Dementia and loneliness

It is common to have periods of loneliness in life. However, chronic loneliness can lead to poor mental and physical health. People with dementia have been shown to commonly experience social isolation and this can put them at risk of becoming lonely.

In July 2016, Alzheimer’s Australia conducted a survey to examine the experience of loneliness for people with dementia and their carers compared to the experiences of the general public.

- 1,505 people in total participated in the survey,
- 62 responses came from people with dementia,
- 745 came from carers, and
- 698 were from the general public.

The survey participants were asked questions on the UCLA three-item Loneliness Scale (UCLA-3) and the Lubben Social Network Scale-6 questions (LSNS-6). These scales were used to (respectively) measure each participant’s experience of loneliness and their number of relationships.

From their responses to the scale items, participants were given a score for loneliness and social connection. The responses from people with dementia were averaged and compared to the average scores from carers and the general public.

**Loneliness**

People with dementia and their carers gave responses that indicated they were significantly more lonely compared to the general public. The results also suggested that people with dementia and their carers experience similar levels of loneliness. As seen in Figure 1, both people with dementia and carers were more likely to have high loneliness when compared to the general public. By contrast, people in the general public were more likely to give responses that indicated low loneliness.

**Relationships**

The results of the survey suggested that people with dementia have significantly less social contacts than carers, who in turn reported less social contacts than the general public.

This result correlated with the loneliness scores suggesting that fewer social contacts are associated with higher loneliness scores. The data suggested that while all three groups had similar contact with family members, the biggest difference between the groups was the number of friendships reported.

People with dementia were also more likely than carers and the general public to respond that they did not have any friends or family that they saw regularly, could confide in or call on for help. The data displayed in Figure 3 highlights this information.

**Figure 3** The percentage of people with dementia, carers and members of the general public who indicated that they had no social contacts that satisfied each question’s criteria.

Based on this data, people with dementia are:

- **More than two times as likely** to not see friends compared to carers and the general public.
- **More than three times as likely** to not have a friend to confide in compared to carers and the general public.
- **Almost three times as likely** to not have a friend to call on for help compared to the general public.
Conclusion

The results of this survey suggest that both people with dementia and carers have a higher risk of loneliness compared to the general public. This clearly correlates with people with dementia and carers having less social contacts. While both people with dementia and carers have smaller social circles than the average member of the public, these results suggest this is greater for people with dementia.

Respondents were encouraged to leave comments in the survey, giving insight into the cause of their loneliness. People with dementia reflected that friends became more distant after the diagnosis and symptoms of dementia - such as memory loss - made it harder to connect with people. Similarly, carers reflected that they felt friends and family were confronted by a diagnosis of dementia. Carers also reflected that the nature of caring left them with less time to socialise.

Loss of social networks leaves people with dementia and their carers more vulnerable to loneliness. Reach out to friends and family living with dementia to stay connected and improve community wellbeing.

Resources available for families and friends

There are many useful resources to assist families, friends and carers to support a person living with dementia to remain socially engaged in our community.

Families and friends matter – a booklet with information on how to stay connected to a person living with dementia

Tip sheets to assist social engagement – tips for friends, visiting, enjoying the holiday season, introducing art and music at home and caring from a distance.

Talk to me – a brochure developed by the Alzheimer’s Australia Dementia Advisory Committee to set out good communication tips for talking to people with dementia.

This report and the resources listed above can be found at fightdementia.org.au/dementia-and-loneliness

To talk to an Alzheimer’s Australia dementia advisor about this information and if you have any other questions, please call the National Dementia Helpline 1800 100 500.
LONELINESS AND PEOPLE LIVING WITH DEMENTIA

COMPARED TO THE GENERAL PUBLIC

2x more likely NOT to see friends

People with dementia and carers are significantly more lonely than the general public.

High levels of loneliness

<table>
<thead>
<tr>
<th></th>
<th>General public</th>
<th>People with dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>31%</td>
<td>57%</td>
<td></td>
</tr>
</tbody>
</table>

2x more likely to experience loneliness

Less than 1 in 3 people in the general public report high loneliness.

1 in 2 carers report high loneliness

High amounts of friend and family relationships

<table>
<thead>
<tr>
<th></th>
<th>General public</th>
<th>Carers</th>
<th>People with dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>16%</td>
<td>8.5%</td>
<td>7%</td>
<td></td>
</tr>
</tbody>
</table>

3x more likely NOT to have a friend to confide in

3x more likely NOT to have a friend to call on for help

© Alzheimer’s Australia September 2016