



# **LIVING WITH DEMENTIA IN THE COMMUNITY: CHALLENGES & OPPORTUNITIES**

**A REPORT OF NATIONAL SURVEY FINDINGS  
ALZHEIMER'S AUSTRALIA**

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**STUDY ALZHEIMER'S  
EDUCATE AUSTRALIA**  
FIGHTDEMENTIA.ORG.AU

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# KEY FINDINGS

Alzheimer's Australia conducted its first national survey of people with dementia in 2014 to identify priorities for tackling stigma and social isolation associated with dementia in the community.

**188** **Australians with dementia responded to the survey and provided insights into their experiences living with dementia.**

The findings of the survey indicate that dementia can have a devastating impact on the social lives of people with dementia. A diagnosis brings with it not only the difficult reality of changing cognition, but also a change in how friends and families respond to the person.

**59%** Of survey participants thought that people avoided spending time with them because of their diagnosis of dementia or were unsure.

**41%** Wished that they had more social contact with people in the community.

People with dementia indicated some of the barriers to staying involved in the community and kept them from going out and doing the things they enjoyed were:

**57%** Indicated that they are afraid of becoming lost

**48%** Said that they have difficulty communicating with staff in stores

**25%** Said that people seem to feel uneasy because of their diagnosis.

People with dementia indicated a need for changes to our communities to make them dementia friendly and to support people with dementia to continue to live well and continue to be involved in the things they enjoyed before a diagnosis.

People with dementia identified the following as priorities in creating dementia-friendly communities:

- Increasing community awareness and understanding about dementia
- Improving access to social activities and opportunities for engagement including employment and volunteering
- Access to appropriate health and care services to support them to continue to live at home for as long as possible
- Access to affordable and convenient transportation options
- Improved physical environments including appropriate signage, lighting, and colours.

A common theme across all of the responses was the need for better communication to support people with dementia to participate in their community.

# BACKGROUND

The term dementia refers to a range of different conditions which all have an impact on thinking, memory and behaviour. There are over 100 different conditions that can cause dementia, the most common types being Alzheimer's Disease and Vascular Dementia. There are more than 332,000 Australians living with dementia in 2014. This number is expected to increase to nearly 900,000 by 2050.

The majority of people with dementia (approximately 70%) live in the community, many with support from family and friends and in some cases formal care supports. It is estimated that approximately 1.2 million Australians are involved in the support of people with dementia. Of people living in the community, it is estimated that approximately 20% (or 46,200) live alone.

Government policy and services often focus on the health and care needs of a person with dementia. While care services are an essential component to supporting a person with dementia and their family carer, the disease has profound impacts on the social life of a person with dementia and their families as well.

Often after a diagnosis people with dementia give up work and other activities that they enjoy, including hobbies, shopping and sport. Anecdotal reports suggest that family and friends often stop visiting as they may be uncomfortable with how to interact with a person with dementia. Research suggests that there is also profound stigma which is associated with dementia. A 2012 survey of Australians by University of Wollongong, Centre for Health Initiatives found that:

- A third said they found people with dementia irritating
- 60% of people would feel a sense of shame if they developed dementia
- 1 in 5 would feel uncomfortable spending time with a person with dementia

Alzheimer's Australia is working to tackle the stigma and social isolation associated with dementia through supporting the development of dementia-friendly communities. The goal is to create places where people with dementia are supported to live a high quality of life with meaning, purpose and value. Every community will look different but may include:

- Businesses that have staff who are trained to understand dementia and know how to communicate well with people who have dementia
- Volunteering and employment opportunities for people with dementia
- Memory cafe's, choirs, walking groups, sporting clubs and social groups that are welcoming and inclusive of people with dementia

Listening to people with dementia about their needs and preferences is at the heart of creating a dementia-friendly community. For this reason, Alzheimer's Australia conducted its first-ever survey of people with dementia in 2014. The goal was to find out directly from people living with dementia what their experiences are like and how they want the community to change to better support them.

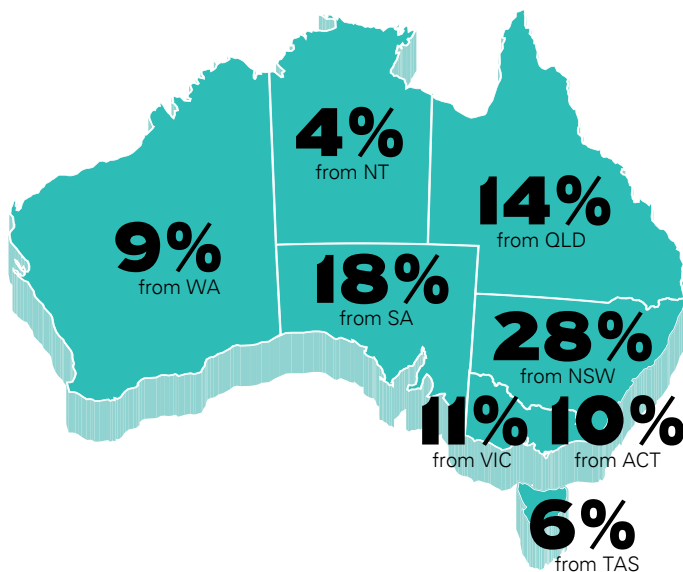
We are very grateful to the 188 people with a diagnosis of dementia who devoted their time to respond to the survey. We would also like to thank Kate Swaffer, Chair of the Alzheimer's Australia Dementia Advisory Committee, who provided feedback on the development of the questions.

## PROFILE OF RESPONDENTS

The survey was completed by 188 Australians living with dementia. Over a third (37%) completed the survey on their own, with two-thirds receiving assistance from a family member or support person.

People with younger onset dementia were overrepresented in the sample with 37% of respondents indicating that they were under the age of 65.

We received responses from every state and territory with the breakdown as follows:



# SOCIAL ISOLATION

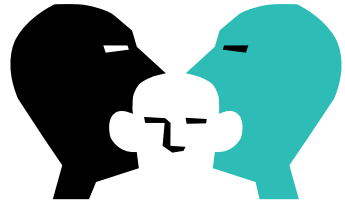
The survey results suggest that for many people with dementia, a diagnosis has a significant impact on social relationships, with many people experiencing family and friends no longer wanting to spend time with the person because of their diagnosis.

**42%**

of participants thought that people avoided spending time with them because of their diagnosis. An additional 17% were unsure if people avoided spending time with them.

**41%**

of people with dementia wished that they had more social contact with people in the community.



Survey participants described the experience of this social isolation:

*"No one wants to spend time with me now that I have a diagnosis. It is like they think I no longer count and I am not a person anymore. It makes me so sad and I end up sitting at home wishing life was different".*

*"Sometimes my social death makes me more sad than the changes to my brain and the loss of my memories. It makes me so angry. I just want to be counted as a person again".*

*"I have lost almost all of my friends and the few I have I see once a year or even once every 2 years. I have one friend who I see about every 4 months".*

*"I've lost all my friends and I'd love to meet more people my age".*

While the majority of respondents to the survey get out of the house almost every day, 10% indicated that they only get out of the house a few times a month or less.

A number of barriers to participating in the community were identified with 57% of people saying that they limit their activity because they are afraid of getting lost, 48% indicating that they have difficulty communicating with staff in stores, and 25% finding that people seem awkward or tense around them because of their diagnosis.

# LIVING ALONE

Social isolation is even more common amongst people with dementia who live alone. Of people who completed the survey, 16% indicated they live on their own. This percentage is slightly lower than the estimated 20% of people with dementia who live alone in the broader community. It is likely that it was more difficult to reach this group of people as they may not be linked in to traditional support services.

Respondents who live alone highlighted that assistance with finding appropriate services and supports is critical. They indicated a need for services to be flexible including the option of care on weekends, to better support people to live at home.

## CREATING DEMENTIA-FRIENDLY COMMUNITIES

People with dementia indicated that there is a need for changes to communities to better support people with dementia. Many survey participants expressed their eagerness to contribute and be active within their community but they also indicated a number of barriers that keep them from being as involved as they would like to be.

People with dementia identified community awareness and understanding as critical to developing dementia-friendly communities.

