



A Guide for Service Providers
September 2013

**LIVING
ALONE**

**WITH
DEMENTIA**

**RESEARCH TO
PRACTICE GUIDE**

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

This Research to Practice Guide has been developed by the Alzheimer's Australia NSW Policy, Research & Information unit. The content has been adapted from Alzheimer's Australia NSW Discussion Paper 7 – Living Alone with Dementia. The full discussion paper is available on the Alzheimer's Australia NSW website at:

<http://www.fightdementia.org.au/new-south-wales/research-nsw.aspx>

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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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LIVING ALONE WITH DEMENTIA

The number of Australians living with dementia is increasing every year. At the same time more and more people are living alone. This means that the number of people living alone with dementia is set to rise.

More than 321,000 Australians currently live with dementia and that number is expected to increase to almost 900,000 by 2050. 70% of people with dementia live at home in the community. It is estimated up to one-third of those people may live alone.

It is often assumed that people with dementia are supported by a co-resident carer. People living alone with dementia are a vulnerable population who frequently fall through the cracks.

Yet, when they are well-supported, people with dementia can live independently in their own home for quite some time.

This Alzheimer's Australia NSW Research to Practice Guide will assist service providers to support people living alone with dementia. It will also be useful for people who have family members or friends who live alone with dementia.

MARGIE

Margie, aged 88, has lived on her own since her husband, Don, died 7 years ago. Margie was diagnosed with Alzheimer's disease 4 years ago. With support of her three children, friends, and a range of services, Margie has been able to remain in her own home, rather than move to residential aged care. Margie has discussed her wishes with her family should the time come that she can no longer live independently at home. She has appointed her eldest daughter as her enduring power of attorney and guardian.

Care workers visit Margie every morning to assist her with personal care and a cleaner comes to help with domestic chores once a week. Twice a week, Margie attends a dementia cottage and every Thursday she has morning tea with friends from the local church. Two of Margie's children live nearby and they each visit her once a week and make regular phone calls to make sure Margie is keeping well. Her neighbours also keep an eye out for Margie and contact her family if they have any concerns.

THE TOP 6 ISSUES

- 1. OFTEN LATE OR NO FORMAL DIAGNOSIS**
- 2. FINANCIAL AND LEGAL ISSUES- MONEY MANAGEMENT, ABUSE AND EXPLOITATION**
- 3. MEDICATION MISMANAGEMENT**
- 4. SELF-NEGLECT, MALNUTRITION AND POOR HEALTH OUTCOMES**
- 5. LONELINESS AND SOCIAL EXCLUSION**
- 6. SAFETY CONCERNS - FALLS, FIRES, WANDERING**

GOOD PRACTICE IN SERVICE PROVISION

Flexibility

People living alone with dementia often need more support than traditional community care packages have been able to provide. Flexible service delivery, an increased number of home visits throughout the day, and a higher level of case management may be required. A challenge for service providers is to do this within the limitations of funding arrangements and service systems.

Relationships

Services should aim to provide continuity of care for people living alone with dementia so they have regular and familiar care staff coming into their homes. Staff should have dementia-specific training and have high-level interpersonal skills to be able to build a rapport and relationship with their clients who live alone with dementia.

Risks

There are risks for people with dementia who live alone. Service providers have a duty of care to their clients; however clients also have the right to exercise dignity of risk. Maintaining an ideal balance between the two can be an ongoing challenge.

Client-centred

Some service providers have expressed concerns about the capacity of people living alone with dementia to participate in Consumer Directed Care (CDC), and also goal-based and enablement approaches. However it is possible for people with dementia, especially in the early stages, to set and achieve goals. Support services should emphasise a social model that sustains remaining capacities of a person with dementia, rather than focus on deficits.



DIAGNOSIS

People living alone with dementia are less likely to have a formal diagnosis or receive a timely diagnosis than those with dementia who live with others. Home care providers may be the first to recognise changes in behaviour and other symptoms of dementia. Collaboration with GPs and other local health professionals will be necessary to start the process of diagnosis.

Of course, individuals have the right to refuse to visit the GP and may not want to know that they have dementia. However people often need a diagnosis to access some dementia-specific services. Services need to be delivered with this in mind.

People living alone with dementia may be reluctant to accept both the diagnosis and help from services. Service providers can explain to the person with dementia that they have a better chance of staying in their home for longer if they accept some help from services and informal supports. Home care providers should refer their clients living alone with dementia to local dementia advisors and dementia support workers.

Re-assessments need to be proactively sought and the progress of the disease needs to be monitored, especially in the presence of behavioural and psychological symptoms of dementia (BPSD), to ensure appropriate and timely support is delivered. Links with local allied health providers should be built and maintained to facilitate a holistic approach to supporting people living alone with dementia. Case conferencing with key stakeholders can be a good way to manage this.

FINANCIAL AND LEGAL CONCERNS

A diagnosis of dementia does not automatically mean that a person no longer has capacity. However completion of legal instruments, such as wills, enduring power of attorney, enduring guardianship and advance care plans, should be encouraged.

Planning ahead enables people with dementia to have choice and control about their own care and living arrangements while they have the capacity. When the capacity of a person living alone with dementia is in question, a formal assessment by a specialist is required.

Planning ahead processes also reduce the risk of a person living alone with dementia being taken advantage of, exploited and abused. People living alone with dementia are vulnerable to scams and financial abuse. If you have concerns or suspect someone is being financially abused, contact the police to report a crime and legal aid /commission in your State for legal advice.

People living alone with dementia who have not planned ahead, who do not have family support or who have family in conflict will often require an application to a guardianship tribunal/board. A publicly appointed guardian may be needed in some circumstances.

MEDICATION MANAGEMENT

People living alone with dementia are also at increased risk of medication mismanagement. Strategies that may help with medication management include:

- Use medication carousels and Webster packs
- Provide medication management as part of home care packages
- For clients on multiple medications, liaise with their GP for a referral to their local accredited pharmacist for a Home Medicines Review - for more information contact Medicare





MALNUTRITION AND SELF-NEGLECT

People living alone with dementia are at increased risk of malnutrition and self-neglect including poor hygiene.

People with dementia may forget to eat or overeat because they forget they have eaten. Strategies service providers can employ to monitor meals and malnutrition include:

- Monitor the fridge, freezer and garbage bin to see what has been eaten during the week
- Refer clients to the local Meals on Wheels service
- Schedule care staff to visit at meal times to eat with clients
- Ensure healthy snacks and meals are easily accessible
- Arrange for a main hot meal to be provided at a centre-based program
- Organise an assessment by a dietician
- Hygiene may be a concern for people living alone with dementia. Home care providers can implement strategies to assist. These include:
 - Make bathing a pleasurable activity
 - Ensure wounds are treated and managed
 - Provide assistance with continence management
 - Organise an assessment for the Continence Aids Payment Scheme through Centrelink to assist with cost of continence pads - for more information contact Centrelink

ELLEN

Ellen, 73, has lived on her own since getting divorced over 20 years ago. She was diagnosed with dementia 2 years ago. As a lawyer, Ellen prided herself on her intellect and has found the diagnosis very hard to accept. She refused all offers of help from family, friends and health professionals.

Recently Ellen had to give up her drivers' license and she has found managing her finances increasingly difficult. These events prompted Ellen to reach out to her son and close friends for help. They discovered that Ellen was hoarding rubbish in her townhouse and not eating regular meals. Ellen allowed her son to meet with her GP and together they discussed what support might help Ellen maintain her independence and remain living alone in her own home.

Ellen now receives a low-level community care package which provides assistance with cleaning, meals and medication management. Ellen also volunteers at her local library three mornings a week. This provides Ellen with a sense of purpose and an opportunity to make a meaningful contribution to her community once more.

LONELINESS AND SOCIAL EXCLUSION

People living alone with dementia may be lonely and social isolated. As well as attending to day-to-day personal care needs, services should support participation in local communities and facilitate opportunities for social engagement.

- Informal support networks, such as family and neighbours, should be fostered particularly where they are lacking
- Utilise volunteers for buddy programs and one-on-one support
- Encourage involvement in community group activities e.g. The Men's Shed program
- Provide or organise transport to group activities
- Foster partnerships and communication between organisations

Wellness centres providing meals, social support, therapeutic activities and medical management are an ideal service option for people living alone with dementia.

Programs and groups specifically designed for people living alone with dementia should be developed to enable them to meet others in a similar situation and provide opportunities for peer support. However mainstream services also need to be up-skilled to support people living alone with dementia.



SAFETY CONCERNS

Safety concerns for people living alone with dementia include wandering, falls and fires.

Falls are often a trigger for premature entry into residential aged care. A physiotherapist can conduct a falls and mobility assessment to reduce the risk of falls.

Assistive technologies can be helpful, however, in order to maximise their utility they need to be introduced during the early stages of dementia to establish a pattern of use. The assistive technology may only be useful within a limited timeframe as dementia progresses. Devices that respond to the user rather than those that are user-activated are more likely to be helpful and appropriate for people living alone with dementia.

Occupational therapists can conduct home safety assessments to assess for adaptive equipment, environmental changes and give advice on assistive technologies.

Examples of assistive technologies that may help people to live alone with dementia include:

- GPS tracking devices
- The Safely Home Program - for more information contact Alzheimer's Australia NSW
- Fall detectors
- Emergency call pendants
- Smoke alarms
- Gas detectors
- Sensor lights

HELPFUL RESOURCES

CHECKLIST

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

- ✓ **Are staff trained to recognise symptoms of dementia (pre-diagnosis) that may indicate additional support is required?**
- ✓ **Does your service have guidelines for how to best support people living alone with dementia?**
- ✓ **Do staff receive dementia-specific training to help them support people living alone with dementia?**
- ✓ **Do staff know who to go to for support within your organisation if they have concerns about clients living alone with dementia?**
- ✓ **If you are using this resource in a team training exercise, consider how you might extend the services you provide beyond what has been described here.**



CONTACT US

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**NATIONAL
DEMENTIA
HELPLINE**
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