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THE ALZHEIMER  
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# Dementia and Loneliness



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# Introduction

In September 2018 the Alzheimer Society of Ireland commissioned a team of researchers from University College Cork to carry out a focused piece of research that would inform current understandings around dementia and loneliness in Ireland. A detailed review of literature in this area was conducted as well as interviews with people living with dementia. A total of eight individuals aged 55 years and older, who were each diagnosed with dementia participated in individual interviews. The duration of diagnosis for participants ranged from eight months to several years. In four cases, participants were interviewed as dyads with their respective partner were present. In addition to this, consultation with stakeholders provided valuable feedback on the policy position paper. This policy position paper sets out the Alzheimer Society of Ireland's position on dementia and loneliness, and how loneliness in dementia can be addressed and alleviated. The Alzheimer Society of Ireland is committed to advocacy for people living with dementia and is dedicated to influence policy and services to support people living with dementia and their caregivers.

The focus of this policy position paper reflects the experience of loneliness from people living with dementia. Numerous international studies have previously highlighted that caregivers encounter loneliness<sup>1,2</sup> and research shows that caregivers report higher levels of loneliness than non-caregivers<sup>3,4,5</sup>. Loneliness and social isolation are recognised as important societal challenges<sup>1</sup>. To address the challenge of loneliness and dementia, it is first important to understand dementia.

Neurocognitive disorders, of which dementia is the major form, are a broad class of impairments in cognition, usually associated with ageing<sup>8,9</sup>. By and of itself, dementia involves the progressive loss of cognitive functions such as memory, attention, language, and reasoning. As follows, dementia represents many challenges: it interferes with cognitive function and performing activities of daily living. According to the existing literature, this may cause individuals to feel a sense of loss in terms of their independence and a disruption to their sense of self<sup>10,11,12</sup>. There are a number

of known risk factors for dementia, however key contributing factors such as social isolation and lack of social integration may, in themselves, be risk factors for dementia. In such a way, evidence supports that social isolation may contribute to increased risk of dementia<sup>12,13</sup>, and the lack of social integration may contribute to cognitive decline at older ages<sup>14,15</sup>.

Living with dementia necessitates adaptation, from small adjustments to significant alterations, a dementia diagnosis will have a momentous impact not only on those directly affected, but on their spouses, families, and friends. Hence, it is very important that every person with dementia has the opportunity and the support to develop their own personal response to the challenges of their condition, so that they can lead self-determined lives at home, connected to their neighbours and community<sup>16</sup>.

To date, very little research has been carried out in terms of trying to understand whether living with dementia causes feelings of loneliness in individuals who've been diagnosed. As with dementia itself, however, loneliness is a complex phenomenon that impacts on both mental and physical health. Some studies suggest that the effects of isolation and loneliness on health and mortality are on par with other risk factors such as high blood pressure, obesity, and smoking<sup>17,34</sup>.

As follows, the research upon which this policy position paper is based sought to understand whether individuals living with dementia felt lonely as their lives progressed and their conditions worsened. Do persons living with dementia in Ireland have opportunities to engage in social activities? Are they able to maintain meaningful relationships with others? Do they have the adequate public supports to help them and their families through their journey? Or, do they feel that they are isolated and alone? The next section draws on the literature reviewed to explore these questions and is followed by the accounts from people living with dementia in Ireland.



# **The Issues**

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**Living with dementia**

**Loneliness**

**Loneliness and dementia**

## Living with dementia

Increasing numbers of older people in a society will mean that more and more individuals will have cognitive impairments commonly associated with ageing<sup>18</sup>. Today, there are 47 million people living with dementia worldwide<sup>19</sup> and it is estimated that there are approximately 55,000 people diagnosed with dementia living in Ireland<sup>7, 20</sup>, roughly 4,000 of whom are less than 65 years of age<sup>7</sup>. According to figures from the Department of Health, it is predicted that the number of people with dementia in this country will reach 113,000 by 2036<sup>7</sup>.

Although many people with dementia are able to live well with their condition, individual experiences can vary drastically and there remain significant gaps in Ireland's dementia service provision<sup>22</sup>. Moreover, evidence suggests that many people with dementia who live alone have few social connections or meaningful relationships outside of their own families<sup>23, 24</sup>. People with dementia often attribute reductions in their social interactions to the cognitive deficits that accompany their condition<sup>25</sup>. However, how others react to their dementia also plays an important role.

