



Discussion Paper #7
June 2013

**LIVING
ALONE**

**WITH
DEMENTIA**

**TALKING ABOUT ALZHEIMER'S
ACROSS AUSTRALIA**
FIGHTDEMENTIA.ORG.AU

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Alzheimer's Australia respectfully acknowledges the Traditional Owners of the land throughout Australia and their continuing connection to country. We pay respect to Elders both past and present and extend that respect to all Aboriginal and Torres Strait Islander people who have made a contribution to our organisation.

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ACRONYMS USED IN THIS PAPER

ABS	Australian Bureau of Statistics
ACAP	Aged Care Assessment Program
ACAT	Aged Care Assessment Team
ACHA	Assistance with Care and Housing for the Aged
ACT	Australian Capital Territory
ADHC	Ageing, Disability and Home Care
ADL	Activity of Daily Living
AIHW	Australian Institute of Health and Welfare
AlzNSW	Alzheimer's Australia NSW
BPSD	Behavioural and Psychological Symptoms of Dementia
CACP	Community Aged Care Package
CDC	Consumer Directed Care
DAN	Dementia Advocacy Network
DOHA	Department of Health and Ageing
EACH	Extended Aged Care at Home
EACHD	Extended Aged Care at Home Dementia
GP	General Practitioner
HACC	Home and Community Care
IRT	Illawarra Retirement Trust
LASA	Leading Age Services Australia
NSW	New South Wales
RSL	Returned Services League
UK	United Kingdom
USA	United States of America

EXECUTIVE SUMMARY

The growing number of people living alone, coupled with the increasing number of people with dementia, suggests that the number of people with dementia who live alone is set to rise. Yet there is often an underlying assumption in dementia and aged care policy of the presence and support of a co-resident carer which is reflected in the design and delivery of services. Supporting people with dementia who live alone will become increasingly important requiring social policy and service delivery changes.

People with dementia, when well supported, can continue to live at home alone. However, they can be at heightened risk of economic insecurity, loneliness and depression and have an increased need for community-based or residential aged care. The importance of timely diagnosis and early intervention for all people with dementia, and particularly for those who live alone, cannot be overstated. The earlier community care services are accessed and supports are put in place, the better chance a person with dementia has to live at home in a safe and familiar environment.

People living alone with dementia are particularly vulnerable and it is critical that aged, community and health services are well equipped to support them to maintain their independence in their own home for as long as is possible to avoid premature entry to residential aged care.

This discussion paper aims to inform the Australian and NSW Governments, policy makers and service providers about people with dementia who live alone and to provide recommendations to better support this cohort. The paper will also be of value to people living

alone with dementia, their non-resident carers, and their families and friends.

Alzheimer's Australia NSW is committed to continuing to advocate for people living alone with dementia. We will ensure that the services and programs we deliver reach people living alone with dementia and make a difference to their lives. We will continue to provide counselling, education and support services that address the needs of people living alone with dementia.

Alzheimer's Australia NSW recommends the following:

Australian Government

1. The Australian Government extends the dementia key worker program for people with younger onset dementia to older people with dementia, with a priority target group being people living alone with dementia.
2. The Australian Government ensures community services are targeted and funded to respond to the individual support requirements of people living alone with dementia.
3. The Australian Government provides funding for community dementia education for workers who have contact with people living with dementia, for example, GPs, chemists, bank tellers and retail staff.

4. The Australian Government extends the provision of the Community Visiting Scheme from residential aged care facilities to people living in the community, with priority access provided to people living alone with dementia.
5. The Australian government funds further research on people living alone, including epidemiological studies and investigation into the needs of people living alone with dementia, such as how they can better navigate dementia services and ease their journey into residential aged care.
6. The Australian Government, as part of the *National Framework for Action on Dementia 2013-2017*, develops and funds an ongoing campaign that aims to increase understanding of dementia, to decrease stigma, to increase acceptance of diagnosis and promote help seeking behaviours in people living alone with dementia.

NSW Government

7. The NSW Government ensures that people living alone with dementia are able to access supports identified by the *NSW Dementia Services Framework* and *Draft Implementation Plan 2010-2015*.
8. The NSW Government targets its promotion of planning ahead to people living alone with dementia through actions outlined in the *NSW Ageing Strategy*.
9. The NSW Government invests in volunteering schemes to support people living alone with dementia through the *Community Builders Program*.
10. Housing NSW prioritises people living alone with dementia in social

housing for its daily monitoring service – Tenant Connect.

11. Housing NSW develops and coordinates social events, gatherings and activities targeted to people living alone with dementia in social housing.
12. NSW Health funds and develops a post-hospital community-based program, similar to ComPacks, which accommodates the needs of people living alone with dementia.

Local Governments

13. Local Governments ensure that the safety of people living alone with dementia is addressed through the creation of dementia-friendly environments and neighbourhoods.

Aged, Community and Health Care Providers

14. Aged, community and health care providers provide education and training, such as the 'Experiencing Dementia' program, for staff who support clients living alone with dementia.
15. Aged, community and health care providers discuss planning ahead and long-term care needs with clients living alone with dementia to minimise the risk of crisis situations and premature entry to residential aged care.

Further recommendations for providers will be included in a Research to Practice Paper available in September 2013 on the Alzheimer's Australia NSW website: www.fightdementia.org.au/new-south-wales/research-nsw.aspx

PURPOSE

“All over the place is my memory, I forget everything! It’s been happening for a few years now. But I do everything myself. I’m independent!”

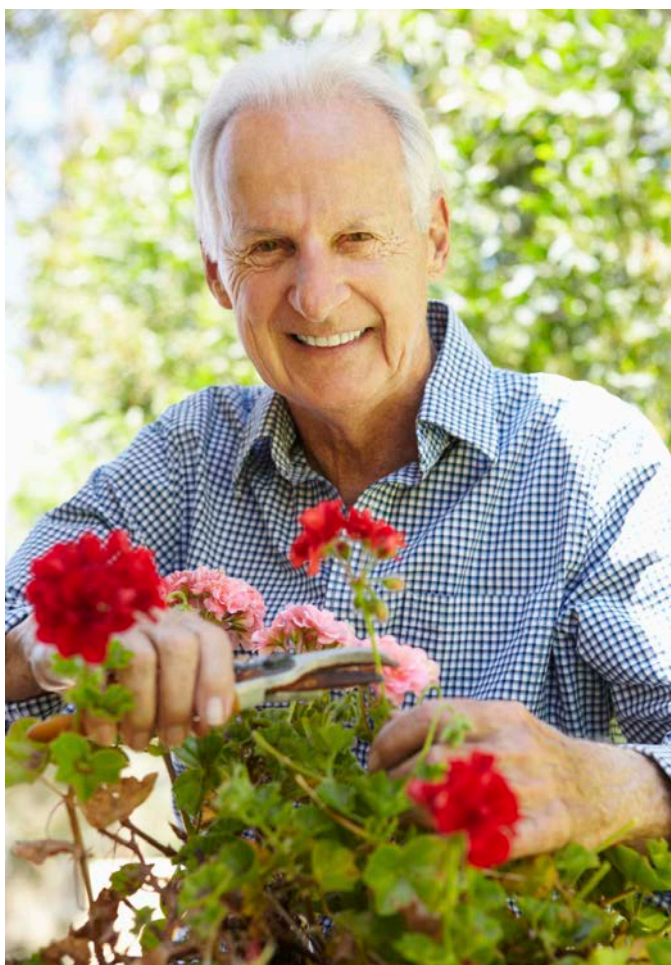
(Jim, 90 years old and living alone with dementia)

This Alzheimer’s Australia NSW (AlzNSW) discussion paper aims to provide a greater insight into the experience of living alone with dementia. It also aims to examine how Governments and service providers can best support people living alone with dementia to maintain their independence.

Current research on the experiences and needs of people with dementia living alone is limited. AlzNSW seeks to expand the body of knowledge about how people with dementia manage to live on their own including what coping strategies they employ, what services assist them, and how their informal networks support them. It also aims to find out how case managers support this client group and to identify improvements that can be made to policies and services to better meet the needs of people living alone with dementia.

This discussion paper will inform the Australian and NSW Governments, policy makers and service providers about people with dementia who live alone and provide recommendations to better support this cohort. The paper will also be of value to people living alone with dementia and their families and friends. People living alone with dementia are particularly vulnerable and it is critical that aged, community

and health services are well equipped to support them to maintain their independence in their own home for as long as is possible to avoid premature entry to residential aged care.



BACKGROUND

What is the issue?