Other important features of a dementia-friendly community identified by survey participants included:

- Access to social activities (64%)
- Supports to stay at home (56%)
- Appropriate health care (54%)
- Transport (40%)
- Improvements to the physical environment (35%).

## Community Awareness

Respondents to the survey indicated that many people in the community do not understand dementia. They found this to be a significant barrier to participating in community life. As survey participants explained there needs to be:

*“Enhanced community education around the issue of dementia. Myths about dementia need to be dispelled.”*

*“A greater awareness and acceptance by other people.”*

*“Educational support to make people in professional care roles aware of what it is like.”*

*“Education about dementia especially around the fact that a person living with dementia may take a little longer to perform some of the day to day functions that everyone takes for granted especially when interacting in public environments. A person living with dementia can at times be simply a little slower at completing day to day tasks and have as much to contribute to society as the next person. Society needs to be educated in understanding the disease.”*

*“Society needs to be educated in understanding the disease and to learn to demonstrate a little tolerance and patience”*

## Access to Social Activities

Many respondents to the survey indicated that increasing access to social activities was essential to creating dementia-friendly communities. These activities can range from creating opportunities for employment or volunteering to involvement in social groups or sporting activities.

The importance of access to social activities was highlighted by one respondent:

*“There needs to be better options for people like me to stay active. I end up staying at home worried that I will forget and becoming more and more depressed. If only I could do the things I used to like to do. I feel so hopeless and there is no meaning to life any more”*



Easily accessible and comprehensive information about available services and supports was also highlighted as a strategy that would help people with dementia access appropriate supports and activity groups within their community. As a survey participant explained,

*“There are some groups that are open to people with dementia but nobody knows about them because there is no ‘database’ for these groups. It would be great to encourage all groups in society [who are open to involvement of people with dementia] to advertise their existence and most importantly it would be essential to have a common place to do it.”*

## Transport

Access to appropriate transport options is essential to ongoing involvement in the community for people with dementia. People with dementia will need to give up their drivers licence at some point following diagnosis. Often this creates a crisis as it means a significant loss of independence and control. With access to appropriate community transport people can continue to engage in activities they were involved in before losing their licence.

People with dementia commented extensively on this issue:

*“As I no longer have a driving licence I would like to have more public transport available or more transport from services”.*

*“I am now wheelchair bound. I need to be accompanied and use access cabs which are not freely available during the week”.*

*“I can’t drive, shops are too far, family works and has no time. My kids take me to church I enjoy that”.*

*“My wife and I no longer drive and live on a farm in a small community. There is no public transport so rely on family and friends to attend to our shopping”.*

## Physical Environment

Some survey participants (35%) explained that changes to community physical environments would improve their ability to access and interact within their community. For example, minimising noise where possible, less reflective surfaces such as glass and better maps, signage and directional cues.

A survey participant described in detail changes to the community environment that would greatly improve their experience,

*“Attention paid to reducing hard surfaces, minimising noise, muzak and use of microphones to advertise wares, providing clues as to directions, painting doors to toilets in different colour, minimising reflective surfaces in toilets, providing maps of shopping centres etc.”*

Alzheimer’s Australia in collaboration with University of Wollongong is creating a dementia-friendly audit tool for public spaces which will assist organisations and communities to identify ways to improve the physical environment to make it more dementia friendly. This tool will be available in October 2014.

## Access to Health and Care Services

Not surprisingly, people with dementia identified access to appropriate health and care services, including support to live at home as essential to a dementia-friendly community. This includes access to a timely-diagnosis, support and services after diagnosis, access to respite, affordable assistance with housework and gardening and opportunities for flexible support within the home.

One participant described this:

*“I would like to see more in the home respite care and cheaper home nursing so that my wife will have a break but I would not have to be accommodated else where. My wife will be needing lots of help further down the track to support me and I have noticed that there are not many services available.”*





Visit the Alzheimer's Australia website  
for comprehensive information about  
dementia, care information, education, training  
and other services offered by member organisations.

**WWW.FIGHTDEMENTIA.ORG.AU**

Or for information and advice contact the  
National Dementia Helpline on

**1800 100 500**

The National Dementia Helpline is an Australian Government funded initiative

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