Furthermore, dementia affects not only persons who are diagnosed but all those within their social circle. A diagnosis can thereby alter the lives and dynamics of whole families, friendships, and communities. There are an estimated 50,000 individuals in Ireland caring for (and oftentimes living with) a person with dementia<sup>26</sup>. It has also been estimated that an additional 60,000 individuals may be providing unpaid care for family members or friends with dementia living in their communities. Numerous studies have shown that caregivers are often faced with social isolation and reduction in social interactions similar to those experienced by people with dementia<sup>27</sup>. A recent report in the UK states that 8 in 10 people caring for loved ones "have felt lonely or socially isolated" and the term "The world shrinks" is used to highlight caregivers experience of loneliness which is caused by a range of circumstances, many of which are beyond their control<sup>28</sup>. Less is known about the experience for a person living with

dementia so the literature reviewed informs our understanding of loneliness and dementia.

## Loneliness

As with any emotion, loneliness is subjective by nature. Thus, perceptions of loneliness among individual older adults, with or without dementia, will differ<sup>29</sup>. Generally speaking, however, loneliness can be understood as a self-perceived sense of social isolation, which is separate from any factual, objective situation of alone-ness (or social isolation)<sup>30</sup>. It is an emotional state in which individuals are aware of feeling apart from others while at the same time experience a vague need for contact with others<sup>31, 32</sup>. It has been characterised as being a "pervasive, depressing, debilitating condition that can affect all of one's life"<sup>31, 33</sup>. As follows, it is recognised that loneliness can be emotionally painful and that its symptoms can manifest differently for different people<sup>34</sup>. Feelings of loneliness can be categorized in a number of ways. According to Mushtaq et al. (2014), there are three types of loneliness: situational, developmental, and internal<sup>35</sup>. Each of these are associated with different factors. Situational loneliness is associated with environmental factors (e.g., unpleasant experiences); developmental loneliness is associated with physical and psychological deficits or disabilities (e.g., having a medical condition); and internal loneliness is associated with personality (e.g., low self-esteem or poor coping strategies)<sup>35</sup>. In essence, loneliness is the absence of imperative social relations and lack of affection in current social relationships<sup>31</sup>. Loneliness is not necessarily caused by being alone, but by being without some definite needed relationship or set of relationships<sup>33</sup>. The experience for people with dementia is influenced by other factors which are discussed in the following section.

## Loneliness and dementia

According to the existing literature, there is a close, complex connection between feelings of loneliness, social isolation and dementia diagnosis<sup>10,25,36</sup>. On the whole, people living with dementia or cognitive impairment are at risk of loneliness<sup>37</sup>. For the most part, this is because they commonly experience social isolation, which can increase their risk of loneliness<sup>36</sup>. Research undertaken for the Dementia Understand Together Campaign in 2016 has shown that fear and stigma continue to surround the public perception of dementia in Ireland. In addition, it was proposed that factors contributing to social exclusion can cause unnecessary loneliness and isolation for people living with dementia and their families<sup>38</sup>. These findings echo research previously published in other countries<sup>39-44</sup>.

At the same time, persons with dementia are often faced with a multiplicity of stigmas, which compound factors that contribute to their experiences with loneliness. For instance, individuals living with dementia often downplay their symptoms for fear of others not associating with them<sup>29</sup>. While this is closely related to the prevailing stigma that surrounds dementia specifically<sup>45</sup>, it has been suggested that experiences of depression, loneliness, and isolation can be seen as individual failings<sup>25,30,31</sup>. These attitudes are related to the stigmas surrounding both mental illness and physical disabilities generally – conditions that can be experienced simultaneously by persons with dementia.

In addition, the very nature of the condition makes it difficult for people with dementia to engage in large social networks on a long-term basis. Across the literature reviewed, interpersonally satisfying communication and regular opportunities to have meaningful interpersonal interactions with others were highlighted as key in terms of alleviating both social isolation and loneliness<sup>29</sup>. Loneliness interventions such as dementia supportive communities or other social resources are also necessary<sup>41</sup>. When persons with dementia are able to maintain social networks that foster connections while also partaking in meaningful activities that

preserve their sense of self-worth (e.g., completion of daily living activities and routines), feelings of loneliness are reduced. Furthermore, as not all people experience “aleness” in the same way, a variety of individually-tailored initiatives are essential.

