the capacity to provide helpful insights into factors that impact on their quality of life and are often eager to do so (Wilkinson 2002). As O'Sullivan et al. (2014, p.484) note, 'Memory impairment does not affect the whole person'. It is also an ethical and methodological imperative to offer PwD the opportunity to contribute to research that could affect them and others with the disease. Direct participation in research acknowledges the unique personhood of PwD and can produce more reliable information regarding their preferences than the use of proxies. In the absence of the capacity for informed consent of the person with dementia, however, and with specific regard to carer services, the perspectives of carers and family members are also valuable (Livingston et al. 2010).

The National Statement on Ethical Conduct in Human Research (NSECCHR) notes that 'People with a cognitive impairment, an intellectual disability, or a mental illness are entitled to participate in research' (Australian Government 2007, p.65). However, the NSECCHR also makes clear that there are significant challenges with obtaining consent and that people with these conditions may be more-than-usually vulnerable to various forms of discomfort and stress. In response to both these concerns, the research team have outlined appropriate procedures for obtaining consent. This includes: obtaining consent from next of kin; obtaining verbal consent in the presence of a nominated, trusted carer; and following a model of ongoing or 'here and now' consent that responds to changes in participants' capacity to provide consent throughout the interview process. In addition, the team tried to minimise any discomfort or stress by following appropriate procedures during the interview process. This includes remaining alert to verbal and non-verbal indications that the participant is becoming tired or is any other way uncomfortable with the interview process, and asking participants whether they wish to take a break or discontinue the interviews, and to act according to their responses. Any refusal or distress from the person with dementia/memory loss was taken as refusal to

participate or withdrawal of previous consent. The wellbeing of participants was prioritised at every stage of the data collection process.

The project team sought to describe the experiences of 20 people who are living with dementia in the community (10 in each case site). The number was viewed as sufficient to allow the team to gain in-depth insight into the housing-related experiences and priorities of people with dementia. This number was also sufficient to allow the team to record the experiences of people living in different housing tenures: owner-occupation, private rental, and public/social housing.

The project team began recruitment in Tasmania and SA in July 2014, with the intention of completing interviews by September 2014. Instead, the project team experienced considerable difficulties with recruitment and the final interview was conducted on 16 December 2014.

The team did not meet the recruitment target of 20. Instead, the project team obtained insight into 12 households. Six people with dementia were able to actively participate and respond to questions. A trusted carer was present at three of these interviews. In a further two interviews, people with dementia were present during the interview, but did not participate significantly. Previous research emphasises that people with dementia prefer to have a trusted carer present at the interview and also for the carer to participate in the conversation. They typically respond as a dyad, in that they prioritise shared perspectives arising from the intense experience of the care-giver/care recipient relationship (see Orpin, Stirling & Robinson 2012).

Due to problems experienced with recruitment, the project team sought input from trusted carers. They made contact with carers initially to ask for permission to make contact with their care-recipient and, at this point, some carers expressed a preference to participate directly in the study without their care-recipient present. Four carers provided insight into their parent/partner's experience without their family member present.

Participants were provided with a plain language statement about the aims and risks of the study. They were also advised prior to the interview that it would take around 30 minutes of their time. It was also made clear to the participants that they could take a break from the interview at any time and that if they wanted to stop the interview then this was also fine.

Participants were advised that the study was about how people with memory loss managed in their homes. The interviewer did not use the term dementia throughout the interview (for the reasons detailed in Section 2.2). The interviews began by asking participants to tell them about their home, including how long they had lived there. As the interview progressed, the interviewer asked about the support they received in their home and how they manage at home with memory loss.

Participants were asked if they happy to be recorded to enable us to record their views. In Tasmania, two carers asked for the interview not to be recorded. In SA also, two carers asked for the interview not to be recorded.

At the conclusion of the interview, participants were thanked for their participation and reminded that they can refer to their copy of the information sheet for contact details if they have any questions or concerns about their interview. They were also provided with a \$40 grocery voucher in recognition of the value of their time.

The interview schedule addressed four themes: people's views on their home, how they are managing at home, their satisfaction with the support they receive in their home, and people's views of their neighbourhood (see Appendix 3). Interviewers also recorded demographic information.

The interviews were transcribed. The project team conducted thematic analysis, which entailed reading and comparing the transcripts of participants. They also compared the observations and findings that emerged in our study with insights from other studies, which involved small-scale qualitative interviews with PwD and carers.

Tasmanian recruitment process

The recruitment of potential interviewees for the study relied on valued contacts within key agencies. The first agency contacted was the memory clinic. The project team provided staff with information about the study. The team then asked the service provider to identify people in early or middle stages of dementia. The team explained that the study sought participants who are living in a range of housing circumstances: owner occupiers, private rental housing, and public and community rental housing. The team also asked the provider to identify people in different household types, those who live alone and those who live with their wife/husband. The provider put forward the names of seven clients and the trusted carer of four of these clients.

The team made contact with the five nominated carers to explain the study and to request participation with their parent/wife/husband. Of these five, two people agreed to participate. Three carers declined as their husband/wife/parent had other complex health problems that had arisen since they had expressed interest. One of these was the carer of his wife. She had recently moved into residential care. The other interviewee lived alone in an independent living unit. Her nominated carer was her daughter and she was present during the interview.

The two clients with dementia who were living alone and who did not have nominated carers were contacted by phone. The interviewer explained the study and requested that they be able to meet with them to explain the study further and obtain their consent.

The project team then made contact with Alzheimer's Australia and Advocacy Tasmania. While these agencies had provided valuable insights about people's experiences of living in marginal housing during the consultation with housing and community care providers, they were unable to provide any contacts who met our criteria, which was people living in low cost, marginal housing.

Given the problems we were experiencing finding participants, the team decided to broaden the criteria to include younger people who were experiencing memory loss as this was a critical issue that arose during the consultation with housing and community care providers. The project team presented an overview of the study at a homelessness forum to raise awareness of the project and recruit potential participants. The team also made contact with Housing Connect; an organisation which had recently been established in Tasmania to provide a single entry point for people to access housing support services. Housing Connect staff circulated an email message about the project to a range of agencies who work with people at risk of homelessness. This did not result in any new participants.

The project team then contacted three Community Care providers. One provider, District Nurses, was able to assist with recruitment for the study. The operations manager made contact with the next of kin to ask about their parent's participation in the study. She was then able to provide the team with the contact details of four potential participants. We interviewed three of these clients; two of whom were a couple living together (both had a diagnosis of dementia). The fourth potential participant was experiencing health problems and no longer able to participate in the study. Instead, we interviewed her carer about her experiences. In each of these four cases, the person with dementia was living alone in their own home.

Finally, through collegial networks the project team identified an associate whose parent lived in public rental. The team were keen for the study to shed light on the experiences of people living in a range of housing circumstances, but had experienced considerable difficulties achieving this through formal channels. Although a different method of recruitment was applied, it was highly valuable to have the input of a carer who could articulate the significance of housing security in her parent's life.

In summary, in Tasmania the project team interviewed six people with dementia; four of whom had their carer present. These carers provided some input into the discussion, mainly through qualifying key points raised. The project team also conducted interviews with three carers.

These interviews provided important insight into the carers' experience and were important in articulating the significance of housing security to their family member's quality of life.

Table 3: Description of Tasmanian interviewees

Participant pseudonym	Participant type	Carer present	PwD present	Housing tenure and type	Household composition	Date
John	Live in carer—husband	yes	no	Owned home	Couple (PwD now in res. care)	9 Sept
Anna	Person with dementia	yes	yes	Owned home—Leasehold, independent living unit	Living alone	12 Sept
Jack	Person with dementia	no	yes	Owned home	Living alone	16 Sept
Harry	Person with dementia	no	yes	Public rental	Living alone	23 Oct
Cassie	Person with dementia	yes	yes	Owned home	Living alone (daughter next door)	12 Nov
Bob and Jane	Person with dementia	yes	yes	Parents owned home	Couple	16 Nov
Lisa	Family carer—daughter	yes	no	Parent owned home	Living alone	27 Nov
Christine	Family carer—daughter	yes	no	Parent lived in public rental	Living alone	9 Dec

South Australian recruitment process

In SA, the project team experienced considerable difficulties reaching the proposed recruitment target and recruiting participants living in a range of housing circumstances. Consistent with the Tasmanian recruitment process, the recruitment of potential interviewees for the study relied on valued contacts with key agencies. Service providers who had participated in the first phase of consultation were able to provide referrals. Alzheimer's Australia, SA, assisted with this process, which resulted in one interview with a PwD and their carer. Seeking further referrals, the project team then contacted the Carers Association and advertised on their facebook page, but that did not result in any responses. The next stage of recruitment entailed targeting some of the council areas in metropolitan Adelaide where there are relatively high levels of public housing and private housing for low-income people. While the project team placed advertisements in community centres and spoke at relevant community forums, these efforts did not elicit any further participants.

Given the problems experienced with recruitment, the team sought participants through collegial networks. This resulted in three additional participants. Importantly, the team were able to speak to a carer who was living in private rental. It was highly valuable to have the input of a carer who could articulate the significance of housing security to their family member's quality of life.

Despite concerted efforts to identify potential people and then get them involved, only four households participated in SA. In two of these households the person with dementia was present throughout the interview, but they were unable to comprehend the questions and so the interview was with their partner and carer. In two instances the person with dementia was at respite care or was now living in residential care. The interviews with the carers were

informative and showed the individuality of each situation and what was appropriate in terms of housing, the neighbourhood and access to services from the carers' perspective.

Table 4: Description of SA interviewees

Participant pseudonym	Participant type	Carer present	PwD present	Housing tenure and type	Household composition	Date
Maria (and David)	Live in carer—wife	yes	yes	Private rental	Couple	10 Aug
Josie (and Alan)	Carer	yes	no	Owned home	Couple (PwD now in res. care)	11 Aug
Alice (and James)	Live in carer—wife	yes	no	Owned home	Couple and 3 adult children	22 Sept
Claire (and William)	Live in carer—wife	yes	yes	Owned home	Couple	16 Dec

2.4.2 Profile of people with dementia and family carers

Twelve interviews were undertaken with PwD and carers for the project. These interviews were focused on the experiences of 13 PwD; that is, 12 different housing circumstances, including a couple, both of whom had dementia.

Ten carers participated in the interview process. We spoke to four carers alone. In three situations the carers answered all the questions, but their family member was present.

Five PwD were able to respond to the questions and tell their story. In three of these situations, carers were present and provided input into the interview, but the questions were directed towards the person with memory loss.

The carers were predominantly female (nine out of ten). Four wives were supporting their husbands at home and five daughters were visiting carers. One man was supporting his wife.

A mix of men (n=7) and women (n=6) participated in the study. All the participants were 75 years and over; with seven participants aged 75–84 years and six participants aged over 85 years. Most participants were born in Australia, with one person born in Northern Europe.

In terms of their housing situation, six of the participants with dementia owned their house outright, two participants were living in public rental housing, one participant was living in a leasehold property in a retirement village, and one participant was living in private rental. Two participants had recently moved into residential care, with both of these people formerly living with their husband/wife in a home they owned outright.

Of those living in the community, five of the participants with dementia lived on their own with support from a visiting carer. Two participants with dementia lived with their wife/husband who was their live-in carer. Two participants with dementia were a couple who received support from visiting carers (their children). And one person with dementia lived with his wife who was his primary carer and three adult children.

2.4.3 Challenges associated with recruiting and interviewing people with dementia

The difficulties experienced by the project team with recruiting people with a diagnosis of dementia are not unique. O'Sullivan et al. (2014, p.485) observed that it took two years to recruit eleven couples. While they began by seeking referrals through service providers, six of the participants were referred through word-of-mouth about the study. They note that similar stories and concerns were raised across the participants recruited through formal and informal channels. There are numerous examples of studies in the field of dementia that rely on individual insights and small samples to explore critical and sensitive issues relating to the experience of living with dementia. For example, Robertson (2014) examined one woman's

perspective on the quality of life with dementia; De Witt et al. (2009) interviewed eight women with dementia; and Pison-Young et al. (2011) interviewed eight people with early onset dementia (i.e. diagnosed before 65 years).

Undertaking research with people with dementia is challenging if members of the research team are not attached to a clinic, service provider or hospital. The difficulties we experienced with recruitment highlights the importance of having established relationships with key agencies who work with PwD and, more broadly, the need for collaborative project partners in undertaking cross-disciplinary research. One of the key problems for recruitment in SA compared to Tasmania was the lack of an established relationship with important referral agencies prior to the study. In Tasmania, the project benefited from input from the School of Nursing, with Associate Professor Christine Stirling having previously recruited PwD who live alone through established contacts at the memory clinic.

This study faced additional difficulties meeting proposed recruitment targets due to our desire to talk to people in insecure housing situations. Service providers from key agencies involved in the consultation phase of the project highlighted the difficulties of finding people living in insecure housing situations. Most people who have established home-based support services in place or who have sought out community organisations such as Alzheimer's Australia are resourceful and are based in secure housing situations, either they own their own home or are long-term public housing tenants. Finding people in private rental situations was challenging and we were only able to find one couple who were renting their son's home. We did seek referrals from NGOs who are in contact with people who are living in low-cost, private rental situations, however, these discussions did not result in any participants. A key problem was that we tried to recruit participants in a relatively short period of time—four to six months. This made referrals difficult as NGOs are likely to engage with a very small number of clients with dementia and housing need for only a short period of time. A much longer lead-in time and greater engagement of agencies in the study may have generated more referrals.

Beyond recruitment, researchers have also highlighted the problems that can arise when interviewing PwD and using these transcripts to then make claims about the social world. Beuscher and Grando (2009, pp.2–3) documented their personal experiences of conducting a qualitative study of 15 persons with early stage Alzheimer's disease (AD). They identified three major research issues—obtaining consent, effectively communicating, and ensuring credibility and dependability of data. They noted that persons with AD are vulnerable because of their compromised decision-making ability and they recognised the need to seek consent from a surrogate or proxy decision-maker. In relation to effectively communicating, they noted that:

Mild difficulties in word finding, abstract reasoning, and following complex conversations occur in the early stages of AD. Individuals also experience fluctuating awareness and attention and concentration lapses in the early stages.

They emphasised the importance of conducting interviews in people's homes in order to reduce anxiety and distractions. They also emphasised the importance of using straightforward language and being flexible in restating questions in order to enable the participant to respond. They further emphasised the need to allow the person time to respond to questions and being alert to signs of fatigue. We demonstrated awareness of these issues when seeking ethics approval and employed these principles in practice.

Further, in relation to the dependability of the data, Beuscher and Grando (2009) noted the importance of a contextual understanding of the interview transcript, with the researcher relying on observational skills and marrying these with statements, as well as alertness to the message from a participant that is communicated through different comments throughout the duration of the interview. Existing research has also highlighted the value of building relationships with participants over time, which is best achieved through repeat interviews. For example, O'Sullivan et al. (2014) engaged participants in the research process over a period of

three to four years, enabling them to cross-check issues, explore sensitive topics and pursue a collaborative research approach.

While we were able to make observations about people's home environment and use this to elicit further information about managing at home in the interview, the study design did not allow for repeat interviews. Based on our experience in this study, repeat interviews would have provided a more detailed understanding of an individual's situation. However, a repeat interview would have also raised new issues as we found that people's complex health needs meant that their capacity to participate and their availability could change quickly. This was the experience of De Witt et al. (2009) who sought repeat interviews with eight women with dementia over an 18-month period, with two participants unable to participate in a second interview due to a decline in their health.

While in the UK and the USA there has been increased advocacy for the involvement of PwD in research, the attitude of service providers and carers towards the value of this in practice varied. Service providers advised us during the research process that it is important to include the view of carers. However, a study that recruited carers rather than PwD would have omitted the housing experience of PwD who live alone in the community.

In relation to carers, we found that carers are rightly protective of their family member and that they are reluctant to participate in an exploratory study that may not have direct tangible benefits. Carers don't want their family member to feel uncomfortable or to experience any unnecessary intrusions that may be stressful. They recognise their family member's vulnerability within the research process. For example, a PwD may not fully comprehend the aims of a study, they may feel anxious about getting answers to questions right, and they may not remember the interview experience. A PwD may also have complex health issues that can make it difficult for them to participate in a research project. Several carers were initially happy to participate, but then reconsidered and withdrew as they felt that their family member's health had deteriorated or they felt that participation would increase their mother or their husband's anxiety about their situation. The carer's capacity also impacted on participation in the research. Many people are under enormous stress due to high care demands and talking to a researcher is viewed as just an added burden.

More recently, the Scottish Dementia Working Group Research Sub-group (SDWGRS) (2014) identified six core principles for involving people with dementia in research. These include: informing people with dementia and their trusted carers/families about research and the outcomes, valuing people's input into research agenda setting and their knowledge, ensuring research is conducted in a safe and familiar environment for the person with dementia and the interviewer, keeping communication and research instruments simple, being respectful, informed and compassionate when conducting research, and rethinking notions of linear time, that is, stories may not progress linearly, conversations can be tiring and breaks might be needed, and changes in health might preclude people from participating.

Again, in our study, we sought to follow these principles. The idea of rethinking notions of linear time was particularly relevant to the interview process as sometimes questions would trigger unanticipated ideas and memories that were important to the PwD. It was valuable to listen to a person's story without interrupting and directing the person back to the question. The interview in this way took on a conversational form and we found out a lot about the things that were important to a person's life in the past and present. This rethinking of notions of linear time was also important in reporting back on the interviews. While there were sometimes contradictions in the historical accounting of events or in relation to the changes made to a home, our analytical focus was on people's expressions of attachment to the neighbourhood and home and anecdotes that described the lived experience of managing at home with dementia.

3 CONSULTATION WITH HOUSING AND COMMUNITY CARE PROVIDERS

3.1 Chapter overview

In this chapter, we present the results of our consultation with housing and community care providers. This analysis is based on the views of 44 service providers in Tasmania and South Australia. Here we examine service providers' views on dementia in relation to ageing in place and community support; early diagnosis and planning; social housing, including tenancy engagement and support; access to home modification and assistive technology; marginal housing and homelessness; and advocacy for people with dementia. We also examine the specific issues related to particular types of people who are experiencing dementia, including those who live alone, people who are Culturally and Linguistically Diverse (CALD), younger people with dementia, and those who live in rural and regional areas. Finally, we report on providers' reflections on policy reform, including the introduction of Consumer Directed Care (CDC), the National Disability Insurance Scheme (NDIS), and additional insights into policy gaps and innovation.

3.2 Ageing in place and community support

There has been a significant shift in our understanding of dementia within the community over the past two decades. Increases in the number of people affected by dementia conditions, advances in medical research, the availability of home-based care packages, and comprehensive advocacy and education programs from leading agencies such as Alzheimer's International and Australia, have all been critical in raising community awareness of the experience of dementia.