Over recent years there has been an increase of the number of people living alone. At the 2011 census almost 25% of households were single person households, compared to only 11% in 1961^{1,2}. This equates to approximately 2 million people and the Australian Bureau of Statistics (ABS) projects that this number will continue to rise³. 31% of Australians aged over 75 years currently live alone⁴. Living alone becomes more common with age and thus the increasing prevalence of living alone is in part due to the ageing of the Australian population. However other social factors, such as the tendency of younger and middle aged people to live alone and more freedom to end relationships or remain single, are also contributing to the projected increase⁵.

Simultaneously we have an increasing number of people with dementia. There are more than 321,000 Australians currently living with dementia⁶ and without a significant medical breakthrough that number is expected to increase to more than 900,000 by 2050⁷. The Australian Institute of Health and Welfare (AIHW) has estimated that 70% of people with dementia live at home in the community, rather than in residential aged care facilities⁸. Living at home is often preferable for people with dementia as they are in a safe familiar environment with a routine and are known to neighbours and locals⁹.

Growing numbers of people living alone, coupled with the increasing number of people with dementia, suggests that the number of people with dementia who live alone is set to rise. Research indicates that up to one third of people with dementia who live in the community live alone¹⁰.

^{11, 12, 13}. Given these figures, AlzNSW estimates that currently there may be more than 65,000 Australians living alone with dementia¹. It is likely that there are more women living alone with dementia than men, due to trends in living arrangements, life expectancy and rates of dementia^{14, 15}.

Supporting people with dementia who live alone will become an increasingly important social policy and service delivery task. This situation presents challenges for Governments, policy makers and providers of aged, community and health care services.

Policy response

There is an often underlying assumption in dementia and aged care policy of the presence and support of a co-resident carer which is reflected in the design and delivery of services. This is also evident in public perceptions of the capacity of people with dementia to live alone. A recent UK survey about perceptions of people with dementia found that less than a quarter of respondents believe it is possible for people with dementia to live alone¹⁶.

Organisations that have emerged to represent the interests and needs of carers of people with dementia have often supported Government policy implementation which perpetuates reliance on carers and overlooks the needs of people without co-resident carers. As a result, people living alone with dementia are a cohort that tends to slip through the cracks in policy and service provision.

In addition to the increasing prevalence of dementia and single person households,

¹ Estimate based on reports of 70% of 321,000 Australians with dementia living in the community (AIHW, 2012) and 30% of those 224,700 people living alone.

we are witnessing the declining availability of co-resident carers due to people having fewer or no children and adult children not being in a position to care full-time for ageing parents due to family and work commitments. These factors mean it is likely that there will be more people living alone with dementia in the future. Therefore supporting people with dementia to live at home alone and maintain their independence for as long as is possible is an issue that government, policy makers and service providers need to address.

There is a strong desire among Australians to remain at home as they age. Over 90% of older Australians intend to stay in their current accommodation and 'age in place' rather than move to residential aged care facilities or move at all¹⁷. There is also a Government policy emphasis on supporting people with dementia to remain at home for as long as is practically possible, with a strong focus on the provision of community care services¹⁸. Yet programs often presume that there is a co-resident carer in place and are thus funded and managed accordingly.

There is limited acknowledgement of people living alone with dementia in Australian policy documents. The *NSW Dementia Services Framework 2010-2015* recognises that not all people with dementia have carers with whom they live or have close contact. It notes that people with dementia living alone without carers are at increased risk of adverse outcomes such as social isolation, exploitation, and self-neglect including poor nutrition. The Framework also acknowledges that the number of people living on their own will increase and that demand will increase for suitable community models and access to services that can monitor their safety, support them to remain in the community and assist in the transition to supported accommodation when required¹⁹. Yet there is no reference to people living alone with dementia in the *Draft Implementation Plan for the Framework*²⁰.

A priority in the *National Framework for Action on Dementia 2006-2010* was to identify the specific barriers to the access of care and support for people living alone with dementia²¹. Dementia was made a National Health Priority in 2012 and the Consultation Paper of the *National Framework for Action on Dementia 2013-2017* identifies people living alone with dementia as one of eight 'diverse needs groups'²².

The Australian Government's *Living Longer. Living Better.* aged care reform package "will provide additional financial assistance to people with dementia who are receiving Home Care packages through a new Dementia Supplement of 10% on top of the base funding for the package"²³. However people with dementia who live alone are not identified as a special needs group and no additional funding has been allocated to provide specific support for this cohort.

Service response

Support to people living alone with dementia can be provided through a number of services and programs, however there are very few services specifically designed to support people with dementia who live alone. Support to maintain independence may currently be provided by the following Government funded programs.

Home and Community Care (HACC) services are jointly funded by the NSW and Australian Governments and are designed to help older people and people with disability to remain at home and prevent their inappropriate or premature admission to residential care. Assistance provided through HACC includes help with household chores, health and personal care, activities and transport, short breaks and home maintenance and modification²⁴.

Dementia Monitoring services are funded through the HACC program through the Social Support – Monitoring program. These services are designed to monitor



the health and well-being of people who are living in the community and who, in the absence of basic maintenance and support services, are at risk of premature or inappropriate long term residential care. People living alone are one of the target groups for this program. Through regular home visits dementia monitoring programs aim to maximise the ability of people with dementia to remain independent while fulfilling the need for social contact. Dementia monitoring staff can make referrals to other services and introduce their clients to other programs²⁵.

The Australian Government funds aged care services in the community. *Community Aged Care Packages* (CACP) target older people living in the community with care needs equivalent to at least low-level residential aged care. The types of assistance provided through a CACP include personal care, meals, domestic assistance and transport²⁶. *Extended Aged Care at Home* (EACH) packages are provided to older people living at home with care needs equivalent to high-level residential

aged care. Services available through an EACH package may include clinical care, personal assistance, meal preparation, continence management, therapy services, home safety and modification and access to leisure activities. *Extended Aged Care at Home Dementia* (EACHD) packages are available for people with dementia and offer additional levels of service to meet the specific care needs of those who experience behavioural and psychological symptoms of dementia (BPSD)^{27, 28}. To access CACPs, EACH and EACHD packages an assessment by an Aged Care Assessment Team (ACAT) is required.

The AIHW reports that 34% of Aged Care Assessment Program (ACAP) clients with dementia living in the community live alone, with women with dementia more likely to live alone than men (41% and 22% respectively). The Community Care Census in 2008 found that 53.4% of CACP recipients with dementia live alone however only 25.3% of EACH and 23.1% of EACHD package clients live alone²⁹.

The *Assistance with Care and Housing for the Aged* (ACHA) program supports older people who are not in secure housing arrangements, or who are homeless. The program helps clients live in, participate, and feel included in the community of their choice, by facilitating access to sustainable and affordable housing. The program includes activities such as locating suitable accommodation, providing advice on housing applications, coordinating removals and assisting access to accommodation-related legal and financial services. ACHA links clients to appropriate community care and welfare services; it does not provide ongoing care³⁰. Given the target population for this service, it is likely that this program assists people living alone with dementia, and many of the clients of the program will have undiagnosed dementia.

CURRENT LITERATURE

A review of Australian and international literature found that people living alone with dementia are more likely to be female, have lower incomes, and are less likely to have a formal diagnosis of dementia as they do not have others around them observing early changes in memory and behaviour. They are therefore less likely to use support services and may not receive any formal support until a crisis situation arises and they are admitted to hospital or alerted to community services^{31, 32, 33}.

People living alone with dementia are at heightened risk of economic insecurity, loneliness and depression and have an increased need for community-based or residential aged care³⁴.

People with dementia who live alone are placed in residential care earlier on average than people with similar impairments who live with others. This may be related to the increased risk of malnutrition, illness and fall-related injuries among people with dementia who live alone compared to those who live with others³⁵.

Dementia can cause impairments that reduce an individual's ability to remain safe at home due to compromised balance and mobility, judgment, sense of time and place, orientation and recognition of environmental cues, and changes in vision or hearing. The literature^{36, 37, 38} identifies many safety issues and challenges people living alone with dementia may face including greater risk of problems with nutrition, falls, hygiene, household fires, and money and medication management. Given these safety concerns, there is a significant amount of literature^{39, 40, 41, 42, 43} regarding risk and people living alone with dementia.

Limited research has been conducted with

people living alone with dementia about their experiences, the challenges they face, what support they receive and how they cope on their own at home. De Witt et al. (2009) interviewed eight older women with dementia living alone in Canada in a phenomenological study to understand the meaning of living alone for older people with dementia⁴⁴. Frazer et al. (2012) conducted interviews with eight older women with dementia who live alone in the UK to examine how they cope with the impact of dementia. Some interviewees coped through acceptance while others viewed dementia as an adversary to overcome. Maintaining their independence was very important and having to move into residential care was feared and viewed as 'giving up' and as a loss of freedom⁴⁵.

In Australia, Duane et al. (2011) conducted interviews with nineteen older people with dementia who live alone with cognitive impairment or early stage dementia about their lives and how they remain connected to and supported by others. The research sought to develop an understanding of the strengths and capacities of older people who live alone with dementia. Participants in this research often denied having a diagnosis however they did recognize their memory loss and how it affects them^{46, 47}. Another recent study⁴⁸ interviewed seven people with dementia who live alone in Tasmania about what being at home means to them and how they can be supported to remain at home.

Most recently, research by the Alzheimer's Society in the UK found that nearly two-thirds of people with dementia who live alone reported feeling lonely. The Alzheimer's Society argues that addressing health and care needs alone is not enough and that more emphasis needs to be placed on equipping communities to deal with dementia⁴⁹.

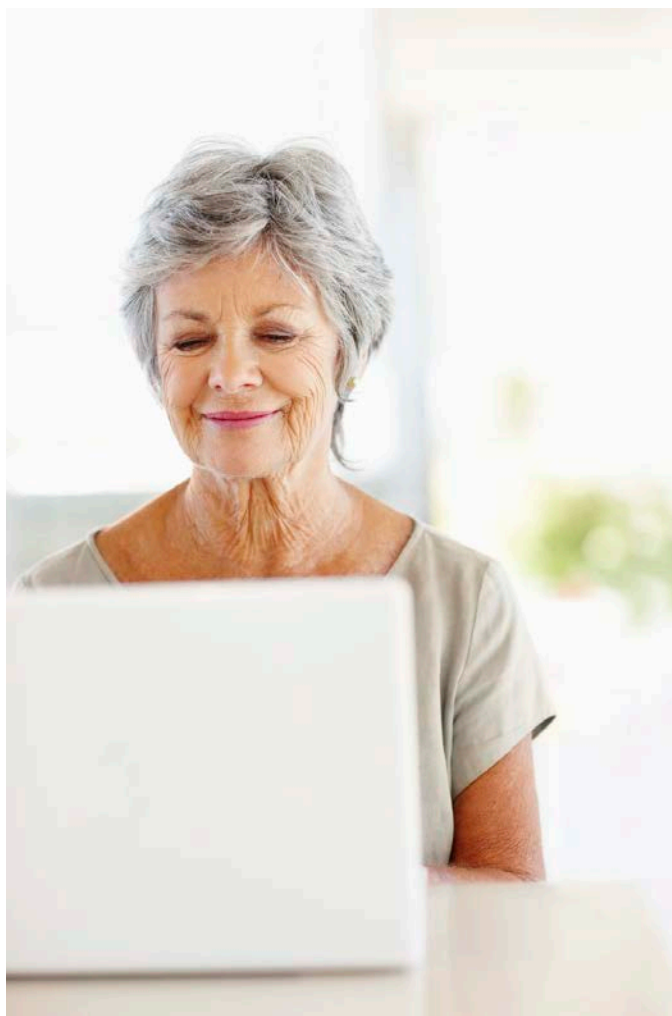
METHODOLOGY

AlzNSW received a grant from the IRT Research Foundation and in-kind support from IRT to conduct the research for this discussion paper. The research received approval from the Macquarie University Human Research Ethics Committee. During the first phase of the project a literature review was conducted. This review included national and international literature on the characteristics and experiences of people with dementia who live alone, government and policy documents, and grey literature.

Case managers who support people with dementia to live at home alone were invited to complete an online survey about their experiences, challenges and suggestions for improvements. This was distributed via a number of organisations including IRT, NSW Community Options, Leading Age Services Australia (LASA) - NSW and Aged and Community Services - NSW and ACT. The survey was open from late-January to mid-March 2013. The quantitative data was analysed statistically and qualitative data was analysed thematically.

Six interviews were conducted with people living alone with dementia during February and March 2013. Five women and one man were recruited through IRT and AlzNSW client bases and their informed consent to participate was obtained. Two participants chose to have a family member present during the interview; the others participated independently. The interviews were semi-structured and conducted in the homes of each participant. Issues explored through the interviews included informal and formal support received, challenges they face living alone with dementia, and strategies they use to help them live at home. The data collected from the interviews was analysed thematically.

Following data collection and analysis, a workshop was held in April 2013 with staff from AlzNSW and IRT to discuss the research findings and the service and policy implications, and to develop recommendations for policy and practice reform.



RESULTS

Survey

The online survey was completed by 101 case managers distributed across NSW Local Planning Areas. Respondents have been working as case managers from one month to thirty years, with the average length of time working as a case manager being 7.3 years. The caseload of clients living alone with dementia varied significantly among case managers, as did the amount of time spent supporting these clients.

Support provided

Respondents indicated that they organise a vast range of supports for their clients who live alone with dementia including domestic assistance, personal care, meal and medication monitoring, and encouraging community participation (see Table 1 below).

Use of assistive technologies

Assistive technologies enable a person to perform a task that they would otherwise be unable to do and can be part of the solution to assist people with dementia to remain independent in their own home. Such technologies include medication reminders, emergency response systems, videophones, temperature monitors for the house and refrigerator, robots for companionship, global positioning systems, and preprogrammed music and lighting⁵⁰. The main types of assistive technology put in by case managers to support clients living alone with dementia are medication dispensers, emergency alarm call systems and timed reminders on clocks and calendars.

Case managers were asked to indicate their level of agreement with the statement:

Table 1: What type of support do you arrange for your clients?	Response % N= 98
Assistance with meals and nutrition	92.9%
Domestic assistance	92.9%
Assistance with personal hygiene and grooming	91.8%
Monitoring general health and well-being of clients through regular home visits	87.8%
Organising transport to appointments and activities	86.7%
Monitoring medication management	85.7%
Assistance with coordinating appointments and planning daily activities	84.7%
Encouraging and engaging in social/community activity	84.7%
Assistance with dressing and undressing	81.6%
Continence management	71.4%
Goal-based planning	69.4%
Telephone-based personal alarm systems	62.2%
Home modifications	53.1%
Telephone-based monitoring services	25.5%
Functional transfers	26.5%

Assistive technology can be very useful for clients living alone with dementia. 70% of respondents agreed that assistive technology can be useful for people with dementia who live alone.

“These technologies assist clients to feel safe and more in control of their own environment and life in general, and helps them feel supported in their own homes.”

Yet several respondents who agreed with this statement conceded assistive technologies can only be useful for some clients for a *limited* amount of time.

“For individuals that have been diagnosed early and have gained a pattern of the use of assistive technologies they can make enormous difference to the quality of life. However as the dementia progresses many clients lose the ability to use the technology.”

These sentiments are consistent with existing research⁵¹ which highlights that technologies are of limited use when the individual lacks the executive function to understand what actions the prompts are designed to help them initiate. Although they have a role to play, assistive technologies often have a narrow time period when they are useful due to the progressive nature of dementia.

Main concerns

Case managers were asked to select their top five concerns about people living alone with dementia from a list of ten items. Overwhelmingly, they were concerned with the safety and the health and well-being of their clients. Consistent with existing research, the top five concerns were:

1. Medication
2. Wandering
3. Falls
4. Malnutrition
5. Exploitation

What is needed?

The survey also asked what would help

individual case managers to better support people with dementia living alone. 87 respondents answered this question and the most common needs included:

- Increased funding and resources

“I feel strongly that the service organisation (in the community care sector) should consider them as a special needs group, and give them top priority. These clients should be allocated more hours and funding. Coordinators of these clients should have reduced caseloads as their case management is more time-consuming than for other clients.”

- Increased flexibility in service delivery

“Greater flexibility in what the package can provide [is required] – at the moment there is little extra, if anything, provided for clients with dementia. They generally need more time in their care package as living alone can mean needing 3 visits a day. They also need an emergency call pendant costed into their package and locked boxes for medications and house access as standard as well. Clients who have dementia and are living alone are often the highest care on a case managers caseload because of the frequency with which issues arise, so more case management time is spent on these clients and this needs to be reflected in caseload weighting and costing of these clients so that providers can afford to hire adequate numbers of good quality case managers to provide adequate care.”

- Higher level of support for people with dementia who live alone

“As a case manager, I have encountered frustration with the ACAT process, where clients with dementia living alone are often assessed as only eligible for a CACP, when many of these clients often need more hours of assistance than CACPs can offer. On occasions where I have tried to

advocate for a client to have their approval reviewed from CACP to EACH, I was told by the ACAT team that because the particular client would only need low care in residential (i.e. would not be high care as she could get in and out of the shower on her own and did not need help with transfers), the client would only be assessed as CACPs. While it was the goal of this particular client to remain in her own home, the services made available to her through the CACP were not enough and she ended up going into permanent care."

