

How can we improve housing and care for people with dementia?

TAILORED AND TIMELY HOME MODIFICATION AND HOME-BASED CARE ARE NEEDED TO ALLOW PEOPLE WITH DEMENTIA TO AGE IN PLACE AND LIVE IN THE COMMUNITY. INTEGRATED RESIDENTIAL AND DAY RESPITE SERVICES WILL ASSIST FUTURE TRANSITIONS FROM IN-HOME TO RESIDENTIAL CARE.

KEY POINTS

- An estimated 70 per cent of all people with dementia in Australia are currently living in the community, with the majority of these living in owner-occupied housing. The number of people with dementia living in public housing was estimated to be 8957 in 2011 and is projected to increase to 12 916 in 2020. The number of people with dementia living in private rental housing was estimated to be 11 756 in 2011 and is expected to increase to 16 952 in 2020.
- People with dementia find changes in their living and care environment distressing. Security of tenure and a stable living environment assist people with dementia to maintain quality of life and to live in the community for longer. Conversely, people in rental or marginal accommodation experience greater difficulties and end up in residential care earlier than those in stable and secure accommodation, such as home owners.
- Home modifications tailored to the needs of individuals, such as clear glass cupboards and contrasting colours to locate or identify items, can assist people to remain in their homes. However, such modifications are more difficult to negotiate for private and public renters than modifications for physical disabilities, such as hand or grab rails.

*This bulletin is based on research conducted by **Dr Michelle Gabriel** and **Associate Professor Christine Stirling** at the AHURI Research Centre—University of Tasmania, and **Dr Debbie Faulkner** at the AHURI Research Centre—The University of Adelaide. The research looked at the housing and support needs of people with dementia.*

- Respite care for carers and people with dementia provides an essential break in the dependent care relationship and can ease the transition from in-home to residential care through providing exposure to a structured residential care environment.
- Better understanding of brain health and dementia is needed for people who work in the homelessness, social housing and private rental sectors to ensure that dementia in vulnerable populations is recognised and individuals are appropriately assessed and supported.
- Enhanced service provision and advocacy are required to assist people with special needs or at risk of social isolation, such as lone-person households, people without family support, people from culturally and linguistically diverse backgrounds and people under 65 years with early onset dementia.

CONTEXT

Dementia is an incurable syndrome that impacts on higher cognitive functions, behavioural and psychological traits and physical function. It will shortly be the leading cause of disability in Australia with the numbers of people affected projected to increase to almost a million by 2050. Currently, an estimated 70 per cent of all people with dementia are living in the community, and this is expected to grow over the coming decades.

This project examined the role of housing in caring for people with dementia, and whether more could be done to assist those in marginal or insecure housing situations.

RESEARCH METHOD

The research team used a mixed-methods approach. This included: a literature review, secondary analysis of data from the Australian Bureau of Statistics and Australian Institute of Health and Welfare, interviews with 44 service providers, and interviews with people with dementia and their family carers (12 cases). The interviews were conducted in South Australia and Tasmania.

KEY FINDINGS

Trends in dementia

Increased risk of developing dementia is associated with age. Dementia rates are relatively low until the age of 70 years and then incidence rates increase rapidly. Because those in private rental tenures tend to be younger, it is not surprising that most people with dementia (85%) were in owner-occupied housing in 2011.

The number of people with dementia living in public housing was estimated to be 8957 in 2011. This number is projected to increase to 12 916 in 2020 and 31 672 in 2050, thereby increasing pressure on the social rental system. The number of people with dementia living in private rental housing was 11 756 in 2011 and is expected to increase to 16 952 in 2020 and 41 570 in 2050.

Familiar environment and housing security are essential

There is growing recognition of the advantages of enabling people with dementia to remain in their existing homes. Familiarity of surroundings and continuity in care help to maintain quality of life and reduce anxiety and stress. A key element in achieving this continuity is housing security.

In contrast to renters, home owners are more likely to be in secure housing situations and to be able to access housing wealth. Housing wealth is important in enabling people with dementia to obtain additional care or to seek and have greater control over alternative housing options as their condition progresses. People with dementia in marginal housing (caravan parks and boarding houses) are more likely to have limited choice and be pushed into residential care earlier.

Home modification can extend independence and quality of life

Home modifications can help people to stay in their existing homes and retain quality of life. Currently, there is greater knowledge and understanding in the community about home modifications related to physical mobility than to dementia.

Modifications for people with dementia are most effective when they are tailored to the specific needs of the individual. Common examples include:

- Clear glass cupboards so that items for use can be seen and good lighting.
- The use of contrasting colours to make it easier to distinguish between surfaces, furniture and appliances.
- Being able to see the toilet from the bed.
- Being able to switch lights on and off from the bed to avoid walking through the house in the dark.

Home-based support and respite services could be improved

Continuity in home-based support and care is important in reducing stress for people with dementia. Changes in care staff and care routines can be distressing. The carers in this study wanted to minimise such changes. Carers also wanted more support in navigating the aged care system and locating supports.

Respite services (especially those with meaningful activities and stimulating experiences for people with dementia) were viewed as critical to relieving care burdens and making transitions to residential care easier by familiarising those with dementia with new environments gradually over time.

Service providers highlighted the specific needs of people under 65 years with early onset dementia. Participants were concerned about the lack of housing options for this group, difficulties in accessing home-based support services and lack of relevant community activities. They noted also that culturally and linguistically diverse (CALD) groups often require specialised support services.

People with dementia require advocacy

The home-based care landscape is changing with the introduction of Consumer Directed Care. Consumer Directed Care is an approach designed to give recipients greater choice and flexibility of care. Service providers noted that the issue of choice was problematic for people with dementia,

including those who live alone and those in marginal housing situations. Consequently, there is a growing need for independent advocates to support people with dementia to navigate a complex and fragmented health care system and to make good decisions regarding home-based support and future residential care.

Increased awareness is needed in social housing/homelessness sectors

Improved community awareness of dementia has led to earlier diagnoses. However, there remains a need to improve awareness of pathways to assessment, especially within the social housing and homelessness sectors.

There is also a need to improve understanding by housing providers and landlords about the value of home modifications. Increasing understanding of brain health is important in enabling service providers to respond appropriately to complex situations where mental health issues, memory loss and a dementia condition may be present. It is also important in achieving inter-agency collaboration and enabling people with dementia to access appropriate and stable housing and support services in a timely way.

POLICY IMPLICATIONS

The most desired 'housing pathway' for people with dementia is to remain in their existing home with appropriate in-home care supports but the expectation of transfer into structured residential care when their disabilities become acute.

Home owners are the largest group affected by dementia in Australia but have the best capacity to manage their circumstances: they enjoy tenure security, can freely modify their dwellings and can draw on their home equity to access supports or alternative housing options as their needs change. Conversely, renters and people in marginal accommodation lack security of tenure, cannot freely or easily modify their dwellings and generally make earlier demands on residential care.

There is a need to promote dementia awareness both in respect to brain health and the supports required to enable people to live well and remain

safe within their communities and to address discrimination against people who experience memory loss. Targeted education about brain health and dementia service support pathways, including but not limited to home modifications and secure tenancy, is also necessary within the social housing and homelessness sectors as well as the wider community.

Respite services should play a pivotal role in mediating and easing the transition from a family or household setting into a structured residential care environment for people with dementia and their families through the provision of short-term day or overnight care, in addition to helping families and carers more immediately to manage and sustain high care burdens.

People who do not have access to family or other supports, people from CALD backgrounds and people in marginal accommodation will potentially require access to additional or specialised supports. Many will also require advocacy in navigating the services available to them in an environment of greater consumer choice.

There is a need for more affordable, service-integrated housing options for people with dementia, as well as housing options and support services for people under 65 years with early onset dementia who are not presently covered by disability or aged care services (and it is unclear how the National Disability Insurance Scheme will address this in the future).

The increasing incidence of dementia and awareness leading to earlier diagnosis will require an enhanced response by a range of stakeholders and effective inter-agency collaboration. Implications for the future include: the need to manage cases over longer periods of time; the requirement to provide home modifications tailored to the needs of individuals; and the need for pathways that provide a transition into respite and longer-term structured residential care.

FURTHER INFORMATION

This bulletin is based on AHURI project 41022, *Future housing and support needs of people with dementia*.

Reports from this project can be found on the AHURI website: www.ahuri.edu.au or by contacting AHURI Limited on +61 3 9660 2300.

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