In the past, dementia was heavily stigmatised and a diagnosis of dementia was associated with significant and rapid decline in cognitive function and a pathway to residential care. As this service provider (SP) participant notes:

What do you get with the 'dementia' label? A bucket-load of discrimination. People weigh up what is the benefit of this. In our society, dementia has the same stigma as cancer used to have: should be in a nursing home. You lose control of your life. (SP 6 June 2014)

Today, the situation is changing. Substantial efforts have been made to encourage people who are experiencing problems with memory and associated behavioural changes to undergo assessment. Increasingly, people are receiving a diagnosis in the early and middle stages of dementia, rather than late stage dementia. As another participant noted:

[It used to be] this person has dementia, they should be in a nursing home, to a culture that says, yes this person has beginnings of something which is going to progress, but they're entitled for as long as possible, to make their own decisions and be supported. (SP 30 June 2014)

Among housing and community care providers there is growing recognition of the advantages of enabling people who are experiencing dementia to remain in a familiar environment.

The sector's taking on board this idea that supporting people to ageing in place, even with high and complex needs, even in marginal financial situations, yeah, and the advantages are just that familiar environment, and the person's social network, access to a social community. (SP 1 July 2014)

It's important to try and help people stay at home to not distort their entire reality by picking them up and putting them into a facility, because physically they may be fine, but mentally they deteriorate quicker in a foreign environment. (SP 9 May 2014)

Service providers noted that with a diagnosis of dementia, there remains a balance between supporting people to remain in their home and ensuring that they are not at risk of self-harm through poor nutrition, accidents and wandering. Service providers noted that there are risks of self-harm if people with dementia living in the community are isolated from adequate support:

There are other factors that we're seeing more commonly like malnourishment and dehydration, hypothermia where people with these kinds of cognitive decline issues, their self-care is really compromised and it's not an active decision not to do something, they just don't think about it, or they can't remember how to do something and so they tend to just withdraw into themselves. (SP 11 August 2014)

We want to support people to stay where they are as long as possible. We're challenging ourselves about what that means, but it may be that when certain people get to a certain point, that they do need to go to something slightly different. (SP 6 June 2014)

With greater understanding and service support, perceptions of the tipping point for moving someone into a residential home is shifting. This is certainly the case for PwD who live with a family member who can support them. In an ideal situation, this person plays a critical role in supporting people to retain their independence where possible through prompts and assistance with tasks. Where this is not possible, this person plays a critical role in reconfiguring the home or household practices to compensate for loss of cognitive function. A family carer can also support the person with dementia to be involved in the decision to transition to residential care.

Service providers observed that there was a need to work with family carers and try to establish a good, working partnership. They noted that caring for someone with dementia is hard work and often stressful and that there is a growing need for respite services to ensure that the carer can cope and can continue to provide care.

For somebody in a carer role for somebody who has dementia, I mean that is endless. It's not like a week or two for us sometimes in a stressful situation and there's an end point to it. What we try to encourage carers to do is to say, if you don't look after yourself, or give yourself permission to have a break, and things fall apart or you become unwell, that person can't stay at home on their own in most cases anyway. (SP 1 August 2014)

Service providers emphasised the importance of continuity of housing and continuity in available supports and care. Continuity was viewed as critical in enabling people experiencing dementia to maintain quality of life.

That would be the flag I wave is that need for continuity of care, particularly for people with a formal diagnosis of dementia. (SP 1 July 2014)

3.3 Early diagnosis and planning

One of the key issues raised by participants was the value of early diagnosis in improving outcomes for people with dementia. This is important in enabling the person with dementia to be able to maximise opportunities to be involved in decision-making and planning in relation to housing and care.

One of the things that would greatly assist to be able to keep people with memory loss in their own homes longer is if we can get them early. If we can get diagnosis early and get referrals early, because often we'll go in when the wheels have fallen off, so and that's really hard, because with people with dementia, you need to be able to build a rapport and not just with the person with dementia, but with the family member. (SP 1 July 2014)

If we can get in early enough and we establish that relationship with the consumer when they're cognitively intact and establish the relationship with the family, then I think

that the decision-making process even as the capacity begins to deteriorate, we can help protect that as much as possible and we can try and guide and really work with the family. (SP 9 May 2014)

The biggest issue we have is that people don't contact services until they really need them, and so therefore the acceptance of the service by the person with memory loss and their family is often difficult, often in a crisis, and often after long-term patterns have emerged. (SP 7 July 2014)

In some instances, it can enable people to transition into a better housing situation such as lower maintenance and improved bathroom design at a stage when they are still able to cope with new experiences and change. More often, it will simply enable the person to receive effective supports and to plan for increasing access to support to enable them to maintain quality of life within their home.

Participants noted that the social stigma of dementia means that often individuals and their families are reluctant to seek a diagnosis. As noted in a recent Alzheimer's Australia (2014) report 'Dementia often goes unrecognised or undocumented and can contribute to the needs of the person with dementia not being adequately met'. Without this diagnosis, people experiencing memory loss may be inclined to continue to try to manage as best as they can without seeking support that may compensate for loss of function and enable them to maintain quality of life.

The more family supports there are in place, the more likely it is that things will happen sooner, but not always. Often families are reluctant to admit that the person has dementia. Sometimes partners or families are embarrassed for them. They cover it up by doing things to support the partner or family member with dementia. (SP 6 June 2014)

The diagnosis of dementia to enable forward planning is difficult both from a service provider perspective and also from a health system's perspective. A hospital clinician in SA noted that:

People come into hospital and it is very obvious they have dementia, but it is not coded. People need to be referred to memory clinics, but these do not exist across the metropolitan area; or people with dementia are diagnosed late so when they are admitted to hospital they are going to need additional care. (SP 29 May 2014)

Early diagnosis was viewed as critical in supporting people in marginal housing situations, such as low cost private rental housing, group housing or a mobile home, and those who are living alone. With a diagnosis in place, people can be linked in with aged care and community services, receive additional support in their home, and their health and cognitive function can be monitored.

Yes. This is an area we're learning a lot about. We are starting to make links with different organisations that assist in that area, so we've made connections with Alzheimer's Australia and also been getting some of our tenants assessed, and also helping them link up with the memory clinic so that they can get the best possible assistance in the earlier stages. ... I think it takes a crisis to get things happening and so there's no room for stepped planning. (SP 15 May 2014)

One participant raised the need for further outreach in this area to locate people at risk, noting that assessment for dementia is currently a low priority in the homelessness sector.

Cognitive screening in that population [homelessness population] is very difficult as prioritised against housing needs, shelter, food, warmth—all placed on higher priority than dementia screening ... Outreach is key for people who are marginalised and itinerant who have difficulty accessing ongoing care. (SP 20 March 2014)

Sometimes people may experience a breakdown in their family relationships as a consequence of changes in their behaviour, which in retrospect may have been linked with their dementia. In other instances, unusual behaviours such as hoarding or becoming reclusive and socially isolated may be linked to dementia. Early diagnosis can clarify the reasons for behaviour changes for individuals and their families.

We see the extreme where relationships break down, but at same time we see the support given by family members—dementia can test that. That's where we step in, where complex relationships—fractured relationships, resentment, susceptibility to abuse—and certainly marriage breakdown because of dementia and then housing at risk. ... If they had had access to early diagnosis and appropriate supports and information, the situation may have been different. (SP 20 March 2014)

In addition, service providers can identify levels of family support and help a family member apply to become a guardian or have power of attorney for the person with dementia. If there is no family available, then case managers can make an application to the Guardianship Board in South Australia or the Guardianship and Administration Board in Tasmania and have a public guardian appointed.

3.4 Social housing: tenancy engagement and support

In relation to state housing authorities, the research team spoke to policy-makers, tenancy managers and support workers. Participants discussed structural changes in the social housing sector and the consequences of these for older people living in public housing who have high health and personal care needs, as well as specific examples of supporting people with dementia to sustain their tenancies.

Participants noted that while state housing authorities in the past had funded housing development that suited particular household types, young families and older people, this practice is no longer the case. Instead, these authorities have stepped away from developing targeted housing in response to concerns that this approach has led to a mismatch between the needs of current public housing tenants and public housing stock. While housing built for target groups by state housing authorities were viewed as the exception, participants noted that new build must conform to sustainability and universal design principles.

We don't build housing for particular population target groups, that's really quite problematic. We build a range of housing which could be appropriate for a range of users and our priority allocation system enables us to be sensitive to high needs. ... We do try to be flexible and universal in design so that we don't end up having a portfolio in 30 years time that is not suitable for a range of needs. (SP 29 May 2014)

In Tasmania, participants noted that they were seeking to better understand the needs of clients with high health and personal care needs. They identified a range of projects that sought to achieve this, including the development of the National Disability Insurance Scheme (NDIS) housing plan: the development of an Affordable Housing Strategy, and the establishment of a working group focused on positive ageing. (SP 29 May 2014)

In Tasmania and SA, there have been significant structural changes in the social housing sector. In Tasmania, this has entailed the establishment of a new central gateway Housing Connect, which operates as a one-stop shop for people seeking social housing and support. Tasmania has also recently transferred significant levels of public housing stock to community housing providers. These structural changes have been accompanied by a shift away from a supported tenancy framework towards a refocusing on core business, which is tenancy management (SP 2 September 2014). In this new approach, tenants are able to access support through a range of providers via Housing Connect. Participants noted that this meant that the SHA's understanding of individual tenant's circumstances was limited. They would only

be alerted to a tenant's circumstances if there is a breach of lease due to failing to pay the rent or anti-social behaviour.

Our records state whether a tenant is receiving a payment for having a disability or not; so it's just a simple yes/no. So we don't know a lot about the nature of their disability or what care arrangements that they'd have in place to support them. (SP 29 May 2014)

Participants noted that the service is moving away from approaches where tenants might receive tenancy plus additional support through Housing Tasmania. With growing recognition that client needs are complex and multi-faceted, the housing provider aims to ensure that appropriate referral pathways are followed and that clients can readily access a range of targeted, professional support services. Participants noted that the capacity for housing providers to take a more active role in supporting individual tenants whose tenancies are at risk is constrained by limited and declining resources.

Participants observed that property inspections were an opportunity to find out more about how a tenant is coping and whether additional support is required to maintain a tenancy. Tenancy officers were able to look for key signs that a tenant might not be coping, such as the deterioration of a property. However, they noted that there has recently been a shift towards longer leases. This is a result of changes to the *Residential Tenancy Act* in Tasmania, which requires tenancy leases to be a minimum of six months, as well as the rationalising of limited resources. While on the positive side longer leases provide security for tenants, they have also been accompanied by a decline in property inspections. For older people on longer term leases, there is limited capacity to monitor their circumstances over time (SP 2 September 2014).

In Tasmania, the approach in the community housing sector is similar to public housing. Community housing providers lack the resources and capacity to provide intensive support to tenants, but they recognise the need for timely referral to appropriate support services. They seek to engage with local services and ensure that there are adequate supports in place to enable tenants to sustain tenancies.

Being a place-based service we have networks with other service providers in the area. We are aware of services that our residents can link into so we can give a referral. (SP 27 June 2014)

However, limited resources remain a barrier to intensive, on-site support for tenants.

So we're a lean model. We have to be a lean model ... We can be their point of contact and link people in, but we would never be a case management type of service. (SP 27 June 2014)

Participants observed that the process of determining what is best for a tenant in terms of their housing is not straightforward. They cited cases of tenants whose health and personal care needs meant that their existing property was no longer appropriate for them. However, the idea of transitioning to a lower maintenance property with easier access was not necessarily embraced by tenants.

If we've got a vacant property that more meets their needs, we would much prefer to transfer that tenant into a property that already has modifications or it will be much cheaper to make any minor modifications. Our difficulty is in the main we get refusals from people to move and that actually makes it very difficult for us. (SP 27 June 2014)

They [SHA] offered her a unit that was wheelchair friendly and modified and she wouldn't go. One, that was about leaving the house, and, secondly, she had other family members that would come and go out of the house and it wasn't in the same area. (SP 1 July 2014)

Like Tasmania, *Housing SA is undergoing change and the Housing SA Blueprint 2013–2018* (DCSI 2013) is providing the 'framework for the modernisation of the housing and homelessness sector' (DCSI 2013, p.5). Over the last 12 months Housing SA has been developing and trialling a new service delivery model to 'invest in early engagement with clients to achieve long-term sustainable outcomes'. This new model includes a 'new team structure that focuses on services from initial access to support to ongoing place and tenancy management' (DCSI 2013, p.7). As expanded upon by a social worker for Housing SA:

This model will have an access team, a compliance team, housing officers and tenancy practitioners and then there are referral processes through to social worker or specialist service ... there will be more people to work with customers. (SP 7 April 2014)

In contrast to the Tasmanian situation, social workers in South Australia were optimistic that housing visits may increase and that frequency of visits might be flexible according to tenant needs.

We just started doing yearly housing visits in the last few years. Prior to that it was only every two years, so people do get overlooked. With the new model we're hoping the frequency of visits will be determined by customer need. So if we know it is an older person we may want to visit a bit more often. Part of this new model is trying to do more for less. (SP 7 April 2014)

While tenancy officers are unlikely to have specific training in the identification of symptoms associated with dementia, they are able to identify if a tenant is not coping.

Most of the Housing Officers have no formal qualifications. They come up through the clerical stream so Tenancy Practitioners will need some type of qualification or training. (SP 7 April 2014)

The more experienced housing officers are able to pick up risks more easily, but the lack of early intervention creates larger problems for social worker. (SP 15 April 2014)

Once they identify that a tenant is not coping, they will arrange for a social worker to meet with a tenant and talk through issues. Social workers noted that in relation to PwD, they try to engage the family in the process of identifying any behavioural changes or deterioration in wellbeing. They also seek to engage the family in the process of identifying care and support needs.

Depends on amount of family support and arming family with knowledge of supports. (SP 15 April 2014)

Sometimes it's about talking to family to see if they have noticed any deterioration in wellbeing, what can we do about it? Sometimes family don't care and sometimes they are really concerned and glad you called because they're not sure what to do. (SP 7 April 2014)

For our own housing clients we have a social worker, she works out what the problems are and tries to sort them out, and make referrals, and so she links with people, especially transition times when somebody is sick, or dementia comes along, or mental illness, or death. Then she'd be working with them to make sure they're linked in and have some supports around them. (SP 7 August 2014)

SA participants highlighted the value of effective support services to refer to such as the Mobile Assessment and Support Team (MAST).

We had a gentleman back a little while ago [who was] extremely thin and the Housing Officer on a regular visit was concerned. That afternoon, MAST sent out a community nurse who couldn't stir him and he was immediately taken to hospital. They worked on his mobility issues, memory issues and all kinds of stuff and he went home safely for four months before passing away. (SP 7 April 2014)

Participants flagged problems with the lack of regular property inspections and home visits as a barrier to identifying changes in people's capacity to manage at home and risks of self-harm.

One client had issues around hoarding and problems with maintaining property, but she has improved now. It is good for people to come on a regular basis to keep an eye on her. (SP 15 April 2014)

3.5 Access to home modification and assistive technology

Home design, home modification and assistive technologies were recognised as valuable contributors to enabling people to retain independence. Participants reflected on some of the simple home design issues that can work against people with dementia.

It's very difficult working with the current architecture to put those sorts of things in place and even with new developments, the current fashion is very modern, all the colours match, it's very soothing, but it's not necessarily helpful for someone who has vision issues and dementia. What they need is these things to be contrasting, so they can easily identify them. (SP 6 June 2014)

Housing is one of the major things we get wrong, and it comes from not seeing the world through the eyes of a person with dementia, but seeing it through the eyes of what looks nice. But it doesn't help the person to do things to remain independent ... Modern design is about neutral colours. Contrasting colour in bathrooms is now seen as old-fashioned. (SP 7 July 2014)

Participants emphasised the value of timely access to home modification. This did not always occur due to lack of education, lack of resources and waiting lists.

Yeah, definitely access to home modification in a timely manner because that's something that can make a huge difference. (SP 1 July 2014)

Participants noted that there was greater knowledge in the community about home modifications related to physical mobility and frailty, than around home design and technologies that can support dementia. These include bathroom modifications, grab rails and ramps.

Most design is focused on physical disability, not for blind people or those with dementia. There are wider doors, bigger showers, but less consideration of the need for contrasting colours, visual cues such as glass fronted cupboards. (SP 6 June 2014)

A sliding door on the toilet rather than an opening door, to accommodate a walking frame, and for people to get in to you if you fall over behind the door. Often, stand-alone toilets are too small to allow someone to turn around. (SP 7 July 2014)

The value of the home modification and assistive technology in supporting people with dementia was less well understood. The uptake of the range of measures as described in the NSW guide, *At home with dementia: a manual for people with dementia and their carers*, is relatively low (Alzheimer's Australia 2011). This is an outcome of lack of knowledge of these measures and how they can benefit people. Yet, there was recognition among aged care service providers about key modifications that can make a significant difference to quality of life. Continence management was viewed as particularly important in retaining people's independence. They emphasised the importance of being able to locate the toilet readily within the home environment.

Being able to coordinate the lights, so that when you get into bed, you can switch off all the lights from your bedside, and not have to walk around in the dark. And also, a bedside light that you can use to switch on the lights leading to the toilet, if you're in your own home. ... Being able to see the toilet from the bed, not hiding behind the door

as is usual in people's homes and some retirement villages. It's an ongoing argument between marketers and universal design. (SP 7 July 2014)

Sometimes it's as simple as putting a sign on the door to say it's a toilet and making sure the toilet can be seen. Sometimes a white toilet, white seat and white tiles can make it hard for the person to see the toilet. (SP 7 July 2014)

If dementia and incontinence are going to be the things that push you out the door because people say this person's not able to manage, then the relatively straightforward idea of illumination in the bathroom could be quite a significant factor in heading off that as an issue. (SP 6 June 2014)

The use of contrasting colours in order to distinguish between surfaces, furniture and appliances within a room was also recognised as enabling people to function more effectively within their home.

There was a man who was very agitated by the shower. The bathroom was all green—walls, sink, green curtains. He couldn't see where he was going. There was no landing and he couldn't distinguish walls from floors, taps and curtains. We broke that up with grab rails and though he didn't physically need rails they gave him some comfort so could step in over threshold and the mat on the ground was a different colour. Visual stuff is often important. (SP 20 March 2014)

In addition, in contrast to modifications for mobility and frailty, which are simple and standardised (e.g. a ramp is a good standard solution to difficulties negotiating stairs), modifications for people with dementia are most effective when they are tailored to the specific needs of the individual.

The other part is simply looking at things the person does regularly and what's needed, and how you can keep that going. So if the person wants to cook or make coffee—what is it that will help them? And so we say, glass fronts on the cupboards that you want them to be able to see into. If they want to make a cup of coffee, they can see what they need in the cupboard. If you ask them to find a cup, cup is an abstract concept. If you can see the cup, that's what you drink out of. (SP 7 July 2014)

Then there are safety and security issues around people's homes: locks on gates so that the family can keep a person from going out and getting lost. Deadlocks: a person with dementia might accidentally deadlock the door and not know how to open it again, so that no-one can get in. So it's about finding doors, locks, ways in and out that will give a person some independence. There is no one solution to that. (SP 7 July 2014)

Participants noted that people with dementia find it difficult to adjust to new home environments and instead they rely heavily on past practices and routines around the home. Therefore, any interventions and modifications need to work with rather than against, these practices.

