



Dementia and Loneliness

This discussion on dementia and loneliness seeks to contribute to the work of The Loneliness Taskforce by considering how people with dementia experience loneliness and exploring specific reasons why people with dementia can feel lonely and have limited social connections. It also explores how this issue can be addressed and the supports that need to be put in place to support quality of life for people with dementia. It is of note that there is a lack of research on dementia and loneliness from an Irish perspective, and therefore this discussion draws strongly on international research findings.

Introduction to Dementia

Currently in Ireland there are almost 55,000 people living with dementia; 19,800 men and 35,650 women. Of these, 4,000 people are under 65 and are classified as having younger onset dementia. It is estimated that the number of people living with dementia will rise to 153,157 by 2046 due to population ageing.

The term dementia describes a set of symptoms that include loss of memory, mood changes and problems with communicating and reasoning. These symptoms occur when the brain is damaged by certain diseases, including Alzheimer's disease. Dementia is progressive, which means that people with dementia and their carers are coping with changing abilities over time. These changes include a reduction in the person's capacity to make decisions, both about major life events and circumstances as well as day-to-day situations. Eventually they will need help with all of their daily activities and beyond.

Definition of Loneliness

Loneliness is a subjective state. Different people experience loneliness in different ways. For example, some people may feel lonely even if they have regular contact with friends and family; others may have few contacts but not feel at all lonely. There are different types of loneliness: emotional and social (Weiss, 1973). Emotional loneliness is the absence of a significant other with whom a close emotional attachment is formed (Burholt, 2011). Social loneliness, on the other hand, is the lack of a social network or group of friends, neighbours or colleagues.

Loneliness in Dementia

While many people with dementia can live well with the condition, quality of life remains extremely varied for substantial numbers of people. The risks of loneliness and social isolation are more profound in people with dementia. Studies have highlighted several personal characteristics which influence whether a person is lonely or not – many of which are common among people with dementia. Living alone (de Jong Gierveld et al, 2011) or living in residential care (The Residents and



Relatives Association, 2010) are factors which are associated with loneliness. Poor health (Victor C et al, 2005), reduced mobility (Tijhuis MAR et al, 1999) and cognitive impairment (Victor C et al, 2005) all increase in line with an older person's chances of being lonely.

A major review by The Lancet has identified nine potentially modifiable risk factors linked to dementia. Risk factors include social isolation and depression. Social isolation is increasingly thought to be a risk factor for dementia as it also increases the risk of hypertension, heart conditions and depression. It was found to contribute to 2.3% of the risk of developing dementia. However, as with depression, it remains unclear whether social isolation is a result of the development of dementia

There is evidence which suggests that the risk of Alzheimer's disease more than doubles in older people experiencing loneliness (Wilson et al, 2007). However, this research concluded that while loneliness is associated with an increased risk of dementia in later life, it is not one of the leading causes. By contrast, another recent study (Holwerda et al, 2012) stated that the link between loneliness and dementia is tentative. This research suggested that loneliness could be considered a consequence of the deteriorating social skills that are part of the personality change as dementia progresses. There is a need for further research in this area. The UK Alzheimer's Society 2013 report suggests that the nature of dementia compounds loneliness, rather than loneliness being a cause of dementia. However, the report found a different reason to explain loneliness among people with dementia. Family members of people living with dementia, as well as dementia support workers with whom Alzheimer's Society had contact for this research, reported that people with dementia may have lots of visitors, but they do not remember that somebody has been to see them. As a result, they do not perceive the social contact and feel more lonely.

Experience of Loneliness and Dementia

A report by the UK Alzheimer Society in 2013 explored the impact of loneliness and social isolation on people living with the condition, particularly for those living alone. Nearly two-thirds (63%) of people with dementia surveyed said they felt anxious or depressed. A third of people with dementia said they had lost friends and 5% said they have not told their friends about their diagnosis. This is actually a slight increase from 2012 when 4% of people said they had not told their friends about their diagnosis. Of those living alone, nearly two-thirds (62%) of people with dementia reported feeling lonely.

The negative consequences of social isolation and loneliness are well-researched internationally. In the UK the Alzheimer's Society examined these issues further with one particular group of people with dementia – those living alone – to see how well they are living with the condition. While a high proportion of people with dementia feel socially isolated, those who live alone are at even greater risk of loneliness, more so than people with dementia who do not live alone.



Cause of Loneliness in Dementia

The causes of loneliness and isolation in dementia are varied, and stigma can play a significant role:

- **Fear of Stigma**

The stigma surrounding dementia – and the discomfort which some people can feel when communicating with people with dementia – can contribute to a smaller social network. Fear of being stigmatised, judged and lack of confidence can hinder people with dementia from interacting with people and letting friends and neighbours know about their diagnosis. Stigma surrounding dementia can lead to a loss of friendships or make it very difficult to form new ones. There is a need to promote an understanding of dementia and to help reduce stigma still associated with the condition.

- **Support Networks and Interaction**

For many people with dementia who live alone, support from family and friends is vital. For some, their friends or family live too far away to be able to visit regularly. The 2013 UK's Alzheimer's Society report on loneliness found more than one in 10 people spoke to friends or family face-to-face less than once a fortnight. This type of contact is important because these conversations provide visual and sensory clues which can help them form memories more easily.

Where face-to-face contact is not possible, having regular phone calls can help. However, if someone with dementia struggles to follow conversations on the phone, does not manage well with technology or simply does not like speaking on the phone, it can make it harder to talk, and the chances of isolation and loneliness increase.

The above UK study found that a lack of neighbourly support could intensify feelings of isolation, given that people with dementia may be worried about dealing with difficult problems or emergency situations when family and friends live at a distance. There is a sense of fear among some people with dementia who live alone about what would happen in an emergency.

- **Activities and Engagement**

Having to stop engaging in regular activities can contribute to loneliness in people with dementia. There are factors specific to dementia that increase the likelihood of people with the condition having to stop doing things they used to enjoy. This can increase social isolation and loneliness. The 2013 UK Alzheimer's Society report states that more than two-thirds (70%) of respondents stopped doing things they used to, due to a lack of confidence. This figure is marginally higher among people with dementia who live alone. Diminished confidence can lead to a loss of independence, as people with dementia may feel concerned about what could happen if they leave their home, or reactions from other people. They may feel they can no longer go out or take part in activities. This, in turn,



leads to social isolation and loneliness. Once an older person loses their confidence, it is very difficult to regain. ASI believes it is important for people with dementia to retain their confidence, or have support that can help them rebuild it.

Losing confidence can be as a direct result of other attributes related to dementia. For example, in the above study more than two-thirds (68%) of all people with dementia stopped doing things they used to do because they worry about becoming confused, and 60% worry about getting lost. Among the people with dementia that were interviewed in the UK study, those who live in urban areas were more likely to worry about becoming confused or getting lost, especially when using public transport.

Anecdotes from people with early-onset dementia show that younger people do not want to join the same groups as people with dementia in their seventies or eighties, and may feel that there is nothing available that they enjoy.

Reducing Loneliness for People with Dementia

There is significant international research indicating that people with dementia who live alone are both socially isolated and lonely. Many people with dementia who live alone have few social connections, as highlighted. Few people living alone with dementia have meaningful friendships outside of their own family, which reinforces the feelings of loneliness. Research has suggested that loneliness can lead to early death (Holt-Lunstadt et al, 2010). The Holt-Lunstad research found that loneliness is just as likely to increase the risk of mortality as smoking and alcohol consumption. Medical research has linked loneliness to heart disease and depression. Further health problems can add to the worries of a person with dementia, particularly if they live alone and are not able to share their concerns with another person they trust. There is a need for Irish research that seeks to understand what people with dementia do, or would like to happen, to overcome their loneliness.

Good health and social care for people with dementia – from before diagnosis until end of life – remains an essential aspect of good quality of life. To achieve this, actions must include a well-funded social care system offering high quality, appropriate services that ensure and maintain quality of life for people with dementia. A wide range of services needs to be in place to ensure that people with dementia are not lonely or socially isolated.

Indeed ASI's Mapping report, produced by the HSE and ASI, which identifies all publicly provided or publicly funded community supports for people with dementia, is indicative of a shortcoming of supports. This report clearly indicates gaps and disparities in terms of service availability for people with dementia. For example, the report highlights that there are significant variations in the types of



dementia services provided in various counties, e.g., three counties, Wexford, Laois and Leitrim have no reported dementia-specific day centre, while CHO2 has no social clubs. It observes that there are extraordinary differences in terms of service provision across counties, ranging from 23 (CHO9) to 44 (CHO1) services, including social clubs, Alzheimer cafes and day care centres. Further investment in dementia services is crucial so people feel connected and supported.

Currently, Dementia Advisers (DAs) play a pivotal role in efficient dementia care in the community by sign-posting families to relevant services and supports available. ASI currently employs 8 DAs who provide service across 13 counties. Their role is to work with people with dementia and their families, giving information and support in a timely manner, directing people to appropriate agencies and supporting them throughout their journey. DAs can play a crucial role in responding to the needs of people with dementia so they do not experience social isolation and loneliness. ASI is advocating for DA services to be expanded and developed to include an additional 35 DAs to deliver a nationwide dementia specific information and advice service.

Dementia-friendly communities (DFC) are an important vehicle for reducing social isolation and loneliness. The DFC initiative, developed by the ASI, works to ensure that people are aware of and understand dementia, and that people with dementia feel included, having choice and control over their day-to-day lives. Nonetheless more now needs to be done to raise awareness of what it means and encourage businesses, organisations and communities to commit to becoming dementia friendly.

It is important to note that not all people who are socially isolated are lonely. There are people who enjoy being by themselves and do not seek the company of others. So it is necessary to distinguish between a person's personality and the symptoms of their dementia. Above all, services for people with dementia must fit around individuals, recognising that not all people will want to join clubs and spend time talking within a group. Some people may prefer a walk outside with one or two other people. There needs to be support for needs-led personalised care whereby people with dementia and their carers are fully involved in planning their care.

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