- Cooperation from GPs and other health professionals
"A better working relationship with the clients' general practitioners (GP). Sometimes the GPs do not return phone calls or are reluctant to speak to the case managers about their concerns for the client."
- Dementia-specific training for case managers and community care staff
"It would also be very helpful if there was more education and training for care workers (e.g. from HACC services) who have to work closely with people with dementia and at times may have a limited understanding of the condition and impact it has on a person's function, ability to communicate, behaviour etc."

- Home visits

Case managers were asked to select the most important thing people with dementia living alone need in order to maintain their independence. 50% of respondents believe an increased number of home visits is the most important thing needed, followed by greater involvement in the community (see graph one below). This finding is consistent with research conducted which highlights the importance of face-to-face contact and community engagement for people with dementia who live alone⁵².

Interviews

Interviews were conducted with six people living alone with dementia. All interviewees were born in Australia; speak English; are supported by services, and; do not suffer from BPSD such as wandering, aggression or disinhibition.

Dulcie²

Dulcie is a 92 year old widow who lives on her own in southern Sydney. She lives in the family home built in the 1950s and has two sons whom she adores. Dulcie likes to reminisce and tells us a lot about her childhood. Dulcie was diagnosed with dementia four years ago and her insight fluctuates. She sometimes talks about her deceased husband in the present tense: *"We have a car and my husband takes me shopping...we're still good mates!"* Yet at other times she acknowledges that she lives alone *"I'm well and truly on my own now"*. Dulcie receives daily visits for meal and medication management as part of a CACP.

Louise

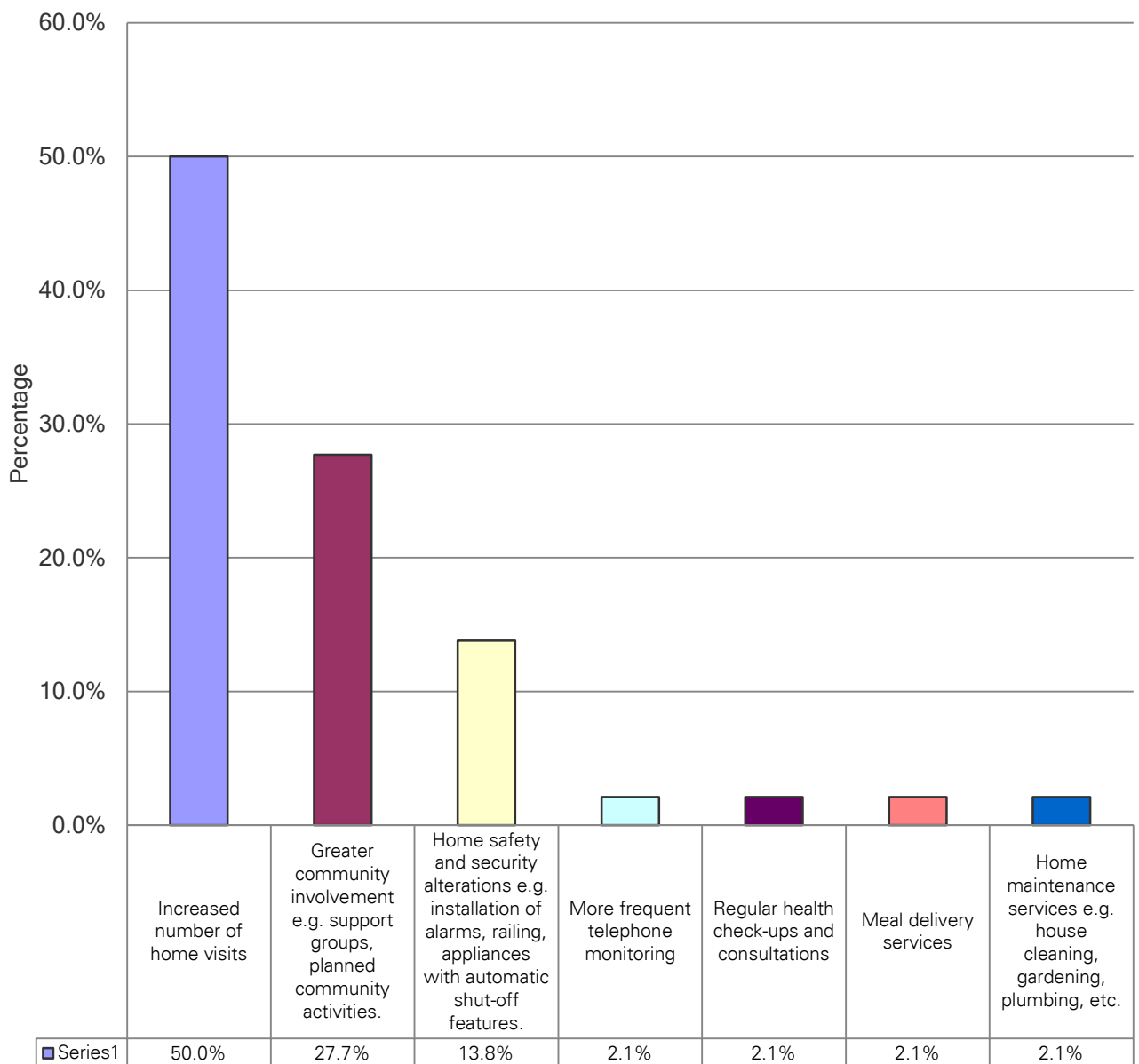
Louise is a 77 year old divorcee who lives with her cat in a small villa in south-west Sydney. She has six children and many grandchildren who live throughout NSW. Louise has mostly lived alone since her divorce over 30 years ago and has lived in her current location for about 8 years. Louise is independent, stubborn and strong-willed. *"I like my independence but I'm getting a bit old for that now. The old grey mare ain't what she used to be!"* Louise was diagnosed with vascular dementia three years ago. She receives support through a CACP which provides medication and meal management, prompts for personal care and shopping assistance.

Gwen

Gwen is 74 years old and has three children and several grandchildren. She lives alone in an apartment in a NSW regional centre. Gwen was diagnosed with Alzheimer's disease eight years ago. Her diagnosis was

² Pseudonyms have been used.

Graph 1: What is the most important thing that people with dementia living alone need in order to maintain their independence?





timely and she has had success with anti-dementia medications which has meant the disease has progressed relatively slowly. *"It has given me more time to plan ahead, to develop strategies to assist to function, to select activities that I can still manage, and to maintain those relationships that are important to me."* Gwen still drives, manages her own affairs and is very independent. She does not yet require any community care services however she is well aware of her limitations and openly discusses the challenges she faces in living with dementia and the strategies she has put in place to manage on her own. Gwen has planned ahead for when the time comes that she can no longer live at home on her own. She has visited hostels in residential aged care facilities and written her directives.

Jim

Jim is 90 years old and lives on his own in the home he built in southern Sydney over 30 years ago. Jim and his now deceased wife divorced in the 1970s and Jim has lived on his own since then. Jim has five children who live all over Australia. He received a diagnosis of dementia several years ago. His hearing is impaired and he walks with a gait but otherwise he is very physically fit and well for someone his age and tells us that keeping fit and eating well are the keys to a long life. Jim was in the navy in the Second World War and a boxer during the 1950s. *"I was in the Battle of the Coral Sea. We saved Australia...and got blown up in a few ships. I've got bumps on my head. I'm lucky to be here...I've kept pretty fit. I boxed all over the world...I was never knocked out"*. Jim receives medication management, prompts for personal care, and transport assistance through a CACP.

Marie

Marie is 77 years old and lives on her own in a regional town in Northern NSW. She has two sons who, although they don't live close by, have been helpful in the past. Marie was diagnosed with cerebral lupus and primary progressive aphasia³ several years ago. Marie has only lived on her own for two years since her husband passed away and describes living alone for the first time as "very scary". She has recently moved into a small housing complex closer to town and feels safer and more secure there. Marie has insight into her limitations and has routines to make the most of her remaining abilities. "I try to schedule appointments in the morning when my brain is clearer and try to have a quieter afternoon." Marie receives support from a case manager and services to assist with meal preparation, shopping and managing her household bills.

The experience of living alone with dementia

Some common traits have been identified that enable these people to live alone with dementia. They are all very independent and the importance of retaining their independence and sense of control over their own lives is evident. They all acknowledge they have dementia and accept that this places some limitations on what they can do on their own. They are therefore willing to accept support from services to assist them in medication and meal management and prompts for personal care.

"I do have some memory problems. Here we go again, how old am I?! [laughs] But I don't think I'm that bad...I think I'm coping okay. I mean, I'm like my mum. At least I know who my kids are. My mum didn't even know who I was, so at least I know my kids...everyone's gonna get old sooner or later and that's it. I mean I can look at myself now and I think geez, I used to get

impatient with my mum and my grandma, you know." (Louise)

"Well my memory's not one hundred per cent! Well, anything important to me is written down, that's how I do it. Over there love, next to the telephone, I write appointments and messages down." (Dulcie)

"People need to recognise and admit to themselves that they are dysfunctional and accept help... if I did not have the help I receive I would not be able to live at home and have my independence" (Marie)

Except for Gwen, who does not require support from services, all participants are receiving low level care through CACPs. Working from a strengths-based approach, they are assisted to continue to do what they still can do and are well supported in areas where they need assistance.

"I keep my place clean, I do all the cleaning. In the navy I learnt how to keep things clean...I'm independent. I do my own cooking and my own housekeeping. I do everything myself." (Jim)

"And these girls [the care workers], I don't know what I'd do without them. I drive them nuts but never mind, they put up with me...I haven't kicked any of them out yet! [laughs] Usually there's someone who comes every day, sometimes I keep up with them, sometimes I don't...but I reckon the old grey mare's not doing too bad." (Louise)

They have supportive families even though they are not co-resident carers. For some it is one particular child who has taken on responsibility for ensuring their parent is coping and is receiving the in-home support needed. Thus even though these people with dementia live alone and do not have a co-resident carer, they are well supported

3 Primary progressive aphasia is the gradual and progressive impairment of word-processing and language function and is a type of frontotemporal degeneration.

by family who ensure that services are well coordinated and advocate on their behalf when required.

"My sons come and check the cupboards and make sure I'm eating well... They're very good and their wives are very concerned. They're lovely girls and when they come over they bring me dinner." (Dulcie)

"If I need anything, I know I can yell. And my youngest daughter and my youngest son are the better ones." (Louise)

All are in the early stages of dementia and/or have a dementia that is not progressing rapidly. Early stage or mild dementia is used to describe the phase when deficits are evident in a number of areas such as memory and personal care, but the person can still function with minimal assistance. Symptoms at this stage may include moderate memory loss for recent events, disorientation in time, difficulties with problem solving, reduced interest in hobbies, and the need for prompting for personal care tasks⁵³. Additionally, they are also relatively physically well for their age cohort.

"For most people it happens much sooner. At the time of diagnosis my expectation, and my doctor's, was that I may have 3 to 5 years before hostel care. I have had 8 years. I am fortunate." (Gwen)

"I've had no trouble [with my health], thank goodness. I've been lucky I suppose. I've managed to stay pretty independent and do everything myself... Everything's a bit worn out now but time carries on." (Jim)

The amount of support they receive from neighbours varies. Living in a small villa complex, Louise knows most of her neighbours quite well and feels comforted knowing that her next door neighbour is a former nurse.

"The lady next door is very good;

she's an ex-nurse too so it's handy to have her." (Louise)

In comparison, Jim and Dulcie do not know their neighbours as their neighbourhoods have changed significantly over time and are now populated by young families.

Although they are living alone they are not necessarily lonely or socially isolated. For example, care workers drop Jim off at the local RSL club every day after they have checked he has taken his medication and showered. Jim spends a few hours there, has a beer or two and then walks the three kilometres back home on his own. Some days he will stop off at the local shops. However Jim also told us,

"I'm a bit of a larrikin! I would go down the pub and have a few beers and race around and have a dance. I used to go out dancing nearly every night. I've probably forgotten how to dance now. But I used to dance all over the world. It stops you from getting too fat! But most of my friends are dead now. I'm getting a bit old... I'm a bit of a loner." (Jim)

There were limited opportunities for social engagement and community participation for some. For example, since relinquishing her drivers' licence Louise can no longer drive herself to the local shops and is frustrated by this loss of freedom. Marie also no longer drives and as a result she finds it more difficult to socialise and feels that she is often excluded.

Dulcie does not get out of the house much anymore but she tells us that she has lots of friends with whom she speaks to over the phone.

"I can't live without the telephone. I have some lovely friends and that. They don't always visit but they're on the phone... I've still got company, they know where the phone is and say don't forget to ring!" (Dulcie)

Gwen and Marie both have specific routines and strategies to help them manage at home on their own. Marie, for example, responds well to colour codes and relies on a wall chart with coloured stickers as reminders for appointments and service visits. While Gwen has developed a morning routine to ensure that she remembers to take her medications.

Elizabeth

The sixth interview participant, Elizabeth, is a contrast to the other interview participants and was included in this project as she is an IRT client who, until recently, lived alone with dementia.

Elizabeth is 85 years old and has vascular dementia as a result of a number of strokes. When her husband died three years ago Elizabeth lived on her own for a while in their duplex house in the outer suburbs of south-west Sydney. Her five children were worried about how Elizabeth would cope without her husband although her youngest daughter, Rebecca, says that dementia has lessened the grief as Elizabeth lives in her memories with her husband. Elizabeth told us that her husband managed their affairs and did most of the household chores. She did not realise how much work was involved and when he died she struggled on her own.

Elizabeth's youngest daughter, Rebecca, has taken early retirement and now cares for Elizabeth at home full-time as the family had concerns about her living on her own. Rebecca told us, *"Mum has never been a person who likes to be on her own, she likes company...and we don't want another fall or broken hip"*.

Elizabeth is physically frail, has mobility limitations, and visual impairment as well as dementia. Compared to the other participants, who continue to live on their own and are able to maintain their independence, Elizabeth's care needs are much higher. Elizabeth and Rebecca appreciate the support they receive through

an EACH package. Elizabeth says, *"I can't find anything I would say I'm disappointed in. I've had so much help"*, while Rebecca tells us, *"Mum loves all the girls who come"*.

Although we cannot generalise from these six case studies, the lives of Dulcie, Louise, Gwen, Marie, Jim and Elizabeth do provide valuable insights into the experience of living alone with dementia.

However the experience of those who we could not access would tell us even more about the difficulties of living alone with dementia. A challenge encountered by AlzNSW in conducting this research project was recruiting people living alone with dementia to participate in the interviews. It appears that many people living alone with dementia either do not understand or accept their diagnosis, or, are embarrassed or ashamed about having dementia. The stigma surrounding 'dementia' is still strong and can present barriers to enabling people living alone with dementia to remain at home independently for as long as possible.

DISCUSSION

This section discusses the research findings and the implications for policy and service provision. Five areas for consideration have been identified and these are examined in detail below.

Acknowledgement of Dementia Diagnosis and Acceptance of Support

One of the most significant barriers to maintaining independence for people living alone with dementia is the lack of acknowledgement or insight that anything is wrong, a lack of acknowledgement of their limitations, and a subsequent refusal to accept offers of assistance and support.

The people living alone with dementia interviewed for this project all recognised that they have dementia and that they need support in some areas of life. They therefore accept assistance from community aged care services to support them with some activities of daily living (ADLs). This may suggest that valuing independence while accepting assistance could be critical to remaining at home alone with dementia.

The survey of case managers highlighted that some of their clients often lack insight and awareness of the extent of dementia and their needs which leads to a reluctance to accept service support. This can be a source of tension and conflict as a survey respondent below explains,

“Another challenge is the client accepting the assistance. Often when it is available, the client does not feel they need it, leading to conflict between family, client and service provider, according to differing values and concerns held by all parties.” (case manager)

There is a tension between independence and help-seeking behaviours; a person living alone with dementia has to acknowledge their limitations and accept help but to do so may impinge on their sense of independence and control. Yet if they do not accept help, the amount of time they can successfully maintain their independence at home, without the support of services and informal supports, is limited.

This also raises the question of what happens to those people who do not receive a dementia diagnosis and consequently do not receive the appropriate support to remain at home. There are documented and anecdotal reports of people living alone with dementia who deteriorate to the point of crisis and who are then placed in residential care prematurely.

The importance of timely diagnosis and early intervention for all people with dementia, and particularly for those who live alone, cannot be overstated. The earlier community care services are accessed and supports are put in place, the better chance a person with dementia has to live at home alone in a safe and familiar environment.

Importance of Informal Support Networks

The survey responses stressed the need for a more holistic community approach to supporting people with dementia to live alone, with support from family, neighbours, local communities, and services required. It is often friends, neighbours and members of local communities that notice the early signs of dementia and raise concerns yet they may not know where to turn for information,



education, support and assistance⁵⁴. Waugh et al. (2004) note that neighbours' knowledge and understanding of dementia and their tolerance of the persons' behaviour are a factor in determining the extent to which a person living alone with dementia can be supported in the community⁵⁵.

The people interviewed for this research who live in free-standing houses reported that they do not know their neighbours because the neighbourhood has changed significantly over time. Could retirement villages and independent living complexes may be more supportive of people living alone with dementia? There is no mention of dementia within the Retirement Village Act (1999) and operators of retirement villages make discretionary decisions about people with dementia living alone moving to residential aged care facilities. This may be done in conjunction with a community aged care provider who is managing the resident's care and support. Further research is required to examine to what extent neighbourhood type impacts on

the capability of people with dementia to remain living alone.

Several case managers indicated that services alone are not sufficient to adequately support people with dementia to remain living at home on their own as the disease progresses and that informal support is also necessary.

Services need be individual, flexible though very coordinated with neighbours and family – otherwise it is not ideal with just service support alone.” (case manager)

“The presence or absence of family support often presents the deciding factor in how long a person with dementia can manage to live alone in their own home.” (case manager)

The people interviewed for this research were well supported by some family members despite not being co-resident carers. The degree of involvement of non-resident carers, rather than their geographic proximity to the person living alone with

dementia, is important. For example, a relative may live hundreds of kilometres away yet if they are in regular contact with the person with dementia and liaise with community care services and other services they can be more supportive than relatives who live nearby who are disengaged.

However, some people living alone with dementia are almost entirely on their own, with limited or no informal support network. Community care workers may be their only real source of support as the survey respondent below explains.

“Service providers supporting people living alone with dementia face the complex issue of being one of the major (sometimes sole) supports for these people. When the service provider leaves for the day, there is often no one visiting until the next service. There is often no one to assist with appointments, medications (insulin is of particular concern), meals, mobility, community access etc.” (case manager)

Living alone however does not necessarily equate to loneliness; loneliness is subjective, whereby an individual can be surrounded by people yet feel lonely. However research conducted by the Alzheimer’s Society (2013), suggests that people with dementia who live alone are both socially isolated and lonely, with few social connections and limited friendships outside of their own family⁵⁶. It is therefore important that services foster and facilitate social engagement and community participation for people with dementia who live alone.

People with dementia often tell Alzheimer’s Australia NSW that they feel a sense of isolation following their diagnosis. Family and friends may struggle to understand dementia and distance themselves from the person with dementia.

Psycho-educational support programs, such as Living with Memory Loss, provide opportunities for professional and peer support. People living alone with dementia should be encouraged to attend programs such as these. Community visiting schemes, resourced by a well-trained volunteer base, as well as centre-based activities can also facilitate community engagement and social participation for people living alone with dementia.

Limitations in the Service System

For people living alone with dementia who do access the formal service system, disadvantages are encountered at the first point of assessment. As previously explained, the design of the service system has largely overlooked people with dementia living alone. The current assessment model directs people into a binary system of high or low care which is aligned to CACP/EACH or hostel/nursing home. What this fails to take into account is the lack of co-resident carer and the resulting additional needs of people living alone with dementia.

“ACAT should have a separate category for this group, at the highest level.” (case manager)

The living circumstances and the progression of dementia in this group heightens the urgency around how quickly formal supports need to be put in place once requested.

People with dementia living alone can have a shorter timeframe for entry to residential aged care than those with a co-resident carer however this process could be slowed through more timely service response. This would require changes to the current approach to assessment and prioritisation.

Survey respondents highlighted numerous limitations within the service system for people living alone with dementia. Several commented that the current system of three levels of packages for

in-home support were not responsive to the additional needs of people who live alone and who do not have family or other informal support nearby. There is a need for more hours in a package for people with dementia who live alone as they do not have a carer present during times of non-service.

“Funding which can be flexible as to its available usage. A lot of funding seems to be aimed at people with carers, leaving a gaping, and dangerous, hole for those without carers, and therefore without any significant available support at all.” (case manager)

Outside of the community aged care packages, the *HACC Program* and the *National Respite for Carers Program* have largely, or solely, been designed around the respite needs of carers. The objectives of the *HACC Program* explicitly acknowledge the primacy of the carer in supporting the older person to remain independent⁵⁷. Therefore, people living alone with dementia are limited in the choices available to them from the range of *HACC* service types.

While *ACHA* is a valuable model in providing short-term, episodic case management towards meeting the housing needs of the clients, it does not specifically identify or address dementia-related needs. *ACHA* services will refer on for this, but then the client will encounter the issues identified above.

The *National Dementia Support Program* also has many activities and programs which are carer-focussed. While people living alone with dementia are not excluded, some have expressed feelings of being marginalised within a group setting as the only single person in attendance, or the education content has not addressed their specific information needs.

The Australia Government aged care reforms will change the way that home care packages are provided. From July 1 2013, four levels of care packages

will be introduced with an additional 10% Dementia Supplement. Access and assessment remains unclear at this stage with little detail available about the Gateway, the new model for information and access to the Australian aged care system. Unless the model changes to encompass a holistic view of what a person living alone with dementia can and cannot do, they will continue to be allocated packages of support which cannot fully meet their needs.

These new packages will be provided according to the principals of *Consumer Directed Care (CDC)*. *CDC* is a way of delivering services that allows consumers and their carers to have greater control over their own lives by allowing them to make choices about the types of care they access and the delivery of those services, including who will deliver the services and when. The consumer can also decide the level of involvement they wish to have in managing their Home Care Package, which could range from involvement in all aspects of the package, including co-ordination of care and services, to a less active role in decision-making and management of the package⁵⁸.

Concerns were raised about enablement approaches and *CDC* and people living alone with dementia.

“Whilst the new enablement approach is exciting, and is what the majority of service providers are already practicing in encouraging people to maintain their independence, I am finding that most clients are unable to identify specific ‘goals’ to work towards. They just want to be able to stay living at home for as long as possible. Many lack insight into their daily issues and the need for support.” (case manager)

Further concerns were expressed in the research about the decision-making capacity of people living alone with dementia, and the challenge that this will present for service providers in finalising care plans and individual budgets.

The AIHW identifies limitations in the hospital system for people living alone with dementia. For example, although people with dementia are neither excluded or specifically targeted by the Community Packages (ComPacks) program, a 6 week case-managed package of care following discharge from hospital, it is not seen as suitable for people with high support needs, including people who do not have a co-resident carer⁵⁹. In addition, research conducted by AlzNSW in 2012 found evidence of people living alone with dementia being transferred to residential aged care directly from hospital. In many cases returning home was not considered feasible due to a lack of suitable support options.

Minimising Risk

The Alzheimer's Association (USA) suggests that "determining the best way to provide a safe environment and adequate care for someone with severe cognitive impairment who chooses to live alone is often difficult and fraught with ethical, societal and emotional dilemmas"⁶⁰. One such dilemma is the tension between allowing a person living alone with dementia the opportunity to take risks, that is, dignity of risk, and the duty of care obligations of service providers under the *Aged Care Act* (1997) and its associated principles. Reporting obligations mean that approved providers must document incidents and minimise instances of risk which in turn may limit the dignity of risk provided to client.

The major issue identified by service providers associated with managing risk to a person with dementia to remain living alone in their own home is determining at what point it becomes unsustainable for them to continue in this situation due to concerns about the person's safety. Providers can be placed in a difficult situation where the person, their family, or 'person responsible' does not want to move to residential aged care, but the provider is unwilling to assume the risk of an adverse

event due to the consequences for them as an Approved Provider under the *Aged Care Act*. The situation is compounded by families feeling that provider can resolve all issues. Often a hospital admission following a major incident will act as a trigger for resolving this tension as a doctor will make a decision that moving to residential care is the only available option for them.

The situation is even more difficult with regard to people living alone with dementia who have no relatives or friends willing to act as their Guardian or Power of Attorney. Such people may be living in squalor, at high risk of exploitation, and not in receipt of community care services. In this instance, whose responsibility is it to ensure that the person living alone with dementia is safe and cared for appropriately, possibly in a residential aged care facility? This is a problematic issue; individuals have a human right to decide where and how they want to live. How and when do we determine that a person living alone with dementia no longer has the capacity to make informed decisions about their own welfare and living arrangements? Determining capacity is a complex matter and applications for a Guardianship Order are a last resort.

For people living alone there is a greater need for informal supports to be in place and act in partnership with formal services. The survey respondent below highlights this dilemma in an increasingly individualistic culture.

"As a society we have to have respect for individuals and their rights. We misread signs and leave people in a high risk until crisis arrives. Community needs to become more aware of this and provide care and support." (case manager)

The introduction of CDC in Australia in 2010 raised many concerns about clients making poor choices and putting Approved Providers in a difficult position



from an organisational risk management perspective. The philosophy of CDC was felt to be at odds with Government requirements and regulations. However, evidence from the evaluation of the pilot has not borne this out⁶¹. Yet for people living alone with dementia, CDC and enablement approaches do present challenges. While people living alone with dementia should be making informed choices, what they choose may not be the best for them. At what point does a case manager need to override the decisions of the client in the interests of safeguarding their duty of care?

The Alzheimer's Association states that "cognitive impairment and dementia do not rule out living alone, but all people with progressive dementia will be unable to safely live alone in the later stages of the disease"⁶². Avoiding premature institutionalisation is a key aim of community care services however many people living alone with dementia will need to move into residential care at some point. This possibility should be openly discussed and planned for soon after diagnosis to avoid crisis situations.

Planning ahead enables the person with dementia to have choice and control about their own care and living arrangements while they have the capacity. Therefore, completion of legal instruments, such as wills, enduring power of attorney, enduring guardianship and advanced care plans, take on a greater level of importance⁶³. These planning ahead processes also reduce the risk of a person living alone with dementia being taken advantage of, exploited and abused.

Dementia Key Workers

The research identified a lack of capacity for intensive case management services in community aged care packages people living alone with dementia often need. The role ACAT used to play in follow-up and service co-ordination has been eliminated from the position.

A key worker model could therefore be a useful resource for people living alone with dementia.

The *Implementation Plan for the NSW Dementia Services Framework 2010 – 2015: Consultation Draft* describes a key worker as a professional with “nursing or allied health qualification, skilled in dementia care and who works closely with the person’s GP/AMS, proactively follows up after diagnosis and builds a continuing relationship”. Further to this, the key worker is proposed to be responsible for “provision of direct care services and care coordination”⁶⁴. The Australian Government’s *Living Longer Living Better* policy includes funding for a national network of ‘specialist key workers’ to give people with younger onset dementia a ‘single point of contact’ and ‘improve access to better coordinated services’⁶⁵. The *Younger Onset Dementia Key Worker Program* is being delivered by Alzheimer’s Australia NSW and at the time of writing is in the early stages of implementation.

The literature identifies that people living alone with dementia are less likely to access services. The Alzheimer’s Society (UK) reports that a lack of support from services can have a more profound impact on people living alone with dementia than on people with dementia who do not live alone. People with dementia living alone find it harder to access information about services and to obtain support if they do not have guidance from another person to help them through these processes⁶⁶. A dementia key worker could assist people with dementia who live alone to access and navigate their way through the dementia services system and help them plan for their future.

To access a key worker requires a diagnosis and acceptance of dementia plus an acceptance of support and assistance. Therefore the success of a key worker model for people living alone with dementia is largely dependent on individuals having insight into their limitations and a willingness to accept help.

The literature review found examples of

advocate programs for people living alone with dementia. For example, Advocacy Tasmania Incorporated in partnership with Alzheimer’s Australia Tasmania developed an early intervention project targeting people recently diagnosed or in the early stages of dementia who live alone or without positive supports in their lives. The program was evaluated in 2008 and found to be very successful in supporting people living alone with dementia to advocate for their needs. This model of advocacy includes ongoing contact with the person living with dementia and a proactive and preventative perspective to avoid problems occurring as much as possible. Through focusing on early identification and enabling support the project empowered people with dementia to articulate their preferred future, establish their wishes, make financial plans, strengthen the environment around them, and to reduce their vulnerability to abuse. The evaluation found that clients and families learnt from the advocate’s approach to advocating and resolving problems⁶⁷.

Similarly in the UK, the Dementia Advocacy Network (DAN) has been established as a support organisation to disseminate best practice for professional advocates working with people with dementia throughout England. DAN is an arm of Advocacy Plus which has developed expertise in advocating for the rights of people with dementia and aims to demonstrate the value of advocacy in enabling personalisation of services, safeguarding people who are vulnerable and achieving positive outcomes for people with dementia by improving their well-being and quality of life⁶⁸.

POLICY IMPLICATIONS

There must be increased recognition of people living alone with dementia in dementia, health and aged care policy. Dementia, health and aged care policy needs to overcome the oft made assumption that people with dementia have a co-resident carer or supportive family and friends nearby.

The needs of people with dementia who live alone need to be considered in the Australian Government aged care reforms, particularly through the introduction of the four levels of community aged care packages and expansion of consumer directed approaches. The reforms should also address the issues identified in relation to assessment, prioritisation, access to programs and levels of support within packages identified in this research.

There are concerns that CDC will reduce the flexibility providers have in being able to accommodate increased needs of some people, such as those living alone with dementia, who need more than the allocated funding provided through existing packaged care arrangements. These concerns must be addressed in the implementation of the reforms. Assessments conducted by the Gateway and allocation to a package should take a holistic view of what the person is capable of doing and what informal supports may exist to assist them with this.

People living alone with dementia could benefit from access to services which have required a carer in order to access them, for example, respite and centre based day care. These services provide meaningful activities, social engagement and are increasingly operating within an enablement approach.

Informal networks of support are vital for people living alone with dementia. Increased and improved connections between volunteers and neighbours with people living alone with dementia will help to sustain them in their own home. A community visiting scheme could benefit people living alone.

Psycho-education and support programs need to be specifically developed to address the concerns and information and emotional support requirements of people with dementia who live alone.

Dementia key workers could work closely with people with dementia who live alone to assist in goal attainment, service planning, and to advocate on their behalf.

SERVICE IMPLICATIONS

Community care service providers should seek to enable and empower people with dementia to maintain their independence and remain living safely at home for as long as is possible to delay premature entry into residential care.

Services need to be flexible, adaptive and responsive to people living alone with dementia. Multiple services need to be well coordinated. The additional challenges for people living alone with dementia with younger onset dementia, from Aboriginal and culturally and linguistically diverse communities, and with a co-existing condition of mental illness also need to be considered.

Community care staff need to be appropriately qualified and trained, understand dementia and the unique challenges living alone with dementia presents. Services need to address the stigma associated with dementia and work to overcome the fear and shame felt by some people with a diagnosis so they accept support and assistance which will maintain their independence.

Services need to consider how CDC will work in practice for people with dementia who live alone, particularly those without supportive family, and especially if people are not in contact with services until there is a crisis point. Services must be person-centred and holistic, and redress an over-emphasis on a clinical model of deficit to focus on a social model of service provision.

Services need to ensure that the day-to-day needs of people with dementia living alone are met including personal care, hygiene and nutrition. Assistive technologies

need to be introduced in a timely manner to increase their effectiveness and to maximise the benefits they can provide.

Dementia monitoring and social support programs need to be appropriately funded and resourced. Community visiting schemes, utilising volunteers, should target people living alone with dementia as a priority group.

Centre-based services operating according to a wellness model, that provide meals and social activities, should be promoted to people living alone with dementia. Access to transport is required to facilitate social engagement and community participation.

Support needs to be provided to people living alone with dementia to help them through transitions and moves to more appropriate care and accommodation options where necessary, for example to retirement villages and residential aged care facilities. A range of dementia specific accommodation settings need to be available for people to move into when they can no longer live at home.

CONCLUSION

People with dementia, when well supported, can continue to live at home alone. This support needs to come from family members, friends, neighbours, and local communities as well as formal support services.

Traits and characteristics which help people with dementia to maintain their independence and live alone have been identified. These include an awareness of their limitations, an acceptance of support, and a determination to remain as independent as possible.

However we must also acknowledge that there will likely come a time when it is no longer appropriate for a person with dementia to continue to live at home alone. Plans should be in place to pre-empt and avoid crisis situations occurring.

As the number of people living alone with dementia appears set to increase, it is essential that service providers are well-equipped to deal with the challenges this cohort may experience. The project has highlighted the need for further research to better understand the experiences and unmet needs of people with dementia who live alone.

Policy and service delivery must not assume the presence and support of a co-resident carer and ensure that people living alone with dementia are supported to maintain their independence in their own home for as long as possible.

RECOMMENDATIONS

Australian Government

1. The Australian Government extends the dementia key worker program for people with younger onset dementia to older people with dementia, with a priority target group being people living alone with dementia.
2. The Australian Government ensures community services are targeted and funded to respond to the individual support requirements of people living alone with dementia.
3. The Australian Government provides funding for community dementia education for workers who have contact with people living with dementia, for example, GPs, chemists, bank tellers and retail staff.
4. The Australian Government extends the provision of the Community Visiting Scheme from residential aged care facilities to people living in the community, with priority access provided to people living alone with dementia.
5. The Australian government funds further research on people living alone, including epidemiological studies and investigation into the needs of people living alone with dementia, such as how they can better navigate dementia services and ease their journey into residential aged care.
6. The Australian Government, as part of the *National Framework for Action on Dementia 2013-2017*,

RECOMMENDATIONS CONT.

develops and funds an ongoing campaign that aims to increase understanding of dementia, to decrease stigma, to increase acceptance of diagnosis and promote help seeking behaviours in people living alone with dementia.

NSW Government

7. The NSW Government ensures that people living alone with dementia are able to access supports identified by the *NSW Dementia Services Framework* and *Draft Implementation Plan 2010-2015*.
8. The NSW Government targets its promotion of planning ahead to people living alone with dementia through actions outlined in the *NSW Ageing Strategy*.
9. The NSW Government invests in volunteering schemes to support people living alone with dementia through the *Community Builders Program*.
10. Housing NSW prioritises people living alone with dementia in social housing for its daily monitoring service – Tenant Connect.
11. Housing NSW develops and coordinates social events, gatherings and activities targeted to people living alone with dementia in social housing.
12. NSW Health funds and develops a post-hospital community-based program, similar to ComPacks,

which accommodates the needs of people living alone with dementia.

Local Governments

13. Local Governments ensure that the safety of people living alone with dementia is addressed through the creation of dementia-friendly environments and neighbourhoods.

Aged, Community and Health Care Providers

14. Aged, community and health care providers provide education and training, such as the 'Experiencing Dementia' program, for staff who support clients living alone with dementia.
15. Aged, community and health care providers discuss planning ahead and long-term care needs with clients living alone with dementia to minimise the risk of crisis situations and premature entry to residential aged care.

Further recommendations for providers will be included in a Research to Practice Guide available in September 2013 on the AlzNSW website:

www.fightdementia.org.au/new-south-wales/research-nsw.aspx

HELPFUL RESOURCES

You may find these resources helpful if you are living alone with dementia or care for someone who is living alone with dementia.

Alzheimer's Australia

Caring for Someone with Dementia Help Sheet 4 – Caring for Someone Who Lives Alone

<http://www.fightdementia.org.au/understanding-dementia/section-2-caring-for-someone-with-dementia.aspx>

Information for People with Dementia Help Sheet 5 – Living Alone

<http://www.fightdementia.org.au/understanding-dementia/section-8-about-you—information-for-people-with-dementia.aspx>

Alzheimer's Society (UK)

Living Alone

http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=107

Remaining Independent

<http://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200349>

Alzheimer's Association (USA)

10 Tips for Keeping Your Independence

http://www.alz.org/living_with_alzheimers_10269.asp

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OTHER PUBLICATIONS

Social Research Publications by
Alzheimer's Australia NSW

Football, head injuries and the risk of dementia. Discussion Paper #6 Mar 2013

Alzheimer's Australia NSW hopes to raise public awareness of the potential risks of later-life cognitive impairment and dementia for football players who suffer multiple concussive and subconcussive injuries throughout their playing career. This paper examines the research emerging from the USA, reports of memory loss in current and retired football players in Australia, and the possible implications for the football codes.

http://www.fightdementia.org.au/common/files/NSW/AlzNSW_Football_head_injuries__the_risk_of_dementia_final_130313_web.pdf

The most difficult decision - Dementia and the move into residential aged care - Discussion Paper #5, Oct 2012

Adjustment to residential care is more than just a discrete event. It begins well before placement actually occurs and continues beyondⁱ. While policy directionⁱⁱ and the wishes of the person with dementia and their carer can dictate that people with dementia may stay living at home for as long as possible, the impacts of the symptoms and behaviours of dementia mean that ultimately a large number of people with dementia will move into residential aged care.

http://www.fightdementia.org.au/common/files/NSW/20121016-NSW-PUB-Moving_To_Res_Care.pdf

What prevents people with dementia making plans for their future? - Discussion Paper # 4, Mar 2012

Planning ahead is important for the whole population. We all need to make sure if we get to a point where we can no longer make our own decisions that our wishes about our health care and financial plans have been set out in legally binding documents. Failure to do this can lead to added stress on our family and carers who will not have the legal ability to make sure our wishes are followed or who could be unsure of our wishes. People with dementia have the right to make decisions about their future while they still have the capacity to do so. It is therefore imperative in the early stages of the disease that people with dementia are provided with opportunities to plan for their future and record their wishes, while they still have capacity.

<http://www.fightdementia.org.au/common/files/NSW/20120328-REP-DiscussionPaper4.pdf>

Building Dementia and Age-Friendly Neighbourhoods - Discussion Paper # 3, July 2011

The needs of people with dementia and other types of cognitive impairment have helped shape the design of residential facilities, but the issue of accessibility to public places and spaces for people with dementia and their carers has been almost completely neglected. In a series of focus group consultations

we asked members of the eight Alzheimer's Australia NSW regional consumer committees to describe how they experienced their surrounding neighbourhoods once they stepped outside the safety and familiarity of their front gate and made their way to the local shopping centre, park, doctor's surgery or club.

[Building Dementia and Age-Friendly Neighbourhoods - Discussion Paper 3 July 2011\(PDF\)](#)

Addressing the stigma associated with dementia - Discussion Paper # 2, Sep 2010

The purpose of this paper is to raise public awareness about the effects of stigma associated with dementia, to address the need to change the way we, as a society, approach dementia, and to make recommendations for further action.

[Addressing the Stigma associated with Dementia Discussion Paper 2 \(PDF\)](#)

Dementia is a condition that carries a heavy burden of stigma. People's attitudes, perceptions and understanding of the nature of dementia can determine how a person diagnosed with dementia, their carer and family accept and learn to live with the condition. The stigma associated with dementia can often lead to social exclusion, discrimination and disempowerment.

[Alzheimer's Australia NSW – Addressing the Stigma associated with Dementia - Executive Summary \(PDF\)](#)

Driving and dementia in New South Wales - Discussion Paper #1, Apr 2010

A new discussion paper, Driving and Dementia in NSW, indicates there is little clear, accessible information about the

rights and responsibilities of a driver after a diagnosis of dementia.

[Driving and Dementia in New South Wales Discussion Paper 1 \(PDF\)](#)

Issues raised include:

- Driver testing for people with dementia must be improved
- Legal obligations for a driver with dementia are unclear
- Call for improved transport alternatives for a person with dementia
- Need for better support for transition from driver to non-driver in NSW

[NSW Discussion Paper Key Recommendations \(PDF\)](#)

Quality Support Groups Research Project

There is little knowledge of the way support groups in New South Wales are currently functioning, or how effectively they are providing support to their participants. The purpose of the Quality Support Groups Research Project is to understand the operation and structure of dementia support groups in New South Wales; ascertain what constitutes a quality support group; and determine how a quality support group can be achieved.

Quality Support Groups Research Project - Phase 3 The purpose of Phase 3 is to analyse findings from Phase 1 and Phase 2 of the Project. The Quality Support Groups Research Project provides a comprehensive understanding of quality in a support group and formulates best practice guidelines to enhance the delivery of quality service to carers of people with dementia. This research upholds the mission of Alzheimer's Australia NSW to minimise the impact of dementia through leadership, innovation and partnerships. This is the third and final report into a research

OTHER PUBLICATIONS

project that spanned 5 years and looked at what comprises a quality support group. This is the first comprehensive state-wide Australian study of ongoing support groups for carers of people with dementia. Over the five years of the project more than 350 people took part, including leaders of the groups and carers who had at some time attended a support group.

Significant findings of the report are:

- Huge benefits of supports groups for people who attend on a regular basis
- The uncelebrated capacity of mutual aid amongst group members to assist each other
- The unexpected finding of the profound impact of grief and loss on the health and well-being of a carer of a person with dementia
- Some carers reported the grief and loss felt at the time of diagnosis was equal to or even greater than the grief felt when the person with dementia dies

[Quality Support Groups Research Project - Phase 3 Executive Summary \(pdf 45 KB\)](#)

The full Phase 3 report is available to purchase from Alzheimer's Australia Online Bookshop.

[Quality Support Groups Research Project - Phase 2 \(pdf 1.92 MB\)](#)

This report presents the second phase of the Quality Support Groups Research Project, which acknowledges the voices of past and present members of dementia carer support groups.

[Quality Support Groups Research Project - Phase 1 \(pdf 764\)](#)

The focus of phase one of the Quality Support Groups Research Project is a literature review of research conducted into dementia support groups and a survey of existing support groups in New South Wales to investigate the views of support group leaders.

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