As a generalisation, the older generation tend to turn everything off at night because they don't like electrical appliances on. And they turn power points off even. You can't try to sort of fudge it by putting a sign on. (SP 1 July 2014)

In addition, the needs of people with dementia who are experiencing deterioration in their cognitive function change over time.

People often don't know what they want or need, so when they're buying a housing unit from us or another retirement village, they're downsizing, they're looking for the beautiful white bathroom, the gourmet kitchen and don't want to see the toilet from the top of their bed. However, further down the track they're going to need it and retro-fitting is expensive and awkward. The ideal is to look like a universal design rather than a disability design. (SP 7 July 2014)

Tenure was identified by participants as a factor in accessing home modifications. Home modifications are more readily available to home owners, who can afford to make these changes with government-funded assistance. In contrast, private rental tenants are less likely than home owners to make home modifications as they face both problems with lack of affordability and the need to gain the landlord's consent.

Modifications to homes, issues with landlords, approvals, the landlord may not want to deal with a tenant with advanced dementia. In one case, a landlord wanted to evict, there was rubbish piling up. (SP 9 May 2014)

We have a service called Stay at Home, which is a service that provides advice and access to builders who are vetted by us, who would be able to make adjustments. Often they would cut down the side of a [shower] hob so that the person can get straight in, or they might take the bath out so the person has better access, and there might be some negotiation with the landlord around that. (SP 7 July 2014)

State housing authorities in both SA and Tasmania are able to match tenants with appropriate housing and to respond to recommendations by occupational therapists regarding the need for minor home modifications. Where modifications were unable to adequately meet the needs of residents, then the resident would be supported to transition to a unit that was better suited to their needs than their existing residence.

Cottage flats are better for people with dementia, rather than walk-up flats, but you need the family to initiate change in housing. (SP 15 April 2014)

Smart and assistive technologies in the home are evolving. In combination with support from carers, they may play a more significant role in supporting people with dementia to remain in their homes in the future. Some of these assistive technologies have become standard within homes.

Also, simple things like cut-offs on kettles, a beeper on the fridge for when the door is not shut. Anything you can retro-fit: heat regulator taps, taps that are easy to turn, and with a red or blue sticker or the words hot and cold on them. This is a prompt without having to be told. It aids independence, as it is easy to identify which tap is which. (SP 7 July 2014)

Heat pumps are ideal for our clients because they can be set, left on, pop the remote somewhere so it doesn't get turned off. (SP 1 July 2014)

Well, I mean, they've got the telephones where you can just put in a person's face and the person can just touch on the actual picture where they can't remember a number anymore, that type of thing. (SP 1 July 2014)

Participants reflected on some improvements in new design of housing that targets older people:

We have units that are beautiful for people with dementia, openly laid out so there are lots of visual prompts for people, but at the same time we have a lot of older units as well, which are small, very narrow spaces, things are easily hidden. It's a bit labyrinthine, or as regards wandering, the path leads straight out onto the road and so that's the logical place for people to go, rather than some of our units which have the circular courtyards in the middle, and so if you do go for a wander, you follow your path, meet your neighbours, interact with whatever is there. It's a good feature. (SP 6 June 2014)

The new building across the road: the apartments are a bit larger and easier to manage for some of the older people. And there are staff there during the day. (SP 15 May 2014)

3.6 Marginal housing and homelessness

The research team asked service providers about the challenges faced by people in marginal housing situations, including low-cost private rental, boarding houses, and caravan parks, and those at risk of homelessness. The team also interviewed providers from supported accommodation facilities about the services available to their tenants.

In relation to marginal housing, service providers' noted that there were more support systems in place in public rental compared with private rental.

People in a community housing situation have some safety net, but those living alone in, for example, private rental housing, who might get moved on because they've done something, and are not understood and have no support, are the ones who are really vulnerable. Housing design must also be affordable, in addition to technological modifications. (SP 6 June 2014)

In marginalised housing the issues are magnified when there is no support, that is, no family support, no advocate apart from us as a service provider. But there are limitations. Often when we hear about it, it has come to breaking point, so instead of being dealt with early in the system, we are fire fighting. (SP 9 May 2014)

As to be expected, private rental was viewed as higher risk, with outcomes dependent on the discretion and understanding of the landlord. Service providers noted that home modifications for private rental were less likely to occur for a range of reasons: tenants not wanting to alert landlords to problems with coping, landlords refusing modifications, and tenants unable to afford costs of modifications.

She has a certain habit of, if she's at home alone, lighting a fire, and she set her house on fire. Their house was damaged, they had nowhere else to go, they were both on Centrelink; they have no back up. If their private rental landlord wasn't understanding they would've been homeless. (SP 1 July 2014)

This lady was a new [SHA] customer. She presented at the front counter with a letter from the landlord saying he was not going to renew her lease. (SP 15 April 2014)

There is an unwillingness to adapt the environment in private rental. (SP 20 March 2014)

Service providers discussed the financial hardship experienced by tenants, which might relate to rental costs and power bills.

There are a lot of elderly people, particularly if they're in private rentals, who can't afford the power bill, you know the power bills are huge, so they're sitting there freezing. (SP 1 July 2014)

In one case, a landlord wanted to evict, there was rubbish piling up. It's about making sure a good system is in place to support that person. They can forget to pay the rent. It can easily be resolved. It is a matter of someone being able to work through it, for example, let's put \$50 a week towards gas or electricity, or setting up systems to help. (SP 9 May 2014)

Financial hardship combined with the onset of dementia can also potentially trigger homelessness.

I can reflect on some issues I see where people have been living in very marginalised communities and very vulnerable housing situations. They have forfeited independent living and essentially some become homeless because of dementia and not having the ability to manage housing needs. (SP 20 March 2014)

Service providers also noted that there can be differences in expectations about standards of living that may make it difficult for a person to receive home care. While declining home maintenance and housework might indicate problems with coping, hoarding behaviour, or in extreme instances, squalor, might indicate complex mental health issues.

We're very mindful for us that we're aware we're going into their home, whether it's private or rental. ... it's more about respecting the way that they've chosen to live their life. You know, we go into a variety of houses and some have ... they've lived their life in certain ways that you or I might walk in and think, Oh my God, I couldn't stand it, you know, this is so dirty, or I would never do that. So you have to sort of work within that. (SP 1 July 2014)

Certainly as part of the aged care assessment program, there's an assessment of their environment ... There are obstacles in terms of some people's homes in that if the home itself is unsafe for whatever reason. A lot of the private providers of services like personal care, showering or domestic assistance won't send their workers in because of the occupational health and safety risk for their workers. Usually what will happen is we try to work with them through our case management service to make the place accessible to the point where the providers will come back in. That's not always possible though particularly with a significant number of people who are living in severe domestic squalor or who hoard and it's literally, you can't get out of the back door or can't get into the bathroom. (SP 11 August 2014)

Service providers also recognised that particular housing situations such as living in a caravan can become problematic as cognitive function declines and care and support needs increase.

They'd moved into the caravan thinking this was their dream retirement and it went very differently to how they'd planned. Night wandering, night wakefulness, she was hearing other noises within the van park, so there was just the lack of physical security at the van ... And then also the lack of adequate hygiene arrangements. They could birdbath in the van but they couldn't shower, so that meant they had to then go across the park to communal laundry, and showering, and it was just not ideal at all. ... Ultimately they got private rental in the town near one of the children, and then with further advocacy they ended up with department of housing. (SP 1 July 2014)

Service providers emphasised the importance of inter-agency collaboration and the need for ongoing case management to ensure that people with complex needs at risk of homelessness were able to continue to access the supports they required. They also highlighted the need for outreach cognitive screening as it is unlikely that this population would attend dementia specialist clinics.

We actually had a case conference where we all came together and discussed the dynamics, because we were all seeing different bits. I'd do it on a more frequent basis for complex people, because I think it's the quickest way to tie everything together and get everyone on the same page ... So we've actually got some collaborative processes going on. (SP 1 July 2014)

So he was referred to our service, managed to get him into a tenancy that's for older people outside of the city But now we also talked about getting a Guardianship order on him because he lends money to people in the complex, doesn't remember whether they've paid it back. He doesn't know how much money he's given them. So short term memory loss. Part of our role is to assist him with accommodation, but you can't just, oh well, they're in now, they're fine. You can't just close them off. (SP 27 June 2014)

However, where resources are limited and care needs are high, there can be a push towards transition into residential care.

There is a very strong philosophy outcome that residential care solves everything, where everyone who is old and problematic needs to go. The policy is that residential care should be the last option, but it is not translated into practice. Majority of my time is trying to keep people out of residential care, to sustain them living in the community as long as possible. (SP 20 August 2014)

There's been at least one incident recently where somebody is now going to be placed in an aged care facility earlier purely because we can't get people into prompt and we do things like go to the GP or the specialist and say, look, is there any way that they can just have the one medication period per day because at least we might be able to get somebody in there once a day, but in her particular case, she needed twice daily. There was no way around that and it just can't be provided in the current climate, so she's going to end up, unfortunately, in an aged care facility probably earlier than she otherwise would have needed to be over one thing. (SP 11 August 2014)

I do think dementia provides blinkers to many of the medical profession—not all, but certainly going into hospital, a lot of things are attributed to dementia, and they will have more frequent presentations. They become a financial burden on whichever local hospital it is, and they go OK, they're presenting too frequently ... into a nursing home. (SP 9 May 2014)

People living in supported accommodation facilities can access regular support and intensive case management when required. Supported accommodation providers observed that memory loss in relation to alcohol and substance abuse and exposure to trauma were present among their resident population.

Service providers raised the problem of the lack of appropriate, affordable housing options for people who have complex needs and who are marginally housed.

You can't send anybody to that boarding house that ... cannot stand up for themselves, and unfortunately a lot of people that go there, that's our last resort to put people into But sometimes you're forced to do it because there's no other options. (SP 27 June 2014)

Service providers were concerned about declining investment in public housing, which would limit affordable and stable housing options for people in the future.

For marginalised groups the priority is to get them some sort of housing. Services are stretched, funding is low, and actually de-prioritised as to whether housing is suitable. This is a roof over their head ... a choice between being homeless and supported in housing. (SP 20 March 2014)

Despite recognition of the prevalence of mental health and cognitive functioning issues among people at risk of homelessness, links between dementia services and the homelessness sector are relatively undeveloped. Across the two case sites examined, there was greater evidence of collaboration underway in South Australia, compared with Tasmania. Common Ground in South Australia had established links with Alzheimer's Australia, and there was a growing awareness of the need for dementia assessment and practically how to access such assessments for tenants at risk.

Alzheimer's not on radar of homelessness services until this project started—everything tends to be referred to mental health, but mental health has a different focus and so continually fall through the gaps ... What I am going to be doing is working with homelessness services to raise awareness of dementia and different types of dementia and how it impacts, and look at how we can create pathways, but key to it is outreach cognitive assessments. (SP 20 March 2014)

Service providers emphasised the value of raising awareness of brain health in the homelessness sector and facilitating access to assessments of dementia. While Alzheimer's

Australia have recently undertaken project work on homelessness and dementia, service providers also noted the need for further research on homelessness dementia risk factors and the need for programs that can target potentially modifiable behaviours that place people at risk of dementia.

We are focusing on two main things at the moment: brain health and palliative care, because some of our tenants are very frail and are embarking on a death and dying process. (SP 15 May 2014)

Big thing is to raise awareness of [the] prevalence [of] risk factors seen in homelessness. There are a whole heap of potentially modifiable behaviours for marginalised people and there are people from multi-cultural migrant backgrounds, who may not have health literacy to access appropriate health supports. (SP 20 March 2014)

3.7 Advocacy and guardianship

A key issue identified by service providers was the increasing need for independent advocates to support people with dementia to make decisions about their housing, health and finances. They noted that there was a growing need in the community for good, independent advice to support people through the process of managing their home-based care.

PwD need one person who is an advocate who is not the person's spouse or child, who can negotiate with GP, health system, and the aged care system. Need a dementia link person—a person with good life skills, communication skills, a person who can match problems with solutions. This could be a role for retired nurses. (SP 29 May 2014)

Some people with mild dementia might not need a service package, but just a contact person they trust, a case manager who can introduce or refer them to things as they are needed. They might be functioning fine but struggling with knowing where to go, and need help to negotiate that tricky level before they get to the point of needing more services. (SP 6 June 2014)

They also noted the growing need for good, independent advice to support people through the process of moving to a more appropriate home or selling their home in order to access residential care (SP 30 June 2014).

How often is it dealing with the end issue and not the preventative issue? Probably a reasonable amount, especially with people in unsuitable housing. To make the move to more suitable accommodation while capable, even if you had a modest house, you could sell that and use the proceeds to move into an independent living unit. But you would need an independent advocate to do that for them. With that lady's advanced dementia, it was hard for her to accept any change, so at a previous time when she was more flexible, it was more of an option. (SP 6 June 2014)

The need for advocacy is particularly critical for people with dementia who are living alone and who do not have family support.

I think it's going to mean they will need access to advocates if they don't have a concerned family member or friend. So we routinely hand out packages of information to everyone we assess just so that there's some connections for them, but again, it relies on a bit of initiative on the person to actually feel that they need that. (SP 11 August 2014)

Some service providers were involved in identifying family members and consulting with them about the person's planning in relation to housing, health and finances. They noted that there can be differences in opinion about future care needs and that this requires negotiation.

We do recognise in our professional capacity when a person is no longer able to manage safely in the community and when we've got jurisdiction, and we do take the necessary steps. That sometimes causes great difficulties, especially where there are families involved. In one case there was a family perception that Mum needed to be placed, although Mum didn't want to be, and was managing in the house, which was clean, she was showering and cooking. ... Because her memory is fading, it doesn't mean an automatic placement. But placement takes the pressure off the family. (SP 20 August 2014)

When relatives are unavailable or unable to take on the role of Power of Attorney, then there is a need to apply to the Guardianship Board and have an independent administrator appointed.

Service providers raised concerns about the rise in elder abuse in the community and identified the need for greater community awareness about this issue. They noted that this was an issue in relation to housing as the high costs of quality residential care may encourage relatives to delay this transition without regard to the person's health care needs and without adequate family supports to compensate for loss of function around the home (SP 30 June 2014).

They emphasised the need to get an independent administrator in place when family members are unable to manage their relative's finances and when conflict arises within families.

So we'd encourage families to do the application [to the Guardianship Board] unless, you know, we're concerned that there is some wrong doing going on. But sometimes if families don't feel able to do that, it all sounds a bit daunting about an application to the Guardianship and Administration Board, then the case manager will do the paperwork. (SP 1 July 2014)

A key issue specific to the Tasmanian case was the high cost of Public Trustee fees compared to other states and territories. A recent report by Advocacy Tasmania Inc. and Community Legal Centres (2014) notes that persons with a decision-making impairment whose funds are administered by the Public Trustee of Tasmania are charged almost \$1500.00 per annum for a service that the majority of other states or territories provide either free of charge or for a nominal fee. The report advocates a fair and proportionate fee structure, which would enable people with limited means to access help without hardship.

3.8 Social isolation and living alone

While managing dementia at home is difficult, the challenges are even greater for those who live alone. The growth in people with dementia living alone is part of a general trend towards single person households in the developed world and also a consequence of population ageing. A report by Alzheimer's Australia (2013) found that PwD living alone are less likely to have a formal diagnosis of dementia, due to a lack of ongoing interactions with intimate others who could observe changes in memory or behaviour and bring them to the attention of the person with dementia and/or health professionals.

Participants reflected on the challenges associated with providing PwD at home with adequate support. Also, an individual might be resistant to accepting a diagnosis of dementia and receiving services in the home.

It's sometimes a lot harder to get in the door if they're living alone. ... Sometimes we can't get into the home because there is a lack of insight, that is, there is no issue. Sometimes it can be as basic as not being able to use a phone properly, or to recognise what has happened on the other end of the phone. (SP 20 August 2014)

Participants raised concerns that sometimes there were gaps in service provision and that there is no co-resident carer to address these gaps. For example, the need for regular prompts to take medication and limited service access over the weekend.

Some people can live alone reasonably successfully if they've got a good service and good supports, and regular activities so they are occupied. So if the person goes out to some sort of a day service, like a club, where they get a good meal in the middle of the day, have interesting activities, physical as well as cognitive and social, they can go home at the end of the day, quite happy to eat something less. Then they can have a service that will prompt them to go to bed. But the weekends are problems, as there are no weekend services because they cost more. So people can get lonely and lost. (SP 7 July 2014)

A person who is living alone may lose their routine ... so they may not sleep, and if they don't sleep, they don't have somebody in the middle of the night saying go back to bed, it's night time. So they might be up all night doing things and then sleeping during the day. They're all mixed up, and so therefore their whole pattern is affected, and nobody is aware of it. (SP 7 July 2014)

There are some clients who have no-one else in their lives—no family or friends—and we are like a surrogate family member. We do a lot of things for them, because there's no-one else to do it. You would probably spend more time working with them because you have to follow up on most things. You don't rely on the carer, you have to check. (SP 20 August 2014)

Living alone puts people at risk of social isolation. The term 'social isolation' refers to 'the separation of individuals from others, especially a lack of strong social ties' (Smith et al. 2009). Social isolation has both physical and psychological dimensions; perceived isolation and a dearth of enacted interactions both contribute to a decline in wellbeing. Participants emphasised the importance of community activities in reducing social isolation.

So we've looked at people that—if you look at the evolution of HACC over the last decade, we moved from doing things for people, to acknowledging that there's more than just cleaning and getting in and out of bed that are in people's lives. So there is a lot more in terms of social type programs. (SP 30 June 2014)

Social isolation [is] huge in public housing communities, and dementia exacerbates that. (SP 15 April 2014)

Participants noted that people with dementia who were living alone were at greater risk of wandering, accidents around the home, poor nutrition and exploitation.

Those living alone are unable to report accurate deficits in their current living arrangements. A carer can add clarity to their current situation and/or function. It is not a one-size-fits-all approach to helping somebody to help remain at home. A lot depends on whether [they are] living alone or have additional support. When they are on their own, they might let anyone in the door. They're vulnerable, open to theft, assault. On the other hand, there are some really good neighbours around, who interact positively and who are very supportive. (SP 20 March 2014)

Participants discussed the difficulty of trying to determine whether or not the person is at risk of harming themselves by remaining in their home and, subsequently, to determine how to support clients to make the transition into residential care.