Finally, feelings of loneliness are influenced by the ability of older persons to adjust or adapt to change and loss<sup>41,42</sup>. In order to continue living independently, individuals with dementia have to adapt to alterations in their lifestyle and routine as their condition progresses. Existing studies propose that individuals with dementia employ coping mechanisms to prevent the onset of loneliness and other negative emotions that may arise in response to these changes<sup>41,43</sup>. These included individually-tailored meaningful activities (e.g., spiritual engagement, relaxation and leisure); long-term ongoing structured support groups) and maintaining interactions with people from a variety of backgrounds<sup>43,44,45</sup>.

## Summary

Countless studies about loneliness centre on the experiences of older adults without a dementia diagnosis. There are some research studies on persons with dementia living in residential care settings<sup>47-49</sup>. Less attention has been given to the way in which individuals with dementia, who live at home, perceive or experience loneliness. Several factors influence the experience of loneliness for people with dementia of which many factors are beyond their control. The opportunity for persons living with dementia to discuss feelings of loneliness needs to be addressed as loneliness is associated with poor health and higher rates of mortality<sup>50</sup>. As follows, the present policy paper seeks to understand not only how individuals with dementia experience loneliness in Ireland, but also identify key factors that contribute to maintain social networks that foster connections.





# Understanding loneliness and dementia in Ireland

Relationships and Family

Public support and social connection

Independence and confidence

The multiple stigmas of dementia and loneliness

Other factors

*“If he wasn’t here... there is not a person that I would rely on... I rely on him an awful lot now... it’s that emotional connection to somebody”.*

Person with dementia describing the importance of a meaningful relationship with spouse.

To further explore the concept of loneliness in an Irish context, interviews were conducted with individuals living at home with a dementia diagnosis. This section outlines the key elements associated with the reported presence or absence of feelings of loneliness by participants. Broadly, four factors listed below were identified. A meaningful relationship was recurring throughout all factors and often the partner or primary caregiver was identified as instrumental in this relationship.

1. Relationships and family
2. Public supports and social connection
3. Independence and confidence
4. The multiple stigmas of dementia and loneliness

### Relationships and family

People with dementia attributed the presence or absence of loneliness to the presence or absence of meaningful relationships, which afforded opportunities to maintain routine and familiarity. In this regard, participants described having to depend on their partner’s support and guidance to a significant extent. For one individual, having her husband around when interacting with others helped alleviate her fear of forgetting a person’s name, or whether or not she was already acquainted with them. By helping her overcome this fear, the individual’s husband and primary caregiver was enabling the participant to continue socially engaging with others.

Another participant described her relationship with nature as similar to that of a spiritual relationship as often there are a lot of things going on inside her head and one needs to escape. This participant described the solace and peace when going outside and watching the beauty of nature.

In addition, people with dementia described consciously planning their daily, weekly, and monthly activities with families and friends. Sometimes, this involved establishing routines and, in some

cases, family members would make sure to “check in” on individuals with dementia. While this helped to alleviate the pressures of having to deal with natural alterations in lifestyle and routine that come with ageing, conscious planning also served as a preventative measure against the onset of feelings of isolation for those with dementia.

## Public support and social connection

As mentioned, a dementia diagnosis affects not only the individual but also their families, friends, and wider community. People with dementia and their caregivers described the difficulties of having to navigate the vast scope of changes to their lifestyles and routines following a diagnosis. For instance, as symptoms worsened, families and spouses were required to dedicate more time and effort into caring for their loved ones. This was oftentimes in addition to working and managing their own lives. In this respect, public supports and social provisions were essential. In particular, access to home care support and public nurses enabled families to manage living life with dementia. By the same token, however, the difficulties of securing these supports were a source of anxiety, frustration, and loneliness.

According to the literature, individuals are more likely to experience feelings of loneliness and isolation if they are financially insecure, live alone, and are female. While some of our participants reported the importance of social provisions and public supports, our findings suggest that these publicly funded programs are even more significant in the absence of a partner or caregiver. For people with dementia who live alone, feelings of loneliness are a significant factor in their daily lives. The absence of meaningful connection with others in a close geographical proximity was a major contributing factor to feelings of loneliness.

## Independence and confidence

In addition to broader changes in their lifestyle, individuals with dementia also reported diminished capacity to engage in basic activities following their diagnosis. Fear of the unknown caused anxiety and hindered their social aspirations. For participants who were able to maintain a sense of independence, however, having a connection to their communities were essential. In one example, an individual with dementia described going into town and watching sports matches on their own. Their ability to do so rested on the fact that they felt comfortable sharing their diagnosis with members of their community. The participant explained that when their symptoms worsened (e.g., confusion, irritability, shaking), someone would ask how they could help. In another example, a participant described losing a loved one. Having members of their community offer their condolences and a chance to talk about their loss helped them feel less alone.

