Inquiry into the prevalence, causes, and impacts of loneliness in NSW

A Dementia Australia submission

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Dementia Australia

Dementia Australia is the national peak body for people impacted by dementia in Australia. We exist to support and empower the more than 421,000 Australians living with dementia and the more than 1.6 million people involved in their care.[i] Dementia is the second leading cause of death in Australia yet remains one of the most challenging and misunderstood conditions.[ii] We involve people impacted by dementia and their experiences in our activities and decision making, to make sure we are representative of the diverse range of dementia experiences across Australia. We amplify the voices of people impacted by dementia through advocating and sharing stories to help inform and inspire others. Dementia Australia is the source of trusted information, education and support services. We advocate for positive change for people living with dementia, their families and carers, and support vital research. We are here to support people impacted by dementia, and to enable them to live as well as possible.

Dementia in Australia

Dementia is one of the largest health and social challenges facing Australia and the world. It is estimated that in 2024, there are 421,000 Australians living with dementia and more than 1.6 million people involved in their care.[iii] Without a medical breakthrough, the number of people living with dementia in Australia is expected to increase to more than 812,500 by 2054. Dementia is now the leading cause of disease burden among Australians aged 65 and over and is the second leading cause of death for Australians and the leading cause of death of women. In 2024, it is estimated there are almost 29,000 people with younger onset dementia, and this is expected to rise to more than 41,000 people by 2054. This can include people in their 30s, 40s and 50s.[iv]

Dementia in NSW

In New South Wales in 2024, it is estimated there are more than 138,200 people living with all forms of dementia.[v] This figure is projected to increase to almost 252,800 by 2054. In 2024, it is estimated there are around 9,250 people living with younger onset dementia in NSW. This figure is projected to increase to more than 12,800 by 2054.

Introduction

We welcome the opportunity to make a submission to this Inquiry. People living with dementia, and their family members and carers, can experience social isolation and loneliness for a number of reasons, many of which relate to poor community awareness and understanding about dementia. The 2008 United Nations Convention on the Rights of People with a Disability (UN-CRPD) recognised dementia as a cognitive disability but unlike physical disability, community understanding of dementia as a disability remains limited. This is at least in part because, unlike a physical disability, the cognitive and other changes that are associated with the condition are often under recognised or rendered 'hidden' or 'invisible.' People living with dementia relate the common experience of being told that they 'can't possibly have dementia' because they don't appear, speak or act in a way that corresponds with community expectations or understanding of the disabling nature of dementia.[vi]

> "If you just saw them and didn't know them, how would you even know if they had dementia?" (Australian resident with no lived experience of dementia)." [vii]

The invisible nature of a cognitive disability and the attitudinal and other societally imposed barriers mean people living with dementia can experience additional stigma or challenges when undertaking daily activities, engaging with the health care sector or interacting with people in the community. This in turn can influence their confidence, capacity and willingness to engage with family members, friends, social networks and the broader community.

Community understanding of dementia and the risk of loneliness and social isolation

The inaugural 2023 Australian Institute of Health and Welfare (AIHW) Dementia Awareness Survey - the largest nationally representative community survey of its kind in Australia - asked more than 5,400 people aged 18 and over what they knew about dementia and their attitudes towards the condition and people living with it. The broad finding of the survey was 'Generally, Australians know little about dementia.'[viii] The survey highlighted that misconceptions about dementia persist, including the erroneous belief that dementia is a 'normal part of ageing.' Two thirds of those surveyed believed that people with dementia are unpredictable and need constant supervision. The survey concluded that there was a clear need to improve the Australian community's knowledge about the condition.[ix]

These findings are consistent with results from Dementia Australia surveys over the last decade, showing an ongoing – and profoundly concerning – lack of awareness and understanding about dementia in the Australian community. A 2019 report on Australian attitudes and beliefs found that, while there was increased awareness and empathy during the past decade, two thirds of survey respondents were not confident about their knowledge of dementia. They were even less confident about talking to someone with dementia and expressed high rates of fear or unease about the way in which someone with the condition might react to them.[x]

In the same survey, 63 per cent of people living with dementia believed that discrimination is common, 74 per cent said people have not kept in touch as they did prior to their dementia diagnosis and 80 per cent had not been invited to social functions. 73 per cent of family, friends or carers of people living with dementia believe discrimination against people living with dementia is common or very common. The report found lower levels of social engagement, inclusion and connectedness within their communities for people living with dementia.

Limited knowledge and understanding about dementia has widespread repercussions. Most significantly, lack of knowledge and insight results in people with dementia, and their family members and carers, experiencing stigma and discrimination in a wide range of settings from the community, state and local government and retail spaces to the health care sector.

Dementia-related stigma is a complex phenomenon that can incorporate public stigma (collective or community-imposed), internalised or self-stigma and stigma-by-association (directed at family members or carers of the person living with dementia). The impacts of stigma can be significant and wide-ranging. Australian and international studies have noted that stigma and discrimination associated with a dementia diagnosis can have deleterious impacts including discouraging health care-seeking behaviour, reducing social engagement with family, friends and the broader community, and associated consequences for the physical, cognitive and psychosocial health of the person with dementia.[xi]

Recent research has highlighted the harmful impacts of social isolation and loneliness, calculating that the effects are as significant a risk for mortality as smoking.[xii] Knowledge, understanding and beliefs about dementia can vary significantly in the ethnically, culturally and socially diverse communities that characterise contemporary Australia and these differences can further complicate and compound experiences of stigma, discrimination and social isolation.[xiii]

Dementia Australia’s 2024 Dementia and Discrimination report reflects the ongoing realities of stigma and discrimination.[xiv] Of the almost 2,000 nationally representative respondents interviewed, a third suggested that people avoid or exclude their loved one with dementia, and nearly half the respondents felt that people don’t keep in touch as they used to. 71 per cent of people with a family member or friend with dementia felt that people patronised their loved one and three out of four people (76 per cent) felt people treated their family member or friend with dementia as though they were not smart. People living with dementia reported being socially excluded, ignored and treated differently or with less respect.

For family members and carers, the impacts of stigma and the associated social isolation and loneliness can be equally consequential. A recent Australian carer wellbeing survey included the following findings:

- Carers were three times as likely as other Australians to regularly experience loneliness, with 35% often or always feeling lonely compared to 11% of Australians.
- 56.8% of carers surveyed felt their caring responsibilities regularly or always negatively impacted their social life.
- 61.7% of carers supporting a person living with dementia felt their social life was more likely to be negatively impacted. [xv]

The connection between social engagement and physical and mental health

Over the last decade, international research has highlighted the critical role that social connection and engagement plays in ensuring a person's mental and physical health and wellbeing.[xvi] Research findings note that higher levels of social isolation and loneliness are associated with increased incidence of a wide range of physical and mental health disorders.[xvii] The immediate and ongoing impacts of Covid-19 intensified research attention on the impacts of social isolation and loneliness, with more recent findings reinforcing the wide-ranging consequences, including the links with premature mortality, depression, cardiovascular disease and cognitive decline.[xviii]

> "Loneliness can lead to various psychiatric disorders like depression, alcohol abuse, child abuse, sleep problems, personality disorders and Alzheimer's disease. It also leads to various physical disorders like diabetes, autoimmune disorders like rheumatoid arthritis, lupus and cardiovascular diseases like coronary heart disease, hypertension (HTN), obesity, physiological aging, cancer, poor hearing and poor health. Left untended, loneliness can have serious consequences for mental and physical health of people. Therefore, it is important to intervene at the right time to prevent loneliness." [xix]

Social isolation and the increased risk of developing dementia

Research over the last two decades has increasingly focussed on the modifiable risk factors associated with dementia, and the role these can play in reducing the risk of developing dementia. The World Heath Organisation's Guidelines on risk reduction in relation to cognitive decline and dementia list social isolation as one of the key modifiable risk factors.[xx] The Guidelines note that studies showed that reduced social participation, social connection and loneliness were associated with higher rates of the incidence of dementia.[xxi] The 2024 update of the Lancet Commission on Dementia Prevention, Intervention, and Care noted the increasingly compelling evidence showing almost half of dementia cases worldwide could be prevented or delayed if the 14 risk modifiable factors, including social isolation, were addressed.[xxii]

It is important to acknowledge that addressing social isolation and loneliness in NSW in the context of dementia risk reduction will not only contribute to the improved physical and psychological health of the Australian population, but reducing population level dementia risk will also have significant economic benefits.

Dementia Australia findings on loneliness and isolation in NSW

People living with dementia are often excluded from research, surveys and other data sets for a range of reasons that include assumptions about their interest in and ability to participate in these activities.[xxiii] It is likely that the experiences of people living with dementia, and their family members and carers are significantly underrepresented in state, territory and federal data analyses of loneliness and isolation. As part of the consultation process for this submission, Dementia Australia surveyed NSW-based Advocates on their experiences of loneliness and social isolation.[xxiv] Their observations, in addition to findings from Dementia Australia surveys over the last decade, were critical in informing this submission. We have included the key findings and a representative selection of observations from the NSW Advocate survey below to reflect the challenges and consequences of social isolation and loneliness for this cohort.

People living with dementia answered the following questions:

In what ways has living with dementia affected your feelings of loneliness or isolation?

> “I tend to withdraw in a group as I often feel overlooked or looked down upon.”
>
> “Living with dementia, my driving licence now has a 20km in daylight restriction. I live alone in the community so I am relying more on public transport, which makes it more difficult to get out and travel for social events.”

When asked what contributes to feelings of loneliness or social connection, these were the most commonly identified factors:

- lack of close relationships (83%)
- limited support networks (83%)
- social stigma or discrimination (67%)

People with dementia made the following observations in relation to strategies that helped cope with loneliness:

> "Engaging with individuals and businesses that have become dementia-friendly or dementia aware."

> "Identify those living in social isolation and encourage and support them to engage within their communities. It is everyone's responsibility so a public health campaign to identify the risks of social isolation, and how to be a good family or community member could help - even though it seems as if it is something everyone should recognise."

Carers of people living with dementia answered the following questions:

In what ways has caring for someone with dementia affected your feelings of loneliness or isolation?

- Social restrictions secondary to the caring role

"I am more restricted in regard to the social activities I/we are now able to be involved with. Visiting family to see our grandchildren, (and stay overnight) or having them come to stay, is no longer an option."

"I am limited as to what I can do (socially or activity outings) by my wife's dementia and her need for me to be there as her carer."

- Loneliness

"The feeling of loneliness came in waves, especially during the hard times, in those "I don't know what's going on or what to do" moments. I would break down, not knowing where to turn, which made the loneliness more intense."

"I think if you choose to care it often means choosing to be a bit lonely."

"Not having enough of a support network does contribute to feelings loneliness or isolation"

- Emotional and physical strain of the caring role

"Sleep deprivation slows down your thinking and your responses and mood and ability to cope."

- Stigma associated with dementia resulting in diminished social networks

“Dementia has a stigma attached to it hence within a year long-time friends stopped contact. Others rang for a while but as the disease progressed, even their phone calls ceased. The loneliest time was in the evening when no one was around and I had no one that I could contact.”

“Most people can't manage to walk alongside people living with dementia because the person often has impaired social capacity so they move on and relationships deteriorate.”

- Loss of connection with their partner or family member

“I am often lonely in our relationship as he doesn't participate verbally or in action as he used to.”

What do you think could be done to help reduce loneliness in society?

- Encouraging community involvement and connection

“Communities, including cafés, neighbourhood shops, businesses, need to be a part of this. It’s not someone else’s problem, we all get old.”

“Schools connecting with their local senior centres and nursing homes, pairing up with the elderly would be great.”

- Improving dementia education and awareness to reduce stigma and encourage social inclusion.

“Education about ageing and understanding dementia.”

“It is my belief that society at large is not aware of the extent of the social isolation full-time carers endure. A campaign to emphasise this would be very helpful.”

- Creating opportunities for social connection including more support groups, including dementia choirs and memory clinics.

“Community dementia awareness groups are very helpful, such as memory clinics and dementia choirs.”

“Establish safe environment platforms for people to talk about what they are going through.”

Addressing social isolation and loneliness by promoting dementia-friendly communities

> “Respect for the individual. By having an inclusive community that is accountable for its actions. By having strong advocacy assistance if needed. By ensuring quality standards are maintained in all care environments i.e. home care and residential care. By ensuring appropriate checks are made of all places providing care and services to people with disabilities.” Person living with dementia

Two in three people with a diagnosis of dementia in Australia live in the community [xxv] and 54% of people living in permanent residential aged care have a diagnosis of dementia.[xxvi] As a person with dementia experiences cognitive and other changes, maintaining social connections and a continued involvement in the broader community can make a powerful contribution to maintaining a sense of identity and mitigating social isolation and loneliness.[xxvii]

Communities play a critical role in encouraging inclusivity, respecting the rights of people with dementia and facilitating access to the services, supports, activities and spaces that every Australian citizen is entitled to. People living with dementia who are supported to live well in the community are more likely to experience a good quality of life, stay in their homes longer and are less likely to enter residential aged care prematurely. For people with dementia in residential aged care and other forms of supported accommodation, remaining connected to their communities within and beyond their care settings is vital for their physical and emotional wellbeing.

> “Not addressing it (social isolation) can lead to more hospitalization, emergency department visits, and nursing home placements. Addressing it lessens the risk of health issues such as dementia, stroke and heart disease thus reducing mortality rates in the community.” Carer

> “Less depression, slow progress of illness, longer life, happier people, less funding needed in healthcare.” Former carer

The global Dementia-Friendly Communities movement is one of the most significant initiatives in promoting social engagement and inclusivity for people living with dementia and their family members and carers. The dual imperatives of improving awareness and knowledge about dementia and promoting social engagement and inclusivity are an integral part of this global movement. A dementia-friendly community can be defined as a community of any size and scale where people with dementia are understood, respected and supported. The concept has been embraced and developed on a global scale over the last decade.

In its analysis of dementia-friendly communities, Alzheimer’s Disease International identified two core objectives that underpin successful dementia-friendly communities. The first is the desire to improve understanding of dementia and reduce stigma by meaningfully engaging people with dementia of all ages in their communities. [xxviii] Secondly and equally importantly, these communities recognise the rights and capabilities of people with dementia and empower them to make decisions about their lives according to their individual capacities.[xxix]

A recent international analysis recognised that dementia-friendly communities are context-dependent, noting that the most effective dementia-friendly initiatives were those led and shaped by the specific needs of the local community.[xxx] In an Australian context, an inclusive NSW community that supports people living with dementia and their families and carers to remain connected must also have a focus on acknowledging and celebrating social, cultural and ethnic diversity and making people feel valued, integrated and included.

The sorts of initiatives that take priority will inevitably reflect:

- The needs or preferences identified by people living with dementia in a given community
- The characteristics of the community itself (for instance, metropolitan; regional; range of cultures reflected; age demographic).
- The availability and nature of existing supports and services and the ways in which these could be improved or expanded.

Each dementia-friendly community will look different but initiatives can include simple changes such as training staff and volunteers to communicate effectively with people living with dementia, promoting volunteering and employment opportunities for people living with dementia, and providing access and support to engage in social activities.

Addressing social isolation and loneliness in NSW

> “Lead by example! From Federal - State to Local government bodies. Those that are most enabling and inclusive are at a local level - recognise and acknowledge this - then build upwards and outwards.” Person living with dementia

The Dementia-Friendly Communities movement has been described as a global endeavour that complements the work of governments, organisations and support services.[xxxi] Dementia Australia has increasing evidence that the movement, and its own Dementia-Friendly Communities program, offers a useful template for embedding dementia-informed and dementia-friendly principles for governments at every level in Australia.

A recent Dementia Australia Dementia-Friendly Communities Inclusion survey sought feedback on what would assist the future growth and development of existing dementia-friendly groups, Organisations and Alliances in promoting a more inclusive community. Increased participation from government was one of the key themes that emerged.[xxxii]

The NSW Government can demonstrate tangible support for the Dementia-Friendly Communities movement by referencing dementia and dementia-friendly communities in inclusion policies, strategies and plans, and in the provision of local funding sources and mechanisms to support the creation of place-based, community-led dementia-friendly initiatives.

In encouraging the NSW Government to actively support and promote dementia-friendly community actions and initiatives, we draw attention to three important Dementia Australia documents. The **Toolkit for Councils** outlines the way in which local governments can make changes to transform their own governance and physical environments to make councils more dementia-friendly and our community guide sets out practical tips for individuals and groups seeking to make their community more dementia-friendly: **The First Steps to Building a Dementia-Friendly Future**. The combined information in these two documents offers a valuable template for governments at state and local level to undertake effective steps towards a more inclusive and dementia-friendly community.

It is essential that people living with dementia, and their family members are carers are consulted in the planning, development and implementation of dementia-friendly initiatives to combat loneliness and isolation. **Half the Story** is our comprehensive guide to meaningful engagement with people living with dementia, families and carers, which sets out practical ways to seek out and affirm the voices of people living with dementia, and their families and carers.

Conclusion

> “Addressing loneliness requires more than just occasional interventions, it needs to become a continuous, embedded part of community life, government support to put policies in place in all areas - not only families, friends and caregivers but also local businesses, healthcare providers, educational institutions etc.” Carer of person living with dementia

For people living with dementia, and their families and carers, the impact of social isolation and loneliness on psychological wellbeing is as significant as the impacts on physical health. Appropriate support, services and skilled professionals are needed to mitigate the negative impacts many people have experienced and to meet the mental, physical and emotional health needs of people living with dementia, and their families and carers, in the NSW community.

The extent to which an inclusive society is realised in practice depends not only on the willingness of the NSW Government to change policy and regulatory frameworks, but on the support from the community for human rights – the attitudes and enthusiasm of community members, people living with dementia and those who provide advocacy and support. People living with dementia have the human right to participate in all decisions which affect their lives and wellbeing. This approach should be embedded in any targeted state-wide strategies.

There is an obligation for the NSW Government to ensure people living with dementia are treated with the same dignity, respect and rights as everyone else. Dementia Australia strongly encourages the NSW Government to support and promote dementia-friendly communities initiatives as an important part of this rights-based approach to addressing the challenge of reducing loneliness and social isolation.

A dementia-friendly community is a place in which a person with dementia is supported to live a high-quality life with meaning, purpose and value but it is also, fundamentally, an inclusive community that is friendly for everyone.

Dementia Australia appreciates the opportunity to make a submission to this Inquiry and trusts the issