

Uncovering the hidden truth

Until recently, very little was known about the needs and experiences of the estimated 65,000 Australians with dementia who live alone. In an Australian-first study, researchers are now starting to build a picture of the lived experience of this group, their level of social isolation, needs and barriers to accessing care services. **Jennifer Fletcher** and **Lee-Fay Low** provide this update on the About People Living Alone with Dementia (APLAWD) Study

Studies of people living alone with dementia in the US and Canada suggest that one third of people with dementia in the community live alone (Webber *et al* 1994; Prescop *et al* 1999; Ebly *et al* 1999). Applying this statistic to Australian population estimates, this would mean that there are around 65,000 people who have dementia that live alone in Australia (Alzheimer's Australia NSW 2013).

The number is set to increase rapidly because on the whole, people are living longer, more people are ending their relationships in middle age, and people are having fewer or no children, such that there are fewer people to take the role of cohabiting carer.

People with dementia that live alone might be at risk for management problems with nutrition, money, personal care, medication, wandering, depression, falls and other factors more than those living with others (Tilly 2010). They might also be more prone to being socially isolated.

What we are doing

The APLAWD research team from the Dementia Collaborative Research Centre: Assessment and Better Care (DCRC:ABC), at the University of Sydney, held an open forum for providers of services to people with dementia in the Sydney area. This was a successful event with over 50 interested attendees.

In break-out sessions led by Associate Professor Lee-Fay Low, attendees brainstormed some of the issues they faced when trying to provide services for people with dementia who live alone. Some of the issues that were raised were:

- It is often difficult to get in contact with, and get consent from people, to provide them with services.
- Service providers said that people who live alone often had no-one else to help monitor their health and nutrition or administer medications.
- They were concerned that people living alone had difficulty getting transport to a range of services and keeping in touch with the community.



- Service providers found that care packages did not provide for the extra time it takes to care for a person with dementia who lives alone.
- Service providers sometimes had a shortage of care workers who were trained for the complex needs of a person who has dementia and lives alone.

To gain an in-depth view of the lived experience of people living with dementia, we have interviewed 19 people with dementia who live alone (and 16 of their carers who do not live with them). As a comparison we have interviewed 10 people who have dementia but do not live alone (and 10 of their carers who live with them).

Preliminary observations from these interviews show that:

- People with dementia who live alone often have unmet nutritional needs and unmet social needs.
- People who live alone also reported that they felt lonely.
- Their carers reported that they had substantial expenses of travel and time (often holidays or weekends), and some had to cut back on hours spent at work to care for their loved one.
- Most of the carers who live separately to their loved one indicated that they

felt stressed and some were concerned about providing adequate care.

How can you help?

We would still like to interview more people with dementia in the South East Sydney area. We need to interview people who have dementia who are living with others, as well as those who are living on their own.

Dr Jennifer Fletcher would like to hear from you if you are a person with dementia, or know (or provide care to) anyone who has dementia and lives in the South East Sydney area (East and Inner Sydney, Randwick, Botany Bay, Waverley, Woollahra). Contact her at: jennifer.fletcher@sydney.edu.au for more information. ■

Acknowledgments

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References

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