There are far better outcomes for people who stay home, usually, but there's also a point at which it's no longer safe to stay home and examples of people who routinely set things on fire on their stove or if you disconnect the stove, they leave food out on the benches that spoils and then eat it, those sorts of things, or that they forget that you're meant to use the toilet to attend to your personal hygiene needs and that will be evident through the house and so there is a point where support is not enough in the community setting. (SP 11 August 2014)

3.9 Culturally and Linguistically Diverse communities

There are currently a range of services in place to support older people from Culturally and Linguistically Diverse (CALD) communities, including those with a diagnosis of dementia. Agencies with CALD expertise are involved in positive ageing initiatives, delivering culturally appropriate training to mainstream health and community service providers, and delivering home care packages. They can add value to home care support by providing translation services, ensuring that culturally appropriate assessment tools are used, being sensitive to cultural differences and priorities, and linking people into services within their community.

CALD communities are listed as a special needs group under the Aged Care Assessment program so there's recognition of that [and] as part of the assessment, confirm their country of origin, their preferred language at home. (SP 11 August 2014)

Consultation with providers highlighted that, in CALD communities, dementia can be associated with experiences of trauma and pre-mature ageing as a consequence of extended periods of hardship and nutritional deficiency.

People, after long periods of time in refugee camps and/or detention, have premature ageing. The connection between trauma and memory loss and dementia is really important. (SP 28 August 2014)

Also, people have lived in wars and depression, and have migrated. Feelings of paranoia and suspicion can come back. With a stricter culture, many aspects come into force. As a provider you have to fully understand what is offensive and what is not. It can be any innocuous thing that can produce a behaviour which they are unable to explain to you, and is often seen as aggression or challenging behaviours. (SP 9 May 2014)

There are also specific issues around communication and dementia in CALD communities, with PwD tending to lose English and instead speaking their first language and the particular dialect that might be. Issues may arise with differences between an older family member who is using language and dialect that second generation migrant children are unfamiliar with (SP 28 August 2014).

Many people revert to their original (childhood) language. So, if there is no carer to interpret for them, it can make life difficult. Even in general communication, it is more complicated with people with dementia. (SP 9 May 2014)

Participants observed that within CALD communities there can be differences in understanding about dementia and that there may be resistance to diagnoses due to stigma about dementia.

The other thing is that different cultures have understandings around or differences in understanding dementia and there are still some senses sometimes of shame with dementia, a sense of the person just [having] a complete lack of understanding that dementia is a life-ending illness, that it actually [means] you will die from dementia, rather than it's just part of getting old. (SP 28 August 2014)

Many culture groups don't talk about it, partly because it's shameful, or seen to be, like mental illness, a stigma. So they try to manage it. I think a lot of families also feel that it's their duty to look after their parents and not to use other services, and often that duty is through gritted teeth. (SP 7 July 2014)

Services were also available to assist older people from CALD communities and their families to make decisions about transition into residential care and to seek out appropriate respite care.

We have people do respite in nursing care and test it out. ... there are places that are better than others, there are places that have really strong cultural connection and cultural activity. (SP 28 August 2014)

3.10 Service gaps for people under 65 years who have early onset dementia

A key issue raised by participants was the specific needs of people under 65 years with early onset dementia and younger people who are experiencing memory loss as a consequence of drug and alcohol use. Participants were concerned about both the lack of appropriate housing options for people under 65 years and home-based support services.

People with younger onset dementia is a group that often gets forgotten because they're not seen as older. They don't fit into aged care or mental health. There's a lot more of it happening now: a point to raise about their special needs and how we address their situation. (SP 6 June 2014)

Participants observed that people with early onset dementia was a grey area, neither recognised as a disability nor an aged care issue. People under 65 years faced problems accessing an Aged Care Assessment in order to qualify for an aged care package (SP 1 July 2014).

But we do have a significant number of people who are under 65 that we're ending up having to assess for aged care placement because disability services are sending us letters saying we can't support their level of need. (SP 11 August 2014)

They noted that there was also a lack of awareness in the community about dementia among people who are under 65 years. This can delay diagnosis.

[Getting a diagnosis of dementia] is such a big issue for people who have younger onset dementia, because it's not the first thing that you think of. They think it's stress, depression, anything else apart from dementia, so even just to get Centrelink to recognise that someone has dementia and that they won't recover from it. It's a huge issue. Yes, and that it's a terminal illness, they're not going to get better in the next two years. In fact they'll get worse gradually. (SP 1 July 2014)

There is an assumption with dementia that it happens only to people in their 70s or 80s, but it's happening to people much younger than that. It's not talked about. (SP 15 May 2014)

When [it] comes to dementia and a dementia-friendly society, people tend to focus on aged dementia, Alzheimer's, and very little flexibility is afforded to younger people and more frontal-temporal presentations. There is less tolerance to younger people. (SP 20 March 2014)

Participants observed that placing PwD in their 40s and 50s in residential homes with older people was not appropriate. However, there were few options for younger people, some of whom have young children.

I had a client who had alcohol related dementia and basically he'd been in hospital for a long time and there was not really any appropriate place to place him where he could get the care that he needed, which was semi around the clock. So, he ended up in a ... home for people who have disabilities, so cognitively he was quite fine. Some of his decision-making wasn't great, but a lot of other people around him were, well certainly different to him in his level of disability. And you could see that he was quite uncomfortable in there, so he wanted to get out. (SP 1 July 2014)

They also noted gaps in terms of community programs and in home support services.

Services for clients who are early onset dementia—someone in [their] 40s, not aged, so no aged care services, no youth services, falls through gaps. (SP 15 April 2014)

People have [an] understanding of Alzheimer's type dementia and may be a little bit more benevolent about that, but young people have frontal/temporal dementia [which] presents aggressively as volatile, irrational, no tolerance, and [we] have examples of [them] being moved out of a rental group as [it] didn't suit neighbours. Appropriate supports would enable [that] person to stay in [the] community longer. (SP 20 March 2014)

People need to engage in a social connection, to keep themselves going, and for people with younger onset dementia, that's the most important thing. Social support doesn't just mean someone coming in for a cup of tea, but meaningful activities such as walking or bird-watching. (SP 7 July 2014)

Participants were hopeful that the NDIS would address this service gap.

I'm hoping that the [NDIS] Scheme, whatever it ends up looking like, will somehow help to provide community-based support because it's not fair for someone 45 with dementia to end up with 90-year-olds. It would be better if they could be supported somehow in the community, whether that's alone or in some sort of group accommodation, but with people of an equivalent age. (SP 11 August 2014)

3.11 Servicing rural and regional areas

Participants highlighted challenges associated with supporting people with dementia who live in rural and regional areas to age in place. Major issues included: a lack of diverse and appropriate community services that can reduce social isolation, the costs involved in delivering care in the home in regional locations, and the additional requirements of travel to access community and health services.

They either make the decision to let go of it or they receive probably less than they potentially could because the package also has to pay for transport costs and things like that, so the money gets chewed up in that regard, or more often than not what happens is the family or friends in the local community rally around and provide the support so the package is not really needed anyway but that's not ideal because it's transferring the burden onto them. (SP 11 August 2014)

The other thing that I'm seeing very commonly in the rural sector is people that can't go to an open day care are really constrained by their social isolation ... so that would have been a 120 kilometre round trip for day care. (SP 1 July 2014)

The challenges associated with supporting someone experiencing dementia to remain in their home are substantial for people living in isolated areas and on large properties that they can no longer manage. While a transition to a lower maintenance home in an urban location might be advantageous, this needs to be balanced against loss of community.

I've got a couple of families that I'm working with at the moment and that's the question they will ask, Should we move? And if we move, where do we move? And it's such a wrenching decision, because they've been there all their life, or they've got the most stunning of homes and environments and you think, gosh you'll never find this again. And then it's also changing their networks, but if not they can become quite isolated. So there's so many dynamics. (SP 1 July 2014)

3.12 Policy reform

3.12.1 Consumer Directed Care

A key recent policy reform in the delivery of aged care services is the introduction of Consumer Directed Care (CDC). From 1 July 2015 all Home Care Packages provided through the

Commonwealth Home Support Program (CHSP) will offer CDC⁴ (viewed 14 Oct 2014). CDC aims to give older people and their carers greater say about the types of care services they receive and the delivery of those services. In general, participants recognised the value of enabling clients and carers to be involved in developing a tailored package of services that might best support the individual person's circumstances and meet their personal care needs.

It is actually seeing the person in a holistic way. It looks at what stresses are impacting on that person and how to help them through their goal-setting. How we are trying to help them achieve whatever it is. (SP 9 May 2014)

However, participants noted that the issue of choice was problematic for people who are experiencing dementia. While a family carer would be able to advocate for their care-recipient, a person living alone would need access to an advocate or would rely on trusted service providers to assist with this process.

People with early onset dementia and mild to moderate dementia, how are they going to be able to appropriately determine what their needs are? A really big priority in community is having a clean and tidy house, people always choose this over showering. And yet, as a community service provider, showering is the one thing we will look at ... whether they are safe at home, not managing personal care. Usually a fairly large proportion of decision-making leads into other decisions as well. (SP 20 March 2014)

It's great to put it back on the consumer, but at the same time, sometimes consumers don't necessarily know what they may need, or what is available. In these situations, a consumer-directed package doesn't necessarily work, confused with the system and living alone with dementia, cannot see CDC package working. (SP 20 August 2014)

Participants expressed concern that CDC had the potential to make an already complex system even more confusing for clients.

For most of our clients, they are not going to be able to manage a package themselves for the level of client that we see. For most of our carers, there might be clients with children who are willing to take on that responsibility, but I can't see that a lot of our elderly carers—the system is very confusing for us sometimes, let alone the carer. (SP 1 July 2014)

We're building a care system that's got a lot more choices in it. That means there's a lot more decisions that people have to make and there's a lot more complexity in the system. [For people with] medium stage dementia ... it's going to be a nightmare. (SP 30 June 2014)

But they will still need someone to sit and help them do those forms, you know what I mean, to be able to submit, to get a reduction in the cost, so then it falls back to having the service to do that then. (SP 1 July 2014)

Participants noted that the CDC model encouraged a more user-pays understanding of service delivery. They were concerned that clients and their carers might make decisions based on costs of particular activities, rather than looking at how services can work together.

Sometimes people will get out their best china and make something the night before and we sit there and we natter and we look at photos. Now we're going to put the clock on. People are going to pay for that. We don't know how to say that to our clients. (SP 28 August 2014)

With current funding, everything is more oriented towards output: how many hours do you need to deliver what service and how much will it cost? (SP 20 August 2014)

⁴ See: <http://www.myagedcare.gov.au/aged-care-services/home-care-packages>.

Participants were also concerned that in an environment that encourages competition between service providers and a focus on discrete service activities, services that are less tangible and not easily calculated, such as building trust and rapport between clients, carers and service providers, might disappear.

Some years ago we had a client who we were visiting at home and he was a gentleman in his 60s who lived with his wife. ... He did get one of the first consumer directed care packages and his wife is very capable and very efficient ... she chose to go through another service, but later rang me and said, would you come in once a week and assist her husband with his shower. Now the main reason that she came back to us was that she missed that person coming in and talking to her about how she was feeling, how she was finding things ... and when to say, do you think it's time that you should be looking at booking some residential respite to give yourself a break. That's what she actually missed. ... All the emotions, and all the emotions about residential respite, medication changes, those day-to-day decisions that, emotionally, are very difficult for people. (SP 1 July 2014)

Participants noted that the costs of delivering services to people with dementia are higher due to extra time that can be required.

There's a lot of extra work, it's not the same as going into somebody who has full capacity and providing them with a service. That's what is difficult to let the funders know about—that showering somebody is all well and good, but if they've got a severe memory dysfunction, then it can [be] three times as long, but the need is still the same, to get somebody showered. (SP 9 May 2014)

Others were concerned that service providers were no longer able to be flexible in targeting, rationing and delivering services to a community of people with a mix of support needs.

On the one hand, having more transparency and choice is good, but ... everything has its pluses and minuses, and the minus is that there are no aggregated funds. Everyone is getting the same. ... [In the past] we determined what the needs were. Some people had more or less than others. [With] no pool of funds, it's all down to individual people. So what's there for them is what they get, which is going to leave some people with big holes in their services. (SP 6 June 2014)

KPMG's (2012) recent evaluation of CDC found widespread support for Consumer Directed Care, including carers of people with dementia. However, among participants who were homeless or at risk of homelessness, the report notes that there was greater need for more intensive care planning and management [than older people generally] and little interest in the consumer-directed aspects of the CDC model, including choice of support and support providers and their individual budgets (KPMG 2012, p.53). Participants shared this view, noting that CDC was problematic for vulnerable people living in marginal housing situations.

The consumer-directed package model is great. A friend who is educated, articulate and assertive is thriving with it. ... However, it doesn't work with our people who cannot make a decision, who may be vulnerable to exploitation. ... One of the questions I have been consistently raising is: What person is going to say 'Yes, I will fund you to come into my home and investigate potential elder abuse going on in my house', or 'Yes, I will fund you to place me in care against my will'? When I raise this there is a glaring black hole. Nobody is able to identify with us how that will be addressed. (SP 20 August 2014)

3.12.2 National Disability Insurance Scheme

The National Disability Insurance Scheme (NDIS) supports people with a permanent and significant disability that affects their ability to take part in everyday activities. The NDIS was launched in July 2013 in seven participating trial sites. In Tasmania, the trial scheme focused

on young people aged 15–24 years. In South Australia, the trial scheme focused on children aged 13 years and younger. The scheme will be rolled out nationally in 2016⁵.

While we asked service providers about the impact of the NDIS on PwD who live in the community, the response was mostly uncertainty about what the scheme meant for PwD. The only exception were service providers who had experience with people with early onset dementia (under 65 years) and young people with mental health and cognitive impairment relating to drug and alcohol abuse.

When asked about the NDIS, service providers raised the issue of existing anomalies in the dementia care system. Currently people with early onset dementia are not recognised as clients of disability or aged care services. They were hopeful that the NDIS might be able to address this situation.

People with younger onset dementia is a group that often gets forgotten because they're not seen as older. They don't fit into aged care or mental health. (SP 6 June 2014)

I'm hoping that the [NDIS] Scheme, whatever it ends up looking like, will somehow help to provide community-based support because it's not fair for someone 45 with dementia to end up in with 90-year-olds. It would be better if they could be supported somehow in the community, whether that's alone or in some sort of group accommodation, but with people of an equivalent age. (SP 11 August 2014)

As well as addressing existing inequalities in service provision based on age, service providers also expressed concern that the NDIS could potentially create new inequalities. Age could potentially become a determinant of access to support services rather than care needs, with people under 65 years accessing NDIS-funded support services compared with people over 65 years accessing home care packages.

So what if you're 64, right, and you've got this wonderful NDIS package and you can live independently and you're getting like say 35 hours a week or 40 hours a week to actually remain. What happens on your 65 birthday? (SP 1 July 2014)

So the NDIS/aged care reform can all be looking at one system for everyone so there's not this line you hit at 65. (SP 30 June 2014)

3.12.3 *Policy gaps and innovation*

Service providers identified major gaps in current service provision to support people living with dementia in their home, particularly for those who have limited family support and who are living in insecure housing situations. They also recognised that it was a growing problem in need of more innovative policy responses.

I think we need to be proactive in looking at how we are going to manage a population explosion of people with dementia and I think there are so many better ways that we could actually be dealing with people in this way. (SP 9 May 2014)

If people are living longer and ageing in their own homes, there needs to be some really good research, ideas and creative thinking done of how we might manage this into the future. The policy responses to date have been quite weak. They're not able to counter the tidal wave that's going to come. (SP 15 May 2014)

It would be good to see more collaborative responses, because this is a societal problem and it's only going to get worse. (SP 9 May 2014)

There were four major issues raised by service providers that could potentially improve the quality of life for PwD who live in the community: building an inclusive, dementia-friendly

⁵ See: <http://www.ndis.gov.au/document/811>.

community; providing access to clear information and support with decision-making; expanding and innovating respite services; and expanding and innovating affordable housing options and housing support services.

Service providers provided some suggestions for moving towards an inclusive, dementia-friendly community in Australia. These included reducing stigma associated with dementia, and being proactive about universal home design.

Make our environment more dementia-friendly. So having some clear prompts, and having somebody to support the person with dementia. Our society is moving quickly to a quick, fast, self-serve approach. People with dementia just don't manage very well with that, and learning to do new things such as using a PIN number for transactions. (SP 7 July 2014)

We should design, build and change the physical environment to suit people with dementia to live. ... You can't change a person's brain, but you can change the physical environment to accommodate that. (SP 20 August 2014)

Service providers also cited examples of discriminatory practices that impact on people's capacity to age in place within retirement village developments.

Independent Living Units are marketed as disability-friendly places for people to age in place, but the common feature we saw was 'we are an independent living unit and people should be independent, and if not, independent—shouldn't be here'. Refused to put in any modifications to make home accessible whether this was threshold ramps, hearth steps that can be removed. (SP 20 March 2014)

There are some places with clauses in their contracts that state if you have diagnosed dementia, you have to leave. There are varying stages of dementia, but it could put people off being diagnosed, because of the clause. It may preclude early treatment. (SP 6 June 2014)

In relation to building an inclusive community, service providers emphasised the need to ensure that there are protections in place for people who are vulnerable and who lack financial resources and family support.

Aged Care has now become a multi-million dollar business. People are going to be driven by profit. There is a core of people, as there always will be, who cannot be driven by the market. Vulnerable people will fall through the cracks. They will be incarcerated against their will. There has to be recognition that there is a need for objective trained persons to work with these people to keep them in the community, even if it costs the community. (SP 20 August 2014)

One provider suggested that a 'circle of support' model could be beneficial to PwD living in the community (SP 28 August 2014). This circle of support involves a group of people coming together to help formulate, promote and support the goals of a person⁶. Further practical insights into building a dementia-friendly society are detailed in Alzheimer Australia's (2014b) recently released guide to becoming a dementia-friendly community.

Service providers also highlighted that access to clear information and availability of support to negotiate a complex system were critical issues for PwD and carers. They observed that the MyAgedCare website is helpful to many, but for those without internet access and who are struggling to cope in a stressful situation, there is a need for face-to-face conversations with people who are knowledgeable about available home care support services, as well as respite and residential care options.

⁶ See: <http://www.resourcingfamilies.org.au/building-support-networks/>.

The government making access to information about it easier would be very helpful because I (and practically everyone I know) is so tight for time that we don't have time to go out and search. We really need the information to be right there, and so the easier they make the information available, the better it will be for us. (SP 6 June 2014)

We need more resources available in the community. We need better communication on services than currently offered. (SP 15 April 2014)

There was also recognition by service providers that case management and individualised support over extended time periods is critical in enabling PwD who are vulnerable due to complex health conditions or insecure living arrangements to remain in the community and to retain good quality of life. Currently, under the Assistance with Care and Housing for the Aged (ACHA) program⁷, the Commonwealth Government provides older people who are homeless or at risk of homelessness with assistance in finding accommodation and financial and legal work. Clients also gain access to Aged Care Assessment Team (ACAT) to assess their needs, Home and Community Care (HACC) home support services and other health care services. While this program was valued, service providers observed that the need for complex case management was growing and more resourcing was required.

I think the Commonwealth Government is viewing longer-term case management as a bit of a non-required item, but I think they're looking at that from the cost point of view only and not from the benefit point of view. (SP 11 August 2014)

One service provider also noted the need for a proactive approach to raising community awareness and supporting vulnerable people with dementia who are living in the community.

Dementia consultants operating out of clinics are not going to get someone who has led an itinerant lifestyle to feel comfortable in this environment. ... They are worried about the cost, about medication compliance, where is this going to go, are you going to force me into residential care as I have no other option. This is why it fails, and there is little capacity to pick up cognitive impairment and analyse it. (SP 20 March 2014)

A third issue raised by service providers was the need for innovation in respite services and the expanded availability of these services. It was observed by many that respite services have a substantial impact on the quality of life of PwD who are living in the community and their carers. Service providers believed that an expansion of these services could effectively reduce the need for premature transition into residential care. They emphasised the need for community respite services and activities that engage and stimulate PwD and reduce social isolation. They also recognised the need for various forms of respite options to support people in a range of situations, including daily activities outside the home and overnight and extended stays away from home.

We really need some innovative respite care. And I think that would certainly support people to stay in their own home ... after hours and weekend respite, access to day centres or in the home respite, emergency respite. (SP 1 July 2014)

So our approach has been over the last few years, around dementia in particular, to identify things that don't look like services, to engage the people with memory loss in doing something meaningful and useful. (SP 7 July 2014)

Respite services were also critical in enabling carers who are supporting PwD to have a break from their demanding carers' role.

They need to loosen the purse strings and provide more respite care. How is someone meant to deal with someone with high care needs without having a break? (SP 7 April 2014)

⁷ See: <http://www.myagedcare.gov.au/aged-care-services/assistance-care-and-housing-aged>.

Finally, service providers felt that there were opportunities to improve the availability of affordable housing, including housing that provides a quality living environment for PwD. They also felt that there were opportunities to raise awareness of the challenges of living in the community with dementia among providers of community housing and homelessness services.

This study is a conversation starter. As a housing provider, we are looking at how we could support our people here to remain at home as long as possible. ... Specialised training would be useful, education and training good for all. It would be good to have courses about brain health ... Really important to establish good relationships with housing officers because they are [the] ones going to properties. (SP 15 April 2014)

At [the] moment the task is just getting housing and homelessness services to providers to consider brain health—Is this a good brain health environment? (SP 20 March 2014)

It would be good to see some dementia-specific public housing where the houses are all very different. It would be great to have somewhere Alzheimer's Australia have had input into ... and it would be good to see a care environment set up, where people are able to stay. (SP 9 May 2014)

There is a need for affordable housing for older people including those with dementia. There are a lot of people in unaffordable housing and housing that is not supportive of their age. It might mean taking away some of the red tape, or finding the money to build appropriate housing and to provide community services that are demonstrated to have efficacy. (SP 6 June 2014)

There's a real opportunity in housing to fix that: group housing or apartments that are mixed, not just old people together, and for a café to be part of that group housing so that a person can get their meals at the café if they can't cook for themselves or don't feel like cooking. (SP 7 July 2014)

The outdoor space is as important as the indoor space, especially for people with dementia. A safe garden to be in, places they can go and sit. Many gardens in residential care homes are for looking at, not to be in, and that's a problem. There need to be paths, and seats placed so that when people are walking they can see where the next seat is. There are some real opportunities, but I fear the business model will move us in the direction of the lowest common denominator. (SP 7 July 2014)

Among marginalised groups, dementia is rarely seen in isolation of other complex health needs. It has to be a very holistic health approach to managing housing needs—that link between health care/medical model and social care model is critical to keeping people living effectively in the community. (SP 20 March 2014)

3.13 Chapter summary

While many issues were canvassed in this wide-reaching and exploratory study, there were three recurring themes raised throughout the consultation: the importance of secure housing, which over time has become a familiar and comforting home, in enabling PwD to maintain quality of life; the importance of continuity in the both the home environment and the care received in the home in reducing anxiety; and the importance of comprehensive home-based care and community support (including innovative respite services) in enabling people to retain independence and dignity as they experience decline in cognitive function.

3.13.1 Housing security

Among stakeholders there is growing recognition of the advantages of enabling PwD to remain in a familiar environment. A key element in achieving this continuity is housing security.

Our consultation with service providers and carers highlighted the advantages of owning your own home and having access to housing wealth for families coping with the challenges and

stress of dementia. People who own their own home are able to readily make appropriate home modifications to support their changing needs. They are also potentially able to afford extra home-based care and support if it is required as their condition progresses. In other circumstances, people who own their own home and who are able to access health wealth are potentially able to seek alternative, more appropriate housing options within the housing market that can better support their needs.

People living in public rental housing share in common with home owners high levels of housing security. However, the process of obtaining suitable home modifications and/or accessing alternative, more appropriate housing options is more complex and more constrained. While service providers noted there was capacity to move tenants to more appropriate housing options, the availability of better designed housing and/or service-integrated housing was limited. Further, the possibility of tenants accessing extra home-based care and support as their condition progresses is less feasible due to financial constraints.

In contrast, housing security was a significant concern for PwD who are living in private rental and/or marginal housing situations, such as caravan parks and boarding houses. The major concerns raised by service providers were the PwD's capacity to maintain the tenancy due to problems with maintaining the residence, confusion about lease arrangements and rental payments, and problems with affording increasing rent and utility bills. They also noted that marginal housing situations such as caravan parks and boarding houses were problematic for managing personal care and accessing home-based support.

Service providers emphasised the importance of inter-agency collaboration and the need for ongoing case management to ensure that people with complex needs at risk of homelessness were able to continue to access the supports they required. Service providers also raised the problem of the lack of appropriate, affordable housing options for people who have complex needs and who are marginally housed. Without this, there can be a push towards transition into residential care.

Service providers noted that an expansion of brain health initiatives among the homelessness population and the introduction of outreach cognitive screening would address current delays in people living in marginal and precarious housing situations receiving diagnosis and support. Across the two case sites examined, there was greater evidence of collaboration underway in South Australia, compared with Tasmania.

3.13.2 Continuity in housing environment and home-based support

Service providers emphasised the importance of continuity in terms of the home environment and also continuity in terms of available supports and care. Continuity was viewed as critical in enabling people experiencing dementia to maintain quality of life and in reducing anxiety and stress.

Home modification was viewed as a critical component of enabling PwD to remain in their homes and to retain quality of life. Service providers were critical of current housing design, which focuses on aesthetics above function for older people including those with mobility and cognitive issues. Service providers emphasised the value of timely access to home modification. This did not always occur due to lack of education, lack of resources and waiting lists. They noted that modifications for people with dementia are most effective when they are tailored to the specific needs of the individual. This is a challenge for public and community housing providers that are operating with constrained and declining budgets.

Service providers also highlighted current challenges with accessing appropriate levels of home-based support. They noted that there was a need to work with families and try to establish a good, working partnership. In situations where people are living alone, it is a challenge to provide adequate levels of care as people's condition progresses. They identified gaps in service provision including the need for regular prompts to take medication, limited

service access over the weekend and shortfalls in adequate respite care. Service providers also cited examples of discriminatory practices that impact on people's capacity to age in place within retirement village developments. There is a need for further research into barriers to ageing in place for PwD in retirement village settings.

Providing continuity in the housing and support environment was recognised as problematic for particular groups in the community. Consultation highlighted that there are specific issues around communication and dementia in CALD communities and consequently that there is a need for specialised support services. In addition, service providers highlighted the challenges associated with supporting people with dementia who live in rural and regional areas to age in place. Major issues included a lack of diverse and appropriate community services that can reduce social isolation, the costs involved in delivering care in the home in regional locations, and the additional requirements of travel to access community and health services.

3.13.3 Comprehensive home-based and community support

Service providers noted that in the past dementia was heavily stigmatised and a diagnosis of dementia was associated with significant and rapid decline in cognitive function and a pathway to residential care, but this situation is changing. Substantial efforts have been made to encourage people experiencing problems with memory and associated behavioural changes to undergo assessment. However, they highlighted that there remained scope for increasing awareness of the importance of early diagnosis in order to access appropriate support and maintain quality of life.

Service providers noted that there was a need for increased awareness about dementia and the pathways to assessment within the social housing and homelessness sector. This is important in enabling service providers to respond appropriately to complex situations where mental health issues, memory loss and a dementia condition may be present. It is also important in achieving inter-agency collaboration and enabling PwD to access appropriate, stable housing and support services in a timely way.

It was recognised by housing providers that structural changes in the public housing sector were impacting on the capacity of staff to provide adequate duty of care towards older tenants. This was a concern in Tasmania where recent structural changes had resulted in SHA staff having reduced knowledge of and engagement with tenants. SA has also experienced some rationalisation of services, however, participants were optimistic that tenancy support would be targeted towards those in need, including older tenants.

Service providers observed that the home-based care landscape was also changing with the introduction of Consumer Directed Care (CDC). In general, participants recognised the value of enabling clients and carers to be involved in developing a tailored package of services that might best support the individual person's circumstances and meet their personal care needs. However, participants also noted that the issue of choice was problematic for people who are experiencing dementia. While a family carer would be able to advocate for their care-recipient, a person living alone would need access to an advocate or would rely on trusted service providers to assist with this process. Participants were also concerned that in an environment that encourages competition between service providers and a focus on discrete service activities, some of the things that are less tangible and not easily calculated, such as building trust and rapport between clients, carers and service providers, might disappear. In particular, participants noted that CDC was problematic for vulnerable people living in marginal housing situations.

Service providers emphasised the growing need for innovative respite services. Accessing respite was viewed as critical to: stimulating PwD, managing high care burdens, and making transitions to residential care easier by familiarising the PwD with this environment gradually over time. In SA, the carers interviewed had been able to tap into peer support from other carers and regular respite services that offered their PwD meaningful activities and satisfying

experiences outside the home. Both peer support and regular respite services had played a significant role in enabling carers to cope with their demands of supporting someone with dementia. Carers observed that PwD who live in the community need access to meaningful activities.

A key issue raised by service providers was the specific needs of people under 65 years with early onset dementia and younger people who are experiencing memory loss as a consequence of drug and alcohol use. Participants were concerned about the lack of appropriate housing options for people under 65 years, difficulties accessing home-based support services, and the lack of relevant community activities. Currently people with early onset dementia are not recognised as clients of disability or aged care services. They were hopeful that the NDIS might be able to address this situation.

Finally, in relation to delivering comprehensive home-based and community support, there is a growing need for affordable and accessible housing options for low-income older Australians. Participants noted that service-integrated housing options for PwD, in particular those who have experienced housing and financial insecurity throughout their life, are limited.

4 CONSULTATION WITH PEOPLE WITH DEMENTIA AND FAMILY CARERS

4.1 Chapter overview

In this chapter, we present the results of our consultation with people with dementia (PwD) who are living in the community and carers of PwD. This analysis is based on a total of 12 interviews undertaken with PwD and carers between August and December 2014. People's level of participation in the interview process varied. While in some instances people with dementia were able to actively participate and respond to questions, at other times the person with dementia was present, but did not participate significantly. Accordingly, the analysis is based on the views of five PwD, two of these interviews were conducted with PwD alone, and three further interviews were conducted with four PwD with support from a carer.⁸ The results presented here are also based on the views of seven carers; four of these interviews were conducted with carers alone, and three were conducted with carers with a PwD present, but who did not participate in the discussion.

We begin the chapter with a discussion of how to read and present the information we have collected from PwD and carers of PwD. We then present our findings, which we have organised into seven themes: housing circumstances and attachment; familiarity and connection in the neighbourhood; managing at home, either alone or with a live-in carer; experiences of home modification and assistive technologies; home-based support; the carer's experience; and meaningful activities and respite services. We then conclude by highlighting the importance of housing security, continuity and support in sustaining quality of life for people with dementia.

4.2 Reflection on and contextualisation of transcripts

*They already see me as fading away. They expect me to evaporate in front of their eyes. But I'm still all an ocean (Professor Richard Taylor, September 2010).*⁹

As noted in Chapter 2, the voices of PwD are increasingly being included in international research on the experience of dementia. Previous studies that have actively involved PwD in interviews and in action research processes have identified a range of issues relating to ethical engagement with PwD and also appropriate techniques for data analysis and interpretation. In relation to the latter, Beuscher and Grando (2009) note the importance of a contextual understanding of the interview transcript, with the researcher relying on observational skills and marrying these with statements. In our study, we were able to make observations about people's home environment and use this to elicit further information about managing at home in the interview.

In a recent article on research practice relating to the inclusion of PwD (SDWGRS 2014), the authors emphasise the need to rethink notions of linear time when listening to PwD and interpreting their transcripts. For example, stories may not progress linearly, conversations can be tiring and breaks might be needed, and changes in health might preclude people from participating. This idea of rethinking notions of linear time was particularly relevant to our experience of the interview process as sometimes questions would trigger unanticipated ideas and memories that were important to the PwD. It was valuable to listen to a person's story without interrupting and directing the person back to the question. The interview in this way

⁸ One interview was conducted with a couple with dementia, Bob and Jane, and their daughter, but only Jane and her daughter responded to the questions.

⁹ Found at <http://www.spiegel.de/international/zeitgeist/interview-with-alzheimer-sufferer-you-turn-into-a-person-you-don-t-know-anymore-a-688049-5.html>, 10 December 2014.

took on a conversational form and we found out a lot about the things that were important to a person's life in the past and present.

The transcripts generated through the interview process are read contextually and reviewed for meaning. This was important as some of the participants did not follow conventional conversational rules. For example, sometimes a question is followed by a statement that is not directly related to the question. This leads to a different topic and a different understanding, sometimes illuminating topics or stories that are important to the person. Sometimes participants gave information about their experience through a series of comments over the interview. Sometimes factual information, for example, the length of residence in their current home, became available through further discussion.

The project team have attempted to reflect on and contextualise the insights offered by participants. We have tried to be explicit about this process by identifying quotes and adding contextualising commentary that illuminates people's experiences. As Beuscher and Grando (2009, p.3) note:

The transcribed interviews may initially seem thin. However, by using multiple readings and triangulation of the interviews with the observations and field notes, the researcher can get a sense of the data in its wholeness.

While there were sometimes contradictions in the historical accounting of events or in relation to the changes made to a home, our analysis focuses on people's expressions of attachment to the neighbourhood and home and statements that capture the lived experience of managing at home with dementia.

4.3 Housing circumstances and attachment

In previous qualitative research, participants with dementia have emphasised their attachment to their home and the importance of remaining independent in their homes as long as possible (Harris 2006; Duane et al. 2011, p.133).

In seeking to explore this topic of home attachment, it was important to find out about the length of time a person had been living in their home. We began the discussion by asking participants about their home and how long they had lived here. In general, participants responded warmly to this question. Their responses reflected their love for their homes and their family lives. Looking around their homes you could readily see that the home was a repository of rich memories. Home attachment was evident in the family photos on display, special ornamental gifts and mementoes from travels.

However, this direct question of how long have you lived in your home also created some tension as a couple of the PwD initially focused on giving us the correct answer. Two of the participants sought to provide us with some form of corroboration for their answers. There was some initial unease perhaps at being in a situation where an official person was asking them questions with right and wrong answers.

I just wanted to start Harry by asking how long have you lived here?

Six years, well someone told me the other day it was six years.

Anna, can you tell me how long you've lived here?

Eleven full years and I'm into my 12th year. I was checking that the other day for something else.

In both these situations, however, the conversation moved quickly to a potted history of their work and home life. This put us both at ease. The participant appeared to enjoy recalling their experiences at their own pace and on their own terms and we enjoyed listening and imagining their past lives. Their past was their story and there were no right and wrong answers.

We grew up in the North Hobart/New Town area, but when I got married we built a house at Claremont and I've always been in this northern suburbs area in a couple of different houses. (Anna)

No, we came from Sandy Bay to out here ... Yeah, but I worked in [an ammunitions and metal manufacturing factory] then and it was too far to travel. Because I was in charge of the warehouse and sometimes you'd start work at 4 o'clock in the morning and you'd still be there at 8 o'clock at night But they were very good people to work for, no problems. (Harry)

Harry was living alone with dementia. Harry was a war veteran and he has lived in his home for a long time. He loves his home and he is strongly attached to it. He does forget some things, but he is aware that he has secure tenancy. We asked:

So how important Harry is it for you to stay in your home?

Well, I don't want to move for the simple reason as I said, I've got everything—if I've got to go to the dentist, the eye specialist, now if I move anywhere else—well, I said to Tom who used to be one of the inspectors years ago, and he said 'they might make you move', but he was only joking. I said 'I tell you what, it'd be the fourth world war because I'm not moving'.

Most of the participants were living in the same home that they had raised their family in and they were strongly attached to the home. For example, Bob, who was a war veteran and a builder, built his family home 67 years ago and his wife Jane likes everything about it and she doesn't want to change any of it. Jane loves Bob and the house and she is also averse to residential care due to her experience of living in institutional care as a child. Jane says she 'will never shift'. Her daughter says that the children are doing all they can to support their parents in their home despite both parents having a diagnosis of dementia among other health conditions. Similarly, Cassie's daughter explained that her mum moved to West Moonah with her husband and they bought their home over 50 years ago. Around 30 years ago, Cassie subdivided the land and built her current home on the second block. Cassie's other daughter lives next door. Cassie reflected:

I love everything about it. My home means everything to me.

Claire (wife and carer) and her husband, William, were also living in their family home. They had lived there since Christmas 1958 and Claire expressed strong attachment to their home, as Claire observes:

William has done a lot to make it how we like it and that's why we are staying here. Moving just wouldn't work.

William has been living with dementia for around 13 years. Claire hopes that William will be able to stay in his home.

Lisa, a carer who we spoke to directly, also emphasised her parent's strong attachment to their family home, which they built in 1947. She recalled that her mum insisted that: 'We were the second ones in and I've got to be the last one out'. She observed that her mum did not feel ready to move out of her home as she didn't want to leave her husband behind nor did she want to desert her long-time neighbour and friend.

Others were no longer living in the home they raised their family in, but they had still lived there for over 10 years and were committed to staying. For example, Alice (wife and carer) and James have been living in regional SA on a hobby farm. They have lived there for 27 years. They own their home and they have three adult children who live with them. Maria (wife and carer) and David have also been living in their home for 19 years. They are the only participants in the study who were renting their home from a private landlord, but their housing situation was secure as the landlord is their son. Their unit and garden is easy to maintain and

they are living near shops, a doctor's surgery, a community centre and a local park. Jack, who was living on his own with dementia, had lived in his current home for around 10 years, but he had lived in the same suburb all his life. His wife had moved into residential care in the same suburb and he was able to see her regularly. He wanted very much to stay in his home: 'It's a lovely spot here'.

Two women with dementia had moved into new accommodation that better supported their needs: one into a private independent living unit; and one into a public rental independent living unit. Anna had moved into a private independent living unit 12 years ago under a leasehold agreement, which suits her needs well. Anna is nearly 80 and she has experienced some complications with her health. There are supported units available onsite, which might be an option in the future. However, she is also aware that she may need nursing support in the future, which is not available onsite. Anna was attached to her home, but she was also able to participate in discussions about a living environment that best suits her health needs with her children.