In such a way, our data suggests that the maintenance of social connection to the wider community fosters a sense of self-worth and self-management, which in turn mitigates feelings of loneliness. In other words, the security that comes with this connection enables individuals to maintain a level of independence that they may otherwise perceive as lost. Furthermore, two other significant factors that influenced the presence or absence of loneliness for people with dementia revolved around their (in-) ability to drive and their (in-) ability to work. These activities provided individuals with dementia opportunities to engage in their community as much as they contributed to their sense of independence. Access to alternative transportation and technologies, and the development of new hobbies and routines were also helpful in terms of enabling individuals cope with these changes.

## The multiple stigmas of dementia and loneliness

When asked to talk about their experiences of loneliness, participants indicated that their responses were influenced by wider socio-cultural factors and the stigmas associated with both mental and physical health. The actual terms i.e., loneliness and dementia, are both stigmatised conditions in Irish society<sup>6,7,22</sup>. This may have influenced not only how participants view loneliness and dementia generally, but also whether they would acknowledge their own feelings of loneliness and the extent of their difficulties regarding their life with dementia.

Research has demonstrated that individuals with dementia will hold back from fully disclosing the nature of their symptoms and condition for fear that others will not associate with them<sup>51</sup>. In kind, one of our participants reported keeping their diagnosis a secret from others in an attempt to maintain some semblance of normality with those in their social network. Another described negotiating trips to the shop as it took her longer to count her change and the fear of delaying the queue or appearing as though they were incapable of counting was a source of concern. One more participant expressed not wanting to “burden” people with their diagnosis and the difficulty of establishing meaningful relationships because of this.

In sum, participants reported feeling discouraged from talking openly about loneliness and dementia. Due to the complex nature of stigma and the compounded factors affecting participants, however, it was difficult to discern between the effects of the two. Yet whether individuals felt ostracised by their own communities following negative interactions with others or whether participants were acting on the basis of their own negative self-perception, the sense that they could not openly discuss their feelings was prevalent.

## Other factors

It is important to note that people with dementia emphasised the importance of “alone time” for self-reflection. This helped them cope with their increased vulnerability to stressors that occurs as a result of their condition. However, being alone on a continual basis coupled with the absence of any meaningful relationships caused feelings of loneliness. In addition, all of our participants were no longer working. In this respect, financial insecurity was a major source of concern for people living with dementia in their day-to-day life. It was also a contributing factor to their lack of social interaction with others.

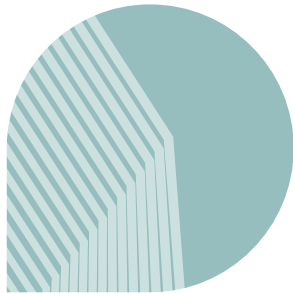


# The Stories

“Anyway, so I tried different things [to avoid being lonely]... but there is very, very little so I would have one or two you know good friends, but they have families and they have their lives and that...I find somehow, and I know this is psychological, it’s kind of not so bad in the week but the weekends tend... to be very very hard, very hard.”

“I love being outside and I find it very relaxing in nature if I am out and about with the animals or whatever there is something very relaxing and if I am in the house sometimes my mind is midered, I feel midered so I like to get out....”

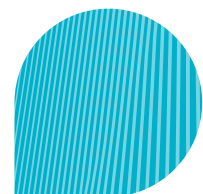
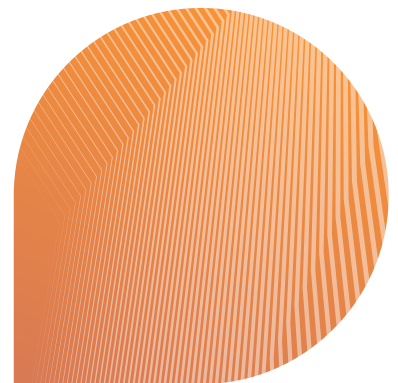
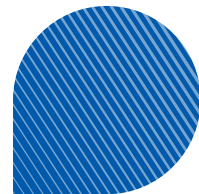
“I suppose society views you like you are not the full shilling, so that would be my concern, you know? Yeah, like sometimes you would go to the shop and you have money. And I find money hard to understand, so I don’t want to say, you know, “okay, I am not going to count out my coins because it is going to take me a long time”. So, I kind of give over notes because you don’t want to be seen to be, you know, that you can’t [count]. Yeah, so it’s kind of, well, if you leave me alone in here in the silence I can do it, you know what I mean? In my own time. But you don’t want to, so I do think in your own mind or not, I don’t know, that there is that, but you kind of, you think of somebody as an imbecile.”





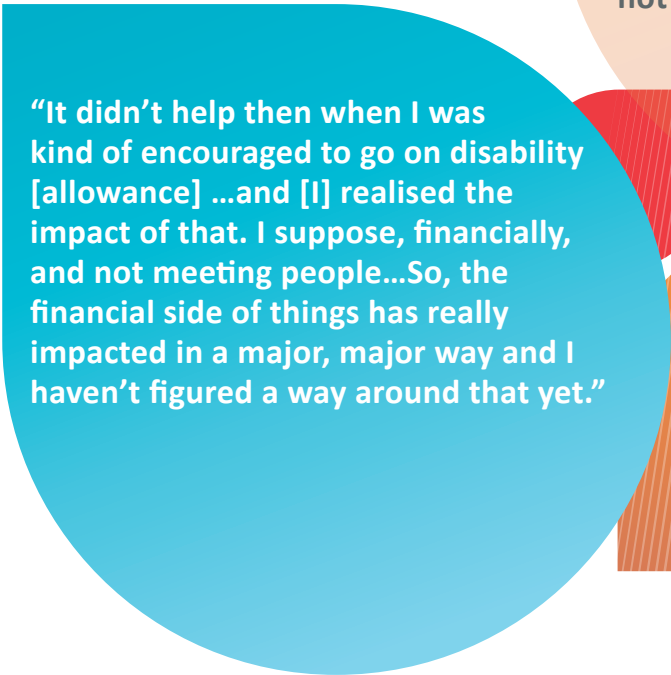

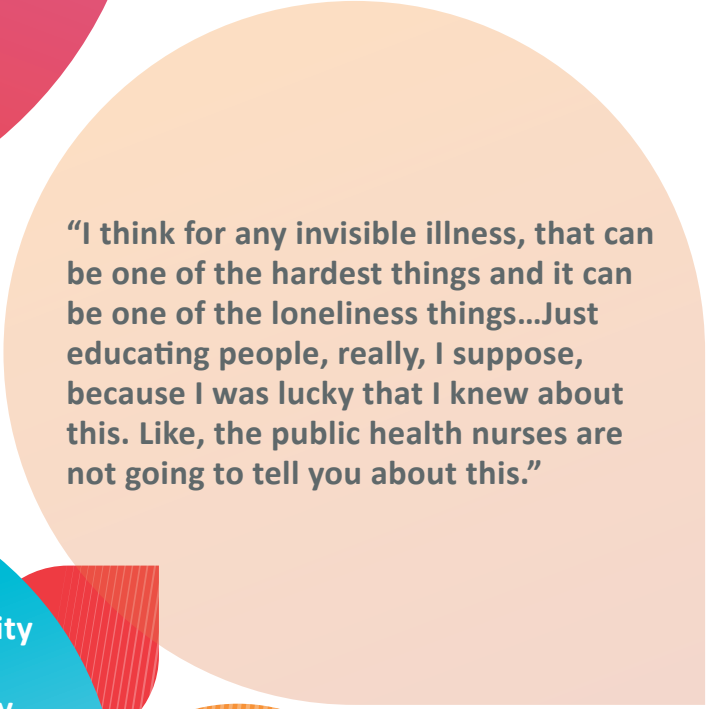


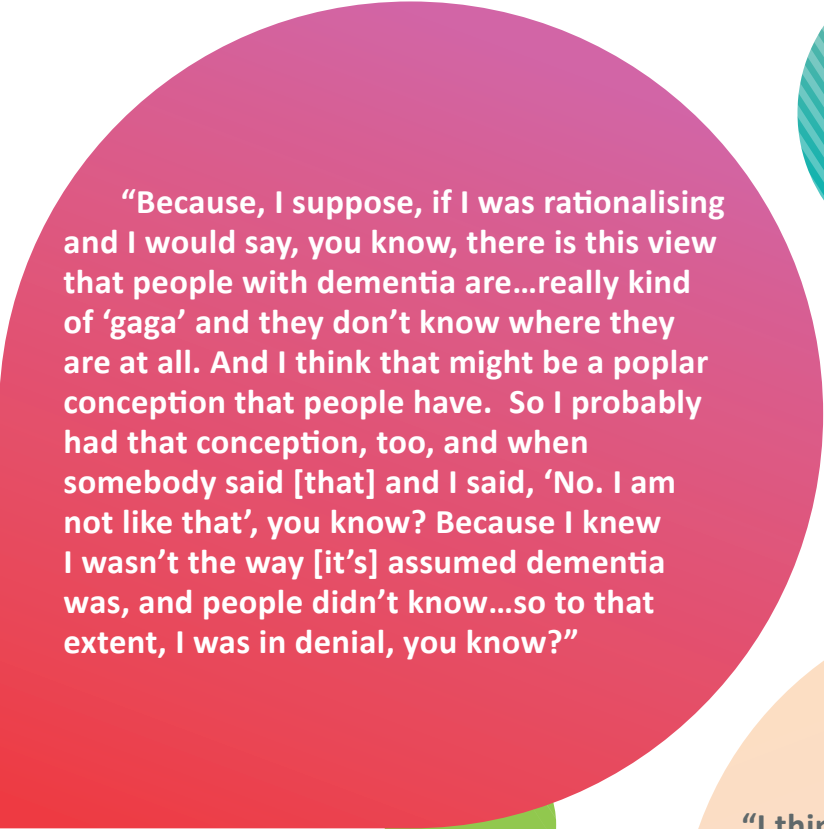
“Yeah we do feel a bit isolated out here [country side] we plan on trying to sell the house and go back in to town...”

“I suppose I can just [get out of the house] if I want to go. I don't go as much as I should do, you know what I mean. I can't go out...compared to last Christmas and, you know...I just stop buying because I always went [into town]...to the shops. It's not that I am lazy, it's just that I don't know – I don't remember to go. I might not remember to walk down to the shops and I would be afraid to...walk down to the shops... But then I [think] I would meet people if I did that, but I just don't I really don't think of it... It would be just something like just going out for a walk, you know? I should really...It's all about that routine, you know?”

“But a good thing that actually happened one Sunday, I went down to my local pub to watch a hurling match...and one of the lads in the pub... I just know him in passing...but he just came over and he said to me, he put his two hands up on my two hands, and he said “are you okay?” and I said, “I am having a bit of a rough morning”. He said, “do you want to go home?”. I said, “Look. I will finish my pint and we will see.” ...That for me is savage comfort... You see, when people that know you and know what's wrong with you are around you, then you are never alone...Being alone is the problem.”







“Because, I suppose, if I was rationalising and I would say, you know, there is this view that people with dementia are...really kind of ‘gaga’ and they don’t know where they are at all. And I think that might be a popular conception that people have. So I probably had that conception, too, and when somebody said [that] and I said, ‘No. I am not like that’, you know? Because I knew I wasn’t the way [it’s] assumed dementia was, and people didn’t know...so to that extent, I was in denial, you know?”

“I think for any invisible illness, that can be one of the hardest things and it can be one of the loneliness things...Just educating people, really, I suppose, because I was lucky that I knew about this. Like, the public health nurses are not going to tell you about this.”

“It didn’t help then when I was kind of encouraged to go on disability [allowance] ...and [I] realised the impact of that. I suppose, financially, and not meeting people...So, the financial side of things has really impacted in a major, major way and I haven’t figured a way around that yet.”



"It's [loneliness] probably the worst single thing a person can suffer from. And I am including dementia and I am including cancer I am including every disease going I don't think there is anything worse for a person than loneliness, it's an awful place to be."

"I would say [advice for someone who is lonely] take them to where somewhere that is really familiar to them whether it's you know sorry, somewhere that's yes, that they have always like, don't lock them up you must take them, the person must get out and even if it's only walking up a road that they used always enjoy in their childhood it will give them such relief to them."

"I think one of the greatest pleasure I get is from nature... just looking at the leaves and maybe even do so much as watching a bird what they are up to, you know if you don't have an animal you have nature and look at the colours. You can spend a lot of your time going over stuff in your mind you know you always have time to think, did I do this and would I do that and what do I have to do, you know you are trying to keep things fresh all the time whereas when you are out in nature you are kind of free...."

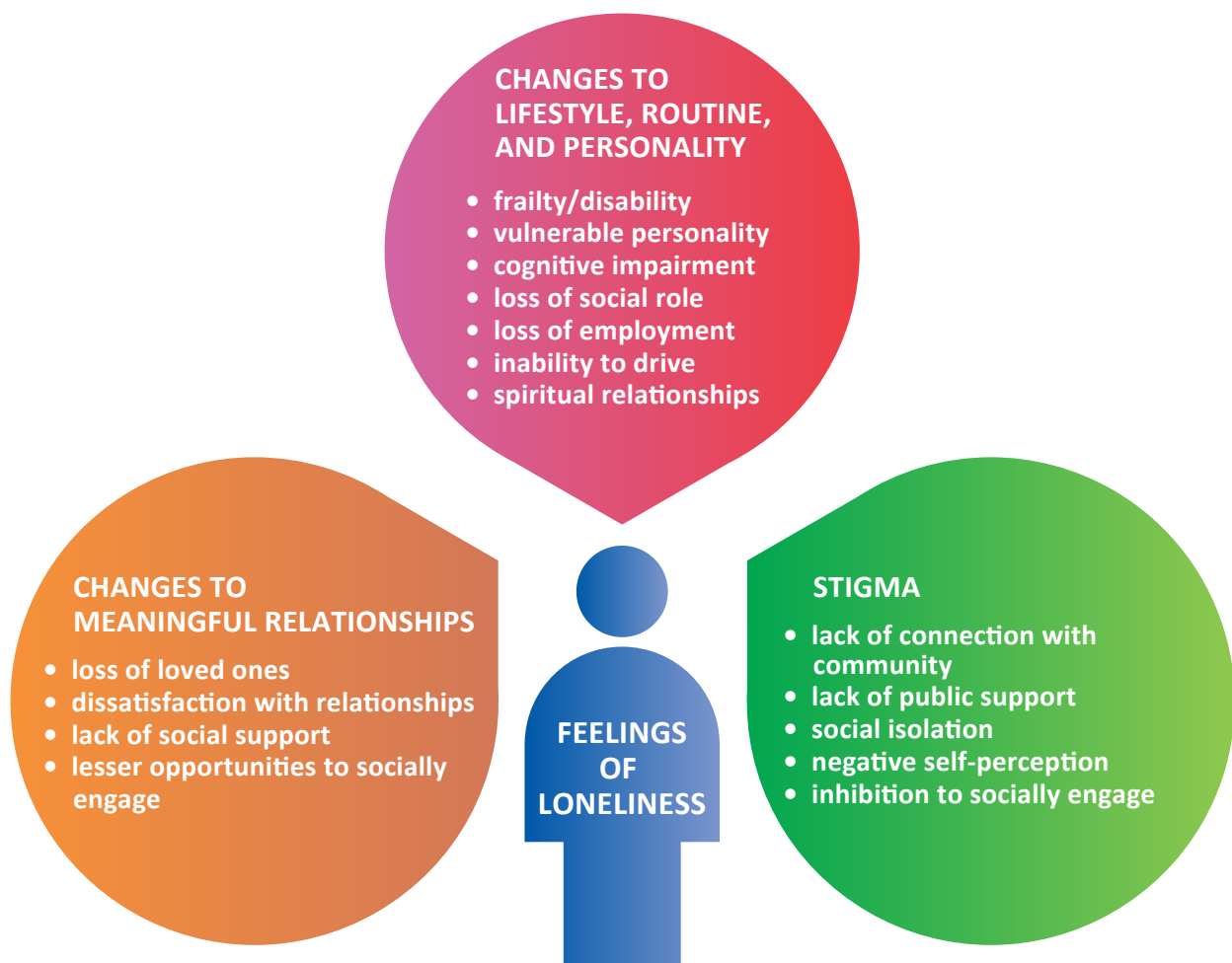


# Summary

The various stories demonstrate the unique nature of loneliness for people with dementia. Overall, not all participants explicitly stated they were lonely but they described various nuances that imply that they are consciously engaging in activities in order to prevent loneliness. The importance of a meaningful relationship was echoed by all participants and demonstrated the support they received from a spouse, partner or family member, not only to prevent loneliness, but also to help them to manage living with dementia. The complexity of living with dementia largely influenced individual

stories. Traditional methods of communication and human interaction were superior to virtual methods of communication. Human contact and a meaningful relationship were described as key factors to maintaining social networks that foster connections and prevent loneliness. In addition, participants reported feelings of stigma which contributed to social isolation and lack of engagement in activities. To summarise the findings from the literature reviewed and the individual interviews, Figure 1 outlines the key factors contributing to feelings of loneliness in individuals with dementia.