Christine, a carer who we spoke to directly, described her mum's housing experiences. Unlike other participants, her mum had experienced housing insecurity in later life. She was living in a large, rental property and following her husband's death she was concerned that she could no longer stay. She was able to access secure and affordable public rental accommodation. The independent living unit she is currently in has a lifetime tenancy agreement and the unit is designed for the needs of older people. There is a registered nurse available to assist residents to access additional care services if required. Christine explained that while her and her brother are concerned about her mum's ability to manage on her own, her mum is not ready to move into residential care and talking about such a move makes her feel anxious:

My brother and I had made some enquiries about her moving into a fully supported aged care facility and we started that process and she was shortlisted so within the next six months that was what was going to happen. She had been contacted and then just put the brakes on and said 'I'm not ready for that' and so, staying there is very, very important to her and she's very upset. ... This [unit] was always the outcome that she wanted and I think that's very much part of the reason why she doesn't want to leave anytime soon. ... I don't think she ever really saw herself leaving here.

4.4 The neighbourhood: familiarity and connection

As well as a strong attachment to home, participants were also connected to their neighbourhood. Many of the participants had lived in the area for the majority of their lives. Jack, in particular, had lived in his neighbourhood all his life and he loved the area.

Oh yes, actually my mother, she's passed away now of course, she came here when she was two, and it was in 1897, and they lived down, almost opposite where that little civic centre is down here, a couple of houses below there.

Right on the water?

Well it's not on the water, it's back a block, it fronts onto a little park down here, on the opposite side of the road. Always been boating all my life, I was a rowing club member for a good many years, so you get attracted to an area.

He valued his long-time friends and neighbours, as well as new, friendly neighbours such as the 'two young kiddies over the back':

So do you feel if you got stuck here, you could sing out for help from your neighbours?

Oh no doubt about that at all, no doubt about that at all. No, it's a darn good spot. Friends over the road in the units there, and people I've known for 60, 70 years.

Similarly, Anna observed that although she had moved several times, she had spent her life in the northern suburbs of Hobart and that she had a network of friends in her local area. She also recalled her sister's plans to move out of the area when she was young, but then her and her husband changed their mind and moved into a newly built house in the neighbourhood. The two families grew up together in the neighbourhood.

Carers' comments supported this, with some noting that when they went out they often ran into people who their parents knew. Lisa, a carer who we spoke to directly, also observed that:

Mum's very sociable, she had four children so over eight years we were going to school, mum just seemed to know everyone. We grew up in Moonah and mum knows everyone through the school contact. So, in that way, she's still part of that contact. When we visit a nursing home, we visit the bank, mum still comes across people she knows everywhere she goes.

However, participants also observed that the neighbourhood had changed around them, with many of the families who they grew up with moving out and new people moving in. For example, Cassie and her daughter talked positively about the neighbourhood. While many young families lived close by and people were friendly, some of her neighbours had passed away and new people had moved in. Like Cassie, Jane said that they knew a lot of the neighbours when their children were growing up. However, Bob said that a lot of them had died or moved on and that he doesn't know the people next door.

In relation to the neighbourhood, carers noted that their wife/husband and/or parent's interest in social engagement and new experiences had declined over time. When I asked Bob and Jane about activities outside the home, they said they didn't do that much now and that they liked being at home. Jane has back pain and neither of them have the mobility to go walking in the neighbourhood. Their daughter said that they enjoyed having their grandchildren visit and they enjoyed each other's company.

The capacity to enjoy the neighbourhood they lived in was constrained by restricted mobility, which prevented some participants from getting out of the home for a walk. Others had lost their licence. This was a source of frustration for Jack:

Can you still drive?

That's a bit of a sore point. I've been restricted in where I can drive. It hurts like heck.

Because you had that freedom?

Yeah there's no reason for it, you know. I've never had a nasty accident or anything like that.

Many of the participants emphasised the importance of location in terms of access to shops and services. For example, Maria (wife and carer) emphasised the importance of the proximity of their home to key medical services and community services such as the library and community centre. David lost his licence following his diagnosis and Maria doesn't drive. Josie (wife and carer) also emphasised the importance of location, noting that she and Alan chose their home because of its proximity to their church, services and public transport.

In contrast, Alice and James live on a hobby farm and they rely on the car to access services. They both prefer living on the land with plenty of space, rather than in town close to neighbours. One of the things they enjoy about their location is that they have a view of the sea. Alice observed that James had been a marine engineer and being able to see the ocean is important to him.

Previous research (Alzheimer's UK 2013) has highlighted that PwD may remain at home and cease activities that had provided purpose and pleasure in public space because of potential problems of disorientation and getting lost, even though they have not yet personally experienced those problems. They may also fear experiencing negative reactions from others if

they become disoriented. One of the carers, Christine, shared her mother's experience of becoming disorientated while walking to the local shop, which is two blocks from her unit.

Does she still do her shopping? Would she walk up to the shop and do her own shopping?

Well she did that a couple of weeks ago and apparently on the way back she was stopped by a woman who told her that she was in no fit state to be out by herself. The woman insisted on accompanying her home and mum said: 'No thank you, I'm okay, I live just there' pointing it out and the woman wouldn't take no for an answer and flagged somebody down, a young fellow who was walking his dog and then entrusted mum to him to walk her home. Mum was absolutely mortified.

So she's lost confidence through that.

Complete loss of confidence through that experience.

4.5 Managing at home

4.5.1 People with dementia's perspective

In the interview, we asked six PwD participants how they managed at home with memory loss. This was not an easy question to ask even after explaining to the participant that the reason that they were involved in the study was because they were experiencing memory loss. It was difficult because the previous questions were fairly typical conversation questions about their home life, their neighbourhood, and their satisfaction with the home help they received. This earlier discussion was valuable in building rapport, whereas this question highlighted differences between us. Moreover, this question was about an issue which carries stigma in our society and which is associated with a lack of capacity to do things: retrieve facts, remember names, complete tasks, and be independent.

As in previous qualitative research, participants varied in the degree to which they accepted that they had memory loss (Duane et al. 2011, p.130). When we asked Cassie about managing at home with memory loss, she said: 'Everything is fine'. Her daughter who was present gently reminded her mum that she did get a lot of help around the home. We tried to elicit further information about her experiences without directly challenging this view by asking whether she used anything to help her remember things. We talked about our reliance on a diary to remember things and wondered if Cassie used something similar to remember important things like medical appointments. Cassie said: 'No, I don't use anything'. Again, her daughter gently reminded her that they do have a noticeboard on the fridge. She explained to us that this is helpful in enabling her and her sister who lives next door to communicate with each other and support workers coming into the home. Cassie's home was well-maintained outside with a beautiful garden. Inside, the home was spotless and comfortable. From an outsider's perspective, Cassie's comment 'everything is fine' seemed right. However, Cassie's daughter observed that this situation was possible through the family providing extensive support. Cassie had a gardener to help outside the home and a nurse visited regularly to assist with managing medication.

While asking participants about how they managed with memory loss at home was significant to us, this wasn't necessarily a big focus for them. Harry responded to the question in very general terms relating to the difficulty of getting things done. In his response he also emphasises his independence, noting that he can do 'everything I want to do'.

So has memory loss affected what you can do in your home? Is there anything that you struggle with?

No, I mean I struggle with everything, but I do it.

Yeah.

I'd rather do it myself, I know it's done. ...

So do you have anything to help you? Any reminders or ...?

No, well my daughter comes. I mean if I want anything done, then my daughter or son will come down, but I don't want them inside working anyway. I can bring my bloody washing out and my vacuum cleaner and do everything I want to do.

Yeah, so you don't feel frustrated you can't do things?

No, well sometimes I might get half way through it, and I say I'll bloody need to have a rest 'til tomorrow.

Harry was as frustrated by his declining physical health as his forgetfulness:

I'll be quite honest, if I do a bit of gardening for a half an hour, it'd take me 24 hours to get over it.

Jack hesitated when we asked about managing at home with memory loss. We followed up by asking him whether he used any reminders. He then briefly talked about how he was habitual about where he put things so he could find them again and that he followed routines, but even so he worried about forgetting things.

Have you found any challenges with memory loss, just managing around the house? Do you have reminders?

I should at times.

What about with turning on and off the stove, or the lights?

With the lights at night I've got a system that I go through, and I stick to that pretty well. At times I go to the same place two or three times, but I've ...

You've got a routine then?

Yes, I'm never convinced that the garage is shut, or the light outside's off.

So you do a few double checks?

Yes I do, and I'm a bit habitual where I put my wallet at night, I get out of bed and I'll think now did I do that, out again, back again.

We also asked Jack if he used a diary. He said he didn't but his wife had always done this and she was the one always taking notes while they were travelling. And the conversation was then back on safer ground as Jack enjoyed recalling his road trip around Australia with Stella: 'All that time we had one puncture!'

Anna was more comfortable talking about a range of strategies for managing with memory loss. She had worked in administration and she took pride in her book-keeping skills. Her daughter noted that her mum kept records of her bills and that she was comfortable with coordinating two diaries; one she could carry on her and one at home. While the diary is helpful with remembering events and appointments, Anna observed that it was frustrating to forget things when going about daily tasks.

So has there been anything about your experience with memory loss that's impacted on your home life? Are there any things that you're finding that are more challenging to do?

Of the home?

Yes at home.

Yes, I forget where I've put things, or—I'm starting to make notes of everything that I know I've got to do. Well, I've had a diary for goodness knows how long to put things in, but anything extra, if I don't write it down straight away, I can forget it like that.

[Anna's daughter] But you're very good at writing things down. Very good.

Yes, *that's a real help.*

Yeah, but it's stupid the way I go to the wrong cupboard for something and I know damn well it's not in that cupboard. All of a sudden I'll turn round and go to another cupboard. It's most annoying.

We asked Bob and Jane, an older couple who both had dementia, about managing with memory loss at home. Their daughter said that they managed at home with support as they are unable to do most tasks around the home, such as cleaning, changing beds, washing, cooking and gardening. We followed-up by asking if they used anything to help them remember things such as diaries, noticeboards, or timers on the oven. Their daughter showed us the whiteboard in their kitchen. She puts the day of the week at the bottom of the noticeboard so they know what day it is. The family carers have a contact book on the dining table. They use this to communicate with the nursing staff and each other. There is also a diary which the family carers fill in to remember appointments. Their daughter observed that they don't have oven timers as they no longer cook. They manage the heater themselves with an on/off button.

4.5.2 Family carer's perspective

In contrast to PwD, carer's emphasised the significant role of support in enabling PwD to manage at home. Many were undertaking a range of tasks inside and outside the home for their family member—shopping, banking, accompanying the PwD to medical appointments, managing medication, driving the PwD to activities, preparing meals, cleaning the house, gardening, doing the laundry, showering the PwD, and preparing them for bed. Often the PwD is unaware of the extent of the support provided by live-in and visiting carers. As Lisa (daughter and carer) observed:

Mum couldn't have been at home without dad there looking after her this year and she couldn't have been at home without me doing all that I'm doing. A lot of it she's not aware of.

When asked about how their care-recipient managed at home, family carer's emphasised the importance of familiarity around the home to the PwD. Maria (wife and carer) noted that David is able to find his way around the house and that the familiarity of the house is good for him. She knows that he likes being at home where he has his own bed and his ensuite. Maria wants to care for him at home, rather than place him in residential care. While David is totally reliant on Maria, he still recognises her and he is continent and she would like to continue to care for him as long as possible.

Claire (wife and carer) observed that William was also able to manage well at home because he has lived there for 56 years and he is very familiar with the layout. Claire does all the housework and supports him with daily tasks such as preparing meals and dressing. William is still able to shower himself. William spends his days watching television, doing puzzles and crosswords and picking up leaves in the garden. A while back Claire had set up an above ground vegetable garden for him, but he is not interested in the garden anymore. Claire observed that she hides things that are dangerous such as matches in unusual places so he won't find them.

Alice (wife and carer) also believes that the familiarity of the home is critical in enabling James to retain some independence and to sustain his quality of life. While caring for James is challenging and tiring, Alice says that his behaviour has never been a problem. He has a gentle nature and she enjoys being with him. She observes that there have been ups and downs, but mostly she has found it easy to care for him and she is able to cope with his condition. She has a positive attitude about future care, noting that she is happy to prioritise his needs and let go of less important things like keeping up with cleaning tasks.

Live-in carers played a significant role in supporting PwD to retain independence around the home. Sometimes this involved breaking up the job into discrete tasks that the PwD could manage. Other times it was just being flexible about the length of time a task takes and adapting your lifestyle to suit the PwD's changing needs. For example, although James can dress himself, sometimes it takes him 1–1.5 hours to get dressed in the morning and then again at night. Alice doesn't like to interfere and take away his independence. When she offers him help, he says no and she accepts that. James also shaves himself and he wants that independence. However, Alice has noticed that James is asking for more assistance at meal times. While he used to be able to make a sandwich and a coffee, he no longer does this. Now she cuts up his food and spreads his toast. She has also noticed that he resists getting out of the car to go shopping. She is worried that this will become more of a concern in summer. She may have to change her shopping habits and organise with her children to be with James while she goes out in the evening to shop.

Family carers also talked about the changes they had made to the environment to enable their care-recipient to retain independence around the home. Josie (wife and carer) noted when Alan was at home his quality of life was good up until the last year before he moved into residential care:

He coped very well really. Yes, he lost track of where everything went and I was forever finding odd things in the fridge and things in wrong cupboards and things like that. But all the time he was happy to put stuff away and I just let him go because I don't think those things are important.

The only major problem was the toilet. Alan had become unsure of where the toilet was and went searching for an outside toilet, which he used when he was a child growing up on a farm. Josie was able to address this by putting a big sign on the door.

Claire is able to leave William alone in the house for short periods. When she goes out at night she puts signs on his pillow, chair and door letting him know where she is. She makes sure the lights and television are on. She uses whiteboards and she has put a note on the door that says: 'Do not leave without telling me'.

While the issue of wandering is a significant risk for PwD who are living in the community, many of the participants had reduced mobility and their carers' had not experienced problems. The exception was William who enjoyed walking. Claire (William's wife and carer) liked that he was able to remain active and the familiarity of the neighbourhood made it possible for him to continue this activity. Still, William had experienced some problems out walking. Claire said that he is attracted to shops and that she had to stop him going to the local shop on his own and buying chocolates.

Alice (wife and carer) talked about the issue of wandering. She noted that it had not been an issue to date as James has restricted mobility and relies on a walker. However, Alice is concerned that this might change in the future and, if so, the surrounds would be a problem as there is a deep creek at the back of the property and no fences. Alice noted that if he started wandering she would just change her lifestyle and perhaps have to lock the door.

4.6 Home modifications and assistive technologies

The main modifications undertaken by PwD and their carers were bathroom modifications to support independent toileting and showering and to reduce the risk of falling. In some situations the modifications were undertaken to support the person with dementia, but in other situations it was just to make the bathroom safer for everyone in the home. Some people had had the bath removed and the shower expanded to ensure it could be accessed by a wheelchair and a carer. Others had installed grab rails in the shower and the toilet. People used non-slip mats in the bathroom and raised toilet seats.

Jack who is living alone with dementia recalled that he and his wife had renovated the bathroom when they first moved in to accommodate their needs as they aged. Jack responded to my questions with good humour.

Have you, since moving in here Jack, have you made any changes to the house? Or any modifications?

Well it's certainly a different house than what it was. ... We rehashed the bathroom totally.

To make it easier to use, or just it was just time it needed to be upgraded?

We just modernised it and certain things. With the shower, it's a glass shower, corner thing, but there's rails and one thing and another, extra rails.

Extra rails—to get in the shower?

A matter of fact people comment on it, you know.

Good comments?

Oh yes, haven't had any nasty ones yet, they leave those until they've gone.

Harry who also lives alone in a public rental property observed that he had the bathroom fixed and that following an injury he had someone helping him with showering. When asked about modifications to his home, Harry talked about his experiences of dealing with the two different government departments that provide for his housing and support needs. While he lost his train of thought and he jumped from various experiences of house inspections and maintenance work, a recurring theme across these statements was that the Department of Veteran Affairs were responsive and helpful and that Department of Housing officials were ineffective. He recalled this experience of an assessment by a Department of Housing officer:

I said, 'Gee it's just as well you got here, it's half past three and you told me half past eight in the morning'. I said, 'I'm stuck at home', but she said different things. I said, 'you can do that or can do that'. When she wrote it, I said, 'What are you writing?' and she said, 'Every page I've written excellent, very excellent' and she said, 'no worries'. I said, 'Well, why come around?'

Another problem he had was that when one department provided him with a new electric heater, the other department refused to remove the old gas heater as it would be needed by future tenants.

Independent toileting was a priority. Carers had undertaken a range of measures to support this, including ensuring the PwD had easy access to a toilet (in one instance an ensuite was installed), using sensor lighting to assist the person to find the toilet at night, providing a commode by the bed, and one couple were considering installing a urinal to make toileting easier to manage.

Beyond the bathroom, carers had placed ramps over back steps. One carer with arthritis has had her kitchen remodelled and the cupboards replaced with easy to manage drawers. In another home, a special chair was used in the kitchen to enable the carer to move her husband in and out from the table.

In terms of assistive technologies, Anna, who lives alone in an independent living unit had a buzzer that she could push if she needed help. Maria (wife and carer) has installed a call button in the unit and in the bedroom in case of an emergency.

Only one family carer had used an assistive technology to support their care-recipient to retain independence outside the home without success. Claire (wife and carer) recalled that her husband, William, did have a wristband with a GPS to enable Claire to locate him if he wandered too far. However, this did not work out as William was continually activating the

emergency orange button and sending out false alarms. Claire also encouraged him to carry a mobile phone, but this was expensive and he did not necessarily answer it. He now carries his ID in his wallet.

When we asked Bob and Jane (both of whom had dementia) whether they would like to make any changes to the house, they said no, they did not. Their daughter said that keeping the house the same was important to them and that this continuity in their living environment was the most important thing.

4.7 Home-based support

PwD were receiving home-based support for various tasks such as house-cleaning, medication management, showering and personal care. Sometimes this home-based support was part of a package; others were paying for home help, including home maintenance and gardening and/or the extra days of showering that were required. Some people were receiving meals on wheels.

Carers identified gaps in the home-based support that is available to them. A number noted that it would be helpful to have access to transport. Some felt that access to podiatry assistance would be helpful. Bob and Jane's daughter reflected that the main challenge for her (and other family-carers) was preparing each meal for their parents/grandparents. She would welcome an in-home service that could prepare simple, nutritional meals for older people. Her parents were not satisfied with Meals on Wheels and they were unable to use a microwave to heat these meals up. Other visiting family carers reported similar issues, with the PwD expressing dissatisfaction with Meals on Wheels and wanting home-cooked meals.

Carers were grateful for the home-based support they received, but they felt that it was not comprehensive and that its effectiveness depended on additional support provided by the family. One carer observed that a lot of the responsibility for managing the health care issues of the person with dementia is pushed back onto families. This carer was responsible for managing her husband's diabetes. Another visiting carer observed that while her parent has assistance from a nurse with insulin, the onus was on the carer to ensure that scripts are up-to-date and that the equipment required is provided. In addition to nursing care, carers would like access to in-home respite services to enable them to take a break from their care routine.

When asked about their satisfaction with home-based support, carers were concerned about being able to readily access information about their options. They felt that they were not being provided with an overview of the range of home-based support services available.

They also observed that changes in service provision and staffing were both a source of anxiety for PwD. For example, Cassie's daughter explained that her mum had a gardener who was friendly and who came on Wednesdays. This worked out well as the house looked good for the weekend when her family might visit. However, last year this service changed. Now there are new people who come and do the lawns on Monday. This day did not suit Cassie, but it was the only day they were able to do it. This was upsetting and came at a time when Cassie didn't need any further change. Similarly, Christine observes:

Change of staff has been a big issue Change is difficult and having to establish a relationship with somebody else is quite problematic for mum so it's a huge issue. ... And because how she views her private space very, very privately and it's very important to her.

4.8 The experience of family carers

This study did not set out to describe the experience of family members who take on the primary care of people with dementia. However, due to difficulties with recruitment and difficulties experienced by PwD in participating in the interview process, we did record the family carer's perspective.

Family carers described the comprehensive demands placed on the carer to support someone with PwD who lives in the community. They also described the deep love they had for their parent or wife/husband and their determination that they live with dignity. For most people, this entailed staying in an environment that was familiar and safe and experiencing continuity in the quality of support they received.

Family carers were exhausted and some observed that high care demands had impacted on their health:

You've got to live with the dementia day in, day out as a carer to understand the pressure of it. You cannot escape the condition when the person is living with you. I cannot even go across the road, worry about leaving him on his own. (Maria)

Everything in life is very difficult and I feel tired all the time. (Claire)

Despite these challenges, Maria expresses great empathy for David's condition and she does not want him going into care prematurely:

I will not place him in residential care as I feel like I can give him better care, one-to-one care. He knows me and he is happy around me. These facilities they are limited in staff and money. If I was in his place I wouldn't like to be pushed away and locked in.

Carers emphasised the importance of peer support. Those who had this in their lives find it very helpful in coping with the stresses of supporting someone with dementia:

I look forward to that more than anything else, even though I have a busy life, still keeping up everything I can. Things that have been a disaster often turn out to be funny when you talk about them. Also I get a lot of information on how to get respite, how to get ACAT, all these sort of things and that is a tremendous help. (Claire)

I found that friendship fantastic because you do lose a lot of so-called friends once you've got [someone] living with dementia in the home. People drop away. And so we formed quite a close group of friends who had that same understanding.

Carers also reflected on problems they had experienced with obtaining a diagnosis and highlighted the need for more awareness-raising in the community about the ACAT assessment and where to go to for help. Josie experienced problems initially with obtaining a diagnosis for Alan from her husband's regular GP, who didn't accept that Alan had a problem. She then experienced delays in obtaining an ACAT assessment.

When we first went out to Alzheimer's, it was suggested that we try and get an ACAT early so that we would then be in the system. Well, it took five years to get that ACAT and bursting into tears in the end because it was a desperate situation. ...

The ACAT lady came out and she said, 'Your husband is high care' and I said, 'Well, yes, I know that'. Once I got the ACAT, I was offered a package.

Carers also experienced problems gaining information about support and navigating a fragmented and complex health care system. They were referred to online content, pamphlets and/or telephone numbers, but what they wanted was face-to-face, human support. This was important as they were time poor and they were struggling to absorb information during a time of emotional upheaval. As Christine notes:

On the rare occasions that I have had an opportunity to actually talk to somebody, they've just referred me to a website. I don't have time to sit down and read a website. I just don't have time to read bulk information. I probably just need somebody to come and sit down with me.

Josie was concerned that the *MyAgedCare* website was not readily accessible to people who are doing around-the-clock care and instead there needed to be someone face-to-face to help a carer navigate the system.

I don't quite know when they expect carers to go up on the computer because it becomes virtually an impossibility because they're right behind you all day. Alan shadowed me continually.

Lisa experienced similar problems with accessing information through the *MyAgedCare* website and she was frustrated that there was no-one to talk to who had an overarching view of the system.

I just feel alone, I feel there should be someone who can take me through it. But I just haven't found anyone.

Children also experienced problems with the process of increasingly taking on more responsibility for their parent's finances, decision-making and support needs.

So as I slowly take on more and more of mum's stuff, I discover stuff that I didn't know. If only mum had been happy to let me do stuff. ... I'm failing all the time of what has to be done. I get about 80 per cent done, but I never ever get up to date. (Lisa)

I've recently just taken on power of attorney, well I thought it was set up but again we found the signed paperwork in among her personal things that were there for 11 years. Everything from little things to big things have just been forgotten At least now people will talk to me. I was just hitting walls and not really understanding why because I had fully considered myself as having already been granted power of attorney because I had signed all the papers, but nothing had ever been lodged because there was nobody following up on that. (Christine)

4.9 Meaningful activities and respite services

We need people who stimulate our creativity. What we get are cleaning personnel (Professor Richard Taylor, September 2010).¹⁰

With only 12 situations described in our study, it is not possible to generalise about people's experiences. However, there was a clear difference in the engagement of participants with activities across the two sites. The four family carers from SA who were involved in the study described the importance of meaningful activities in the lives of PwD. They were able to access respite services, which entailed regular stimulating activities organised outside the home for extended periods (morning and/or the afternoon). In some instances transport was available to and from their home. In contrast, no participants were involved in weekly stimulating activities organised outside the home in Hobart.

In SA, family carers described positive experiences of respite activities. Alice (wife and carer) observed that James had become withdrawn from some of the community activities that he was involved with as his health had deteriorated. However, he had the opportunity to become involved in new activities. He attends respite one day a week, which Alice believes is very important to his quality of life. He also participates in exercise sessions twice a week and a conversation group with a speech pathologist.

Before moving into residential care, Alan went regularly to respite services. Josie emphasised the importance of respite care in providing the carers with a break, but she also saw the activities offered at respite as critical to the quality of life for people with dementia.

On Tuesdays they used to take a bus up to Bunnings and there was a chap there who did craft projects with them. They had little pre-cut kits. Alan made a little wine rack, he made a cutting board with mosaics on it, he painted pots. And if they were doing pots,

¹⁰ Found at <http://www.spiegel.de/international/zeitgeist/interview-with-alzheimer-sufferer-you-turn-into-a-person-you-don-t-know-anymore-a-688049-5.html>, 10 December 2014.

they then were allowed to go out into the garden centre and pick something to put in their pot to bring home. And it gave those guys such a morale boost.

Enabling Alan to be engaged in this activity was a priority for Josie:

I would lose probably a couple of hours in all because of the traffic and so forth but, to me, it was more important that he had that activity.

Both William and David attend respite services regularly; William four days and David 4.5 days a week. William is able to participate in activities or sit on his own and do puzzles or read a book. William enjoys and is good at drawing, which Claire says is a new interest for him. He also enjoys the theatre, which they are able to still attend together.

Respite services were mentioned in the Tasmanian interviews, however, only in relation to overnight stays in residential-type care. These experiences were not positive for the PwD for different reasons; Lisa's mother found it disorientating, and Jack found it noisy and restrictive. Lisa (carer and daughter) recounts:

Dad went to hospital and she did manage for about four days or so, there was enough food in the fridge already and she managed. ... but then she rang me and said 'I feel dizzy'. So we got her into respite the next day. ... She found it difficult, every day she thought she was going home so she said, 'Don't give me a shower, don't change my clothes, I'm going home today'. ... It wasn't that she was unhappy, it was that she couldn't remember.

This is an extract from Jack's interview about his experience of respite services. He didn't enjoy it and although he was with his wife in care, he would prefer to stay at home. It didn't feel homely and he found it noisy.

Have you got plans just to stay here at home?

Well, at the moment I'm not ready to go down yonder [his wife's residential care home]. I had ten days in there, respite thing.

What triggered that, was it a fall?

No, it wasn't, I don't know what it was. I think it was engineered between my wife and my daughter.

So that gave you an opportunity to see what it would be like if you did move in with Stella there?

Yes, where I was—was in a position whereas the system, daily system starts off and it—was in the middle of where the food is put onto the trolleys, and then trolleys are moved from there to there for some reason or other. Then they, there'd be silence for ten minutes and all of a sudden the noise will start off again.

So it was noisy, there was a lot going on?

It was—that particular area.

It didn't feel like home?

Outside the door, there was a piece of faulty flooring, and someone would walk over it and it'd go klonk-klonk, klonk-klonk. At any rate, they wanted me to go in there for a second session a bit later on, and they said, oh well look, we can put you back in the same room.

What did you say?

I said, 'Have you fixed that floor yet?' 'What's wrong with the floor?' I don't know whether they've fixed it or not yet, but I didn't go back.

So you would rather be here?

I'd rather be here. I'm just as close to Stella as I would be if I was in the room virtually.

But here it's quieter?

Oh yes.

4.10 Summary: housing security, continuity and support

There were many issues canvassed in the interviews. People with dementia (PwD) talked about their strong attachment to their home and neighbourhood, as well as happy memories from the past. Children and grandchildren were a source of joy. They had some 'good' neighbours and some 'weird' sorts who had moved into their street. They valued their daily routines and practices that enabled them to manage at home, but sometimes they found their lack of mobility and forgetfulness a source of frustration. They accepted that they needed help around the house with some things, but they liked doing things themselves.

Family carers highlighted the challenges they faced in supporting a PwD. The care needs of the PwD were high and never-ending. Family carers had few breaks as there was no-one available to provide the same level of care required and they observed that any change would create distress for their family member. Family carers valued any home-based support they could access to reduce their care burden. However, they saw gaps in the range of services offered. They wanted help with: transport, the preparation of nutritious meals in the home, podiatry services, and a more comprehensive home-based service to manage medication and health needs.

When asked about their satisfaction with home-based support, carers were concerned about being able to readily access information about their options. They felt that they were not being provided with an overview of the range of home-based support services available. When they asked for information, they were referred to online content, pamphlets and/or telephone numbers, but what they wanted was face-to-face discussion. This was important as they were time poor and they were struggling to absorb information during a time of emotional upheaval.

Consistent with the insights offered by service providers, carers recognised the importance of security, familiarity and continuity to PwD in enabling them to retain quality of life. Family carers observed that any potential changes can be distressing for their care-recipient: changes in care staff, changes in care routines, and conversations about moving house or into residential care. Family carers wanted the PwD to remain at home in an environment that is familiar to them and which makes them feel good for as long as possible. However, children who lived outside the home also expressed concerns about their parents' safety and capacity to manage alone. Many of the carers had made modifications to the bathroom to support their care recipient's independence with showering and toileting. Family carers played an important role in making minor changes to the home environment (e.g. whiteboards, signs on doors, locks on cupboards) to help the PwD to orientate themselves around the home and to reduce the risk of accidents.

In SA, the family carers interviewed had been able to tap into peer support from other carers and regular respite services that offered the PwD meaningful activities and satisfying experiences outside the home. Both peer support and regular respite services had played a significant role in enabling carers to cope with the demands of supporting someone with dementia. Carers observed that PwD who live in the community need access to meaningful activities. Sometimes this might entail supporting people to continue with past interests and passions, but it can also entail the discovery of new interests such as art and craft classes.

In summary, there were three recurring themes throughout the discussions with PwD and their carers: the importance of secure housing, which over time has become a familiar and comforting home, in enabling PwD to maintain quality of life; the importance of continuity in

both the living environment and the care received in the home in reducing anxiety; and the importance of comprehensive care and support (including innovative respite services) in enabling people to retain independence and dignity as they experience decline in cognitive function.

5 CONCLUSION

This Final Report is the concluding output of our research project examining the future housing and support needs of people with dementia. In this chapter, we provide a summary of the major project findings. We present our early project findings in relation to RQ1 and RQ2, which are documented in the positioning paper (Gabriel et al. 2014). We then present a summary of the key findings in relation to RQ3, RQ4 and RQ5, which have been documented in this report. Here we organise our findings in terms of addressing inequalities in the housing and care pathways of PwD, supporting PwD to live well in the community in a range of home environments. and policy responses to address the housing and support needs of PwD. We also discuss future research directions.

5.1 Project findings

5.1.1 Early project findings

In the project positioning paper (Gabriel et al. 2014), the team responded to two research questions:

RQ1: What is known about the links between housing and care provision for PwD?

RQ2: What are the current and projected living arrangements and housing pathways of people with 'mild, 'moderate' and 'severe' dementia in Australia?

In relation to RQ1, our review of literature on dementia and housing found:

- Housing is recognised as a critical protective factor in relation to the health and wellbeing of older Australians.
- A PwD's home is critical to their quality of life, with PwD more likely than others in the community to be spending a significant proportion of their time in the home.
- For PwD, remaining in their own home holds distinct advantages during the mild and moderate stages of the condition, but this situation changes as the condition progresses.
- PwD who live alone are at risk of social isolation, self-neglect, self-injury, depression, and exploitation by others.
- Home modifications are effective in decreasing the incidence of accidents and injury, and they can strengthen home-based social relationships and networks and reduce strain on caregivers.
- An AHURI study of older persons in public housing (McNelis et al. 2008) found that housing authority staff felt that they were not well equipped to assist tenants with dementia and that they have little knowledge of, and limited relationships with, community aged care services.

In relation to RQ2, our review and analysis of secondary data on the housing circumstances of older Australians and PwD found:

- A substantial proportion of PwD live in the community, an estimated 70 per cent of all PwD, and this is expected to grow over the coming decades.
- In 2011, approximately 157 864 PwD were living in an owner-occupied home, with 145 735 living in a home that is owned outright and a further 12 129 living in a mortgaged home.
- In 2011, approximately 11 756 PwD were living in private rental and 8957 PwD living in public housing.
- The number of PwD living in public housing is expected to increase from 8957 people in 2011 to 12 916 in 2020 and 31 672 in 2050.
- The number of PwD living in private rental housing is expected to increase from 11 756 people in 2011 to 16 952 in 2020 and 41 570 in 2050.

→ In 2009, about 9 in 10 (92%) PwD living in the community were receiving care from one or more carers. Most PwD were being cared for by family, either their spouse/partner or their child/ren. Around 42 per cent of main carers of a person with dementia were the spouse/partner of the care recipient and 44 per cent were the son or daughter.

5.1.2 *Current project findings*

In this final report, the team have responded to three research questions based on insights provided by home and community care providers (n=44), PwD who live in the community (n=5) and carers of PwD (n=7):

RQ3: How do people's initial housing circumstances impact on their housing and care pathways, including their transition into residential care?

RQ4: To what extent are existing community care programs able to adequately support PwD effectively across a range of home settings, particularly those in low cost and insecure housing situations?

RQ5: What policy responses and measures could better support practitioners, housing providers and family carers to respond effectively to the future housing and support needs of PwD?

Addressing inequalities in the housing and care pathways of PwD

RQ3: How do people's initial housing circumstances impact on their housing and care pathways, including their transition into residential care?

A consistent theme throughout consultation with service providers, PwD and carers was the significance of a stable and secure living environment to retaining independence and quality of life. Those in stable and secure accommodation can live well for longer periods in the community than those who are not in this situation. PwD find changes in their living and care environment distressing.

Housing tenure is important in maintaining quality of life in the community. High levels of owner-occupation, including outright ownership, among older people is a critical factor in providing people with a secure home base. While the benefits of home ownership are widely distributed among people over 65 years, growth in housing affordability problems in Australia over the past two decades may see declining levels of full-ownership in years to come. There are also key groups in the community who do not experience the same high levels of home ownership and wealth, including Indigenous Australians, refugees and some migrant groups. In an ideal situation, families have access to sufficient financial resources to undertake minor modifications to the environment to support PwD to manage at home and to compensate for loss of function over time. The home is also increasingly managed to support the care and health needs of the PwD, with families accessing a range of home-based services such as home cleaning, gardening, meals on wheels, showering and personal care, and medication management.

While public rental can provide security and stability that is equivalent to owner-occupation, those living in private rental are at risk of housing insecurity. There may be exceptions. For example, in our study one couple had been living in their son's private rental property for 16 years. Most insecure are those PwD living in caravan park accommodation or in short-term lease arrangements. This form of housing is also recognised as problematic for PwD due to lack of access to adequate bathroom facilities and exclusion from home-based service support.

In terms of adapting their living environment, people living in public rental are able to access modifications to support their personal care needs. In contrast, access to modifications in private rental is dependent on the landlord's discretion. It may also require a level of negotiation around the costs of the modification, which may be difficult for PwD and their families. Difficulties such as housing insecurity and an inappropriate environment that cannot

be easily adapted make it difficult for PwD to retain quality of life and can facilitate early transition to residential care.

Notably, regardless of tenure, capacity to adapt the home environment is dependent on the household's capacity to articulate this need. Those who live at home alone in private ownership, private rental or public rental are at risk of not receiving the benefits of modification until this becomes problematic for families or service providers as they are unlikely to initiate change to their environment.

The issue of duty of care towards people living in public rental housing was raised by service providers. SHAs are operating in a constrained funding environment and there have been significant structural changes in the social housing sector. In both states, due to changes in the *Residential Tenancy Act* and funding constraints, property inspections are less frequent. In Tasmania, a model of separated support provision through an external, one-stop agency, *Housing Connect*, has also limited tenant engagement. Without this tenant engagement, there is limited capacity to informally monitor people's capacity to manage at home and their risks of self-harm. In contrast to the Tasmanian situation, social workers in South Australia were optimistic that housing visits may increase and that frequency of visits might be flexible according to tenant needs.

Service providers also consistently noted that household composition is equally important to the quality of life of PwD living in the community. A live-in carer, either husband or wife, provides warmth, love, compassion and companionship, all of which contribute to quality of life. Practically, a live-in carer can organise modifications and can make minor adjustments around the home to compensate for loss of function. Moreover, the support needs of PwD are high and increase as the condition progresses. The family member finds themselves increasingly taking over all the home management tasks, as well as taking on the personal care and health management tasks of the PwD.

Those who live alone can access similar levels of home-based support to couples. In our study, we spoke to six PwD who were living at home well. Their children were attending their parents' home almost every day and their children were also playing a critical role in accessing and coordinating home-based services. Their children, however, were under significant pressure as they juggled to raise children, maintain employment and support their aged-parent. In contrast to live-in carers, regular visiting carers are unable to stay overnight and consequently there are greater risks that emerge as the condition progresses. It is less likely that a PwD on their own will be able to sustain quality of life in the community for the length of time that someone who lives with a supportive husband and wife can.

Housing security and financial security was recognised as important in providing families with choice when seeking out residential care options. However, service providers raised concerns about the rise in elder abuse in the community and identified the need for greater community awareness about this issue. They noted that this was an issue in relation to housing as the high costs of quality residential care may encourage relatives to delay this transition without regard to the person's health care needs and without adequate family supports to compensate for loss of function around the home. They emphasised the need to get an independent administrator in place when family members are unable to manage their relative's finances and when conflict arises within families.

Further, a key problem identified through the consultation was the lack of appropriate, affordable housing options for people who have complex needs and who are marginally housed. Service providers were concerned about declining investment in public housing, which would limit affordable and stable housing options for people in the future. Service providers noted that service-integrated housing options for PwD who have experienced housing and financial insecurity throughout their life are limited. The gold standard in Australia is specialist housing provider, Wintringham.

Supporting PwD to live well in the community in a range of housing settings

RQ4: To what extent are existing community care programs able to adequately support PwD effectively across a range of home settings, particularly those in low cost and insecure housing situations?

The Aged Care sector is currently undergoing significant policy reform, which includes the introduction of a new approach to the delivery of community care programs. A centrepiece of this reform is the introduction of Consumer Directed Care (CDC). From 1 July 2015, all Home Care Packages provided through the Commonwealth Home Support Program (CHSP) will offer CDC¹¹. CDC aims to give older people and their carers greater say about the types of care services they receive and the delivery of those services. The new CHSP incorporates home care service packages previously provided through the Commonwealth's Home and Community Care program (HACC). It will also incorporate the Assistance with Care and Housing for the Aged (ACHA) program¹², which provides older people who are homeless or at risk of homelessness with assistance with finding accommodation, financial and legal work, and accessing personal care and health care services.

In regard to these reforms, participants noted that the issue of choice was problematic for people who are experiencing dementia. While a family carer would be able to advocate for their care-recipient, a person living alone would need access to an advocate or would rely on trusted service providers to assist with this process. Participants were also concerned that in an environment that encourages competition between service providers and a focus on discrete service activities, some of the things that are less tangible and not easily calculated, such as building trust and rapport between clients, carers and service providers, might disappear. In particular, participants noted that CDC was problematic for vulnerable people living in marginal housing situations.

A key issue raised by service providers was the importance of early diagnosis to improving health and wellbeing outcomes. The consultation highlighted that people experienced delays in diagnosis across all home settings and that delays in diagnosis can impact negatively on people's housing and care pathways. The reasons for a delay in diagnosis are multiple: high levels of stigma and discrimination towards PwD in our society, fear of progressive loss of function and terminal nature of dementia, complexity and diversity of symptoms means that it is challenging for GPs to diagnose, cultural differences in understanding about dementia, and people who live alone and who may be experiencing dementia may not recognise what is going on and only in a crisis situation such as hospitalisation does this come to anyone's attention. Service providers saw a need to continue the positive work undertaken by Alzheimer's Australia to raise community awareness about dementia and address discrimination towards people with dementia.

In relation to delivering care in people's homes, a consistent theme through the consultation was the central role played by family carers in supporting PwD to live well in the community. Both service providers and carers emphasised the importance of continuity of care. This included: consistency in care providers who over time get to know the person and their individual needs, and consistency in care routines. Any changes can be distressing for PwD. Service providers noted that there was a need for medical staff and home-based care workers to work with families and to try to establish a good, working partnership.

When asked about their satisfaction with home-based support, carers were concerned about being able to readily access information about their options. They felt that they were not being provided with an overview of the range of home-based support services available. They wanted face-to-face support initially to help them navigate a complex and fragmented system.

¹¹ See: <http://www.myagedcare.gov.au/aged-care-services/home-care-packages>

¹² See: <http://www.myagedcare.gov.au/aged-care-services/assistance-care-and-housing-aged>

Carers also reflected that the period following diagnosis of dementia is very difficult and emotional and they needed more support to absorb information and make decisions. In SA, carers observed that tapping into peer support was helpful in finding information and making decisions. While carers were grateful for the home-based support they received, they felt that it was not comprehensive and that its effectiveness depended on additional support provided by the family.

In relation to people living in low cost and insecure housing situations, service providers saw significant gaps and challenges in relation to: obtaining a diagnosis of dementia and an ACAT assessment; addressing the range of complex health and housing needs to achieve a stable environment; determining elder abuse if present and addressing this through removing the person from that situation; and accessing affordable, secure and appropriate housing, where the person can experience a stable living environment and can receive home-based support.

Service providers identified potential solutions to these issues, including the importance of inter-agency collaboration (i.e. police, nursing staff, housing providers and social workers) and the need for ongoing case management to ensure that people with complex needs at risk of homelessness were able to continue to access the supports they required. While case management is currently available, service providers noted that this required substantially more funding to enable providers to manage cases over a longer period of time. This is essential as older PwD often have a range of complex health needs that take time to stabilise. Service providers also face difficulties in determining the source of problems such as elder abuse and other impacts arising from dementia and behavioural changes such as unpaid bills. Service providers also highlighted the need for outreach cognitive screening as it is unlikely that people living in precarious and marginal housing situations would attend dementia specialist clinics.

When consulted, SHAs noted that they were operating in a constrained funding environment and experiencing significant structural change. There was uncertainty about the role of SHAs in delivering an appropriate living environment for tenants with dementia and supporting tenants to access home-based support services. In Tasmania, in particular, there has been an increasing separation between housing provision and support and a reduction in the frequency of property inspections, which has resulted in a decline in tenant engagement. Without tenant engagement, there is limited capacity to informally monitor people's capacity to manage at home and their risks of self-harm. While SHAs are able to modify properties when requested and are able to move tenants to more appropriate housing if required, there is an issue of duty of care towards PwD who live alone and who often are unable to initiate these agency-responses. Our study was qualitative and exploratory, but in Tasmania the slow, bureaucratic response of SHAs was identified as a source of frustration. This was contrasted with the effectiveness and 'generosity' of the Department of Veteran Affairs. This situation highlights the importance of adequate and sustainable funding for SHAs or community organisations to enable housing providers to take on a duty of care role in relation to tenants who are experiencing dementia.

Regardless of people's housing situation, service providers and carers highlighted that there is growing demand for community services that offer PwD a chance to participate in meaningful and stimulating activities. In SA, carers were able to access regular respite services that offered their husband/wife or parent these opportunities outside the home. This was important in providing the PwD with a sense of purpose and identity. It was also important in providing live-in carers with some time away from the demands of caring for their family member. Service providers also observed that there is a growing need for a range of innovative respite services to ensure that the carer can cope and can continue to provide care. Respite might entail regular activities outside the home, home visits so that the carer can leave the PwD at home safely, overnight and weekend stays, and/or extended stays. Accessing respite was viewed as

critical to stimulating the PwD, managing high care burdens, and making transitions to residential care easier by familiarising the PwD with this environment gradually over time.

Policy responses to address the housing and support needs of PwD

RQ5: What policy responses and measures could better support practitioners, housing providers and family carers to respond effectively to the future housing and support needs of PwD?

The project has highlighted a range of areas for policy reform and innovation. These include increase community awareness and addressing discrimination, expanding advocacy and case management services to support people in marginal housing situations, building knowledge of the experience of living in the community with dementia and pathways to support among housing providers, review impact of social housing policy reforms on tenants with dementia, expand affordable, service-integrated housing, and expand and innovate respite services.

Build community awareness and address discrimination

There is a need to continue the positive work undertaken by Alzheimer's Australia to raise community awareness about dementia and address discrimination towards people with memory loss. This awareness-raising, particularly in relation to living well with dementia, is important in increasing early diagnoses of dementia, which is essential in accessing support and can improve health outcomes for the PwD. More awareness of the potential for elder abuse is also required.

Discrimination towards people with dementia can occur across a range of housing settings. However, our consultation highlighted that currently home modifications are less likely to occur in private rental. A community campaign may build understanding among landlords about the importance of housing security, as well as minor modifications to a home in enabling PwD to live with dignity and retain independence in the community. Service providers also observed that some residential villages exclude people with a diagnosis of dementia. There is a need to provide education about living well in the community with dementia and this entails being able to age in place without fear of losing one's home.

Community awareness raising might also entail the facilitation of additional opportunities for peer support groups for carers who are supporting PwD in the community than are available at present. This can address problems of information barriers and fragmented services and can provide carers with much-needed emotional and practical support.

Advocacy and case management

There is a growing need for advocacy for PwD in the community. This is important for people living in precarious and marginal housing situations, as well as PwD who are living alone and who do not have family support. With a shift towards CDC, there may also be an increased demand for an independent advocate to support PwD to navigate a complex and fragmented health care system and to make decisions regarding home-based support and future residential care. Currently, there are state-based disparities in the costs of appointing a Public Trustee to people whose decision-making is impaired because of cognitive issues.

While case management is currently available to PwD who are experiencing financial and housing insecurity, this requires substantially more funding to enable providers to manage cases over a longer period of time and to facilitate effective inter-agency collaboration.

Build knowledge of the experience of living in the community with dementia and pathways to support among housing providers

There is a need for education about brain health and dementia service support pathways within the social housing and homelessness sector. This is important in enabling service providers to respond appropriately to complex situations where mental health issues, and/or dementia may

be present. It is also important in achieving inter-agency collaboration and enabling PwD to access appropriate, stable housing and support services in a timely way.

An expansion of brain health initiatives among the homelessness population and the introduction of outreach cognitive screening would address current delays in people living in marginal and precarious housing situations receiving diagnosis and support.

Review impact of social housing policy reforms on tenants living with dementia

There is a need for adequate and sustainable funding for SHAs and/or community organisations to enable housing providers to take on a duty-of-care role in relation to tenants who are experiencing dementia.

There is a need to address uncertainty about the role of SHAs in delivering an appropriate living environment for tenants with dementia and supporting tenants to access home-based support services. A comparison of best practice across the states and territories has the potential to reduce disparities and improve service delivery.

Any future reforms to the social housing sector need to review the impact of such reforms on tenants living with dementia. For example, reforms that further contribute to both declining tenant engagement and declining organisational knowledge about tenant needs reduce the capacity of housing providers to provide duty of care towards tenants living with dementia.

Expand affordable, service-integrated housing

The study has highlighted the importance of secure and stable housing for enabling PwD to live well in the community. It is also important that the house is relatively easy to maintain and that it is designed with accessibility issues in mind. Much of Australia's housing stock does not perform well on either of these measures. Across the board, there is a growing need for new housing options that are designed with accessibility in mind and access to onsite-services.

Service-integrated housing options for PwD, in particular those who have experienced housing and financial insecurity throughout their life are limited. The gold standard in Australia is specialist housing provider, Wintringham.

There is also a need for additional housing options and support services for people with early onset dementia (under 65 years).

Expand and innovate respite services

There is growing demand for a range of innovative respite services to ensure that family carers of PwD living in the community can cope and can continue to provide care. There is also growing demand for community services that offer PwD a chance to participate in meaningful and stimulating activities. Respite might entail regular activities outside the home and/or home visits so that the carer can leave the PwD at home safely, overnight and weekend stays, and/or extended stays. Accessing respite was viewed as critical to: stimulating the PwD, managing high care burdens, and making transitions to residential care easier by familiarising the PwD with this environment gradually over time.

5.2 Future research directions

While the project has provided insight into a range of issues relating to the future housing and support needs of PwD, there is scope for further research in this area.

This project has highlighted the central role of stable and secure housing in enabling PwD to maintain quality of life. However, there is a need for further understanding of the economic context in which housing decisions by older people are made. This would build on previous AHURI-funded work by Bridge et al. (2008).

There is also a need for an understanding of supply-constraints in relation to new service-integrated housing models, as well as research that examines the effectiveness of different

housing models to support people to age in place. This includes further research into the extent to which people with dementia are supported to age in place in a range of housing models, including retirement village developments.

While change is distressing for PwD, pre-emptive downsizing to a home that is manageable, comfortable and well-designed (particularly for accessibility) can facilitate quality of life for people as they age. Further research on barriers to people moving to age-appropriate housing is required, including the financial disincentives within the taxation system and the lack of age-appropriate housing supply across urban areas. Another gap is the lack of understanding of the costs to individuals of managing health and housing needs in later life and the impact of care decisions on housing and financial stress. The decision to move a PwD into residential care can have an impact on the wife/husband who is left in the home who must cover the costs of care. They are faced with decisions of staying in the home or downsizing to a more manageable residence. Depending on fee structures, selling the family home and increasing financial assets could potentially result in higher payments for care. Selling the family home also impacts on children's inheritance.

While this project has highlighted the lack of housing options and support services for people experiencing earlier onset dementia, there is a need for further research on the specific housing and support needs of people under 65 who are living with dementia. Younger people faced problems accessing an Aged Care Assessment in order to qualify for an aged care package. On obtaining a diagnosis, they then faced problems accessing appropriate services and housing. This work would be valuable in reforming current disparities in service access based on age rather than health care need. This work would also be valuable in canvassing and evaluating appropriate community-based support services and housing options for this group.

Finally, the initial literature review on housing and dementia detailed in the Positioning Paper highlighted the need for greater understanding of housing and support needs of Indigenous people with dementia. The review found that poor living conditions and poor quality housing exacerbate problems for Indigenous people in remote areas with dementia. There is a need for culturally-appropriate research in partnership with Indigenous communities about the housing and support needs of Indigenous PwD in urban, regional and remote areas. While the consultation with housing and community care providers highlighted disparities between regional and urban areas in terms of service provision, insights into the experience of communities in remote areas was outside the scope of the project.

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APPENDICES

Appendix 1: Interview schedule for housing providers

This project examines the role of housing in supporting people with memory loss. We are particularly interested in the experiences of people living in marginal housing situations.

1. There are increasing prevalence rates of dementia in the community. Is this a concern issue that has implications for your organisation?
2. Has your organisation in place any programs or services to support the health and wellbeing needs of older residents and also, in particular, people with memory loss?
3. Are you aware of any residents in your housing developments who are currently receiving home-based care? Are you aware of those who are receiving high level home-based care (i.e. Home Care Level 4 packages)?
4. To what extent would tenancy managers or support workers in your organisation be liaising/communicating with health and support service providers for older people, including people with memory loss?
5. Do you think housing managers or support workers in your organisation have any direct experience in relation to assisting people with memory loss? Can you think of any examples—positive/negative?
6. Are your tenancy managers or support workers currently playing a role in identifying signs of memory loss among residents and putting those residents in touch with appropriate assessment and support services?
7. Do you think that they are well placed to take on this role of identifying signs of memory loss and putting those residents in touch with appropriate assessment and support services?
8. Do you think that tenancy managers and/or support workers are sufficiently knowledgeable and skilled to be able to support residents with memory loss? Do you think specialised training is required to enable tenancy managers and/or support workers to manage issues arising with tenancies of people with memory loss issues?
9. Can you think of examples where a person's memory loss might impact on their tenancy and whether or not they received adequate support?
10. Are you aware of the challenges associated with residents with memory loss who live alone, as opposed to those living with their wife/husband or family?
11. Are you aware of the challenges associated with residents with memory loss who are from a range of cultural backgrounds, that is. recent refugee and humanitarian intake, long-term migrants from non-English-speaking backgrounds?.
12. Have you any knowledge of how a person's initial housing situation or their housing circumstances (i.e. living with a partner) impacts on her/his housing and care pathway, including her/his transition into residential care?
13. What do you think could be done by the housing, health and human services sector to improve the quality of life for people with memory loss who are living in a range of housing circumstances?
14. What policy responses and measures could better support practitioners and housing providers to respond effectively to the future housing and support needs of PwD?
15. What impact might the National Disability Insurance Scheme have on the provision of housing and support services for people with memory loss?
16. Is there anything else that you would like to add?

Appendix 2: Interview schedule for community care providers

Introduction

1. Could you tell me about your organisation's role in delivering home-based services and care for people with memory loss?
2. What are the major challenges associated with delivering home-based care and support for people with memory loss?

Housing

This project examines the role of housing in supporting people with memory loss. We are particularly interested in the experiences of people living in marginal housing situations.

3. Does your program deliver support services to people living with memory loss in different housing situations and tenure, including owner-occupation, private rental, social housing and public housing?
4. If so, what do you think are the key challenges associated with delivering services to people with memory loss living in marginal housing situations?
5. To what extent would practitioners delivering home-based community care liaise/communicate with housing managers/tenancy officers?
6. How does a person's housing circumstances impact on the quality and nature of the in-home support services they need?
7. How does a person's initial housing situation impact on her/his housing and care pathway, including her/his transition into residential care? Can you think of some cases/examples?

Role of household and support network

8. Does your program deliver dementia support services to people living in different household types, including single, couple, group and multi-generational households?
9. How does a person's household situation impact on the quality and nature of the in-home support services they need?
10. What challenges arise in relation to providing home-based care to people living alone compared with those living with a partner/family situation?
11. What challenges arise in relation to providing home-based care to people with memory loss from a range of cultural backgrounds, that is, recent refugee and humanitarian intake, long-term migrants from non-English-speaking backgrounds?

Recent reforms

12. There have been some recent reforms to provision of aged care support services with 'Extended Aged Care at Home Dementia' packages being replaced with Home Care Level 4 packages and a Dementia and Cognition supplement paid to providers. How has this reform impacted on the delivery of home-based care for people with memory loss?
13. A key area of reform relates to a consumer-directed approach to home-based care. How is this being implemented? What does the introduction of Consumer Directed Care mean in relation to support services for people with memory loss?

Future reform

14. What do you think could be done by the housing, health and human services sector to improve the quality of life for people with memory loss who are living in a range of housing circumstances?
15. What policy responses and measures could better support practitioners and housing providers to respond effectively to the future housing and support needs of PwD?

16. What impact might the National Disability Insurance Scheme (NDIS) have on the provision of housing and support services for people with memory loss?
17. Is there anything else that you would like to add?

Appendix 3: Interview schedule for people with memory loss

About your home

1. Can you tell me about your home?
 - How long have you lived here?
 - Are you renting/do you own this home?
2. How do you like to spend your day?
3. What is it like living here?
 - What things do you like/don't like about living here?
4. How important is it to you to stay in your home?
5. Do you think you will keep living here or do you plan to move?

Support in your home

6. Does anyone help you around the home?
 - Does anyone help you with everyday personal and household tasks—cooking, cleaning, showering etc.?
 - Does anyone help you with your finances—paying the bills?
7. Are you satisfied with the help you receive at home?
 - How could this help be improved?
8. Would you like any extra help at home? Are there any other services that would assist you?

Managing at home

1. Has your memory loss affected what you can do in your home? How has memory loss affected the way you manage at home?
2. Is this home suitable/easy to manage?
3. Have you considered modifying the home to make it easier for you to live here?
 - Requested any modifications/aware of how this might help?

About your neighbourhood

4. Do you know your neighbours? Do you see them often? Do they help you? How do they help you?
5. How easy is to get out to go shopping/visit friends?
6. How safe do you feel in your home/in this neighbourhood? What would make you feel safer (e.g. lighting, security)?
7. Is there anything else that you would like to say about your life in this home and neighbourhood?

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