Figure 1 **Factors contributing to feelings of loneliness in individuals with dementia**



A large, stylized number '6' in a light blue color with a fine, parallel-line texture. It is positioned in the background, partially behind the title. The top of the '6' curves to the right, and the bottom loops back to the left.

# Recommendations

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## The Alzheimer Society of Ireland endorses the following seven recommendations:

### 1. Issue:

People living with dementia can experience difficulties when attempting to engage with their previous lifestyle activities, yet engaging in meaningful activities can help to combat social isolation and loneliness.

### Recommendation:

**People living with dementia should be enabled to continue to engage in the meaningful social activities they enjoyed doing before their dementia diagnosis, should they wish to do so. Facilitation of this continued engagement in social activities may require support from family, formal caregivers and wider society.**

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### 2. Issue:

For people with dementia (because increasing episodic memory difficulties make reflection on distant events more and more difficult), interactions in-the-moment become more and more important for their social and emotional wellbeing. While people with moderate-to-severe dementia may forget the substance or content of a conversation, or the interaction itself, the emotional undertone is likely to linger. Interactions that are perceived as negative, off-putting or threatening are likely to decrease the willingness to engage in future.

### Recommendation:

**Accessible and simple information to help understand dementia should be provided to the general public, service providers, health and social care professionals, and relevant volunteer/community groups. Communication tips and skills relevant to dementia need to be made available to enhance opportunities for effective engagement.**

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### 3. Issue:

Dementia support groups can provide people with dementia with a supportive forum in which they can discuss the impact of their diagnosis, whilst also providing them with an opportunity to socialise. Evidence varies on whether the format for these support groups or similar interventions should be structured or unstructured. It is likely to depend on the individual. For those who wish to participate in dementia support groups there is likely to be a positive impact on the person's sense of connectedness.

### Recommendation:

**People living with dementia and their caregivers should be given an opportunity to participate in local dementia support groups. For this, these groups need to exist, and people need to be facilitated to attend.**

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**4. Issue:**

A lack of societal understanding about dementia and the presence of stigma associated with dementia can impact on the person with dementia's ability to maintain social connections. Furthermore, it can contribute to a person's loss of independence, often making them reliant on family caregivers to help them navigate through social situations.

**Recommendation:**

**It is important that continued attempts are made to address the stigma associated with dementia, at a local and national level.**

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**5. Issue:**

People living with dementia described how they significantly depend on, and rely on being supported by their partner.

**Recommendation:**

**To create a public and professional awareness campaign to raise awareness not only of the person living with dementia but also their partner or caregiver who might be quietly suffering from loneliness; and to encourage people to make connections with others in their community.**

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**6. Issue:**

The impact of loneliness is often rooted in the wider social, economic, political and cultural context. Loneliness and social isolation are absent from a number of government policies e.g. The National Carers' Strategy<sup>52</sup> and the National Dementia Strategy<sup>7</sup>. Equally, the 'Healthy Ireland Plan',<sup>53</sup> the national framework for action to improve the health and wellbeing of the people of Ireland does not address loneliness.

**Recommendation:**

**To include loneliness as a key priority area in government policies and to raise awareness at a local and national level. Also, to commit to provide opportunities for all individuals to maintain social networks that foster connections.**

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**7. Issue:**

The vast majority of individuals living with dementia are unable to work and the cost of care can be substantial. Families and spouses are often faced with hard decisions, such as whether to admit their loved ones into residential care, seek out private nursing services, and/or avail of public supports. Indeed, the provision of care can, in and of itself, be both time-consuming and economically straining. For these reasons, persons living with dementia are more likely to be financially vulnerable and insecure.

**Recommendation:**

**The process of securing public support for persons living with dementia should be made as accommodating and accessible as possible for both individuals diagnosed and their caregivers and families. It is also recommended that communities provide opportunities for people living with dementia to engage in community projects and work or service.**

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The Alzheimer Society of Ireland is the national leader in advocating for and providing dementia-specific supports and services. Our vision is an Ireland where people on the journey of dementia are valued and supported and our mission is to advocate, empower and champion the rights of people living with dementia and their communities to quality support and services.



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**The Alzheimer Society of Ireland National Helpline  
is open six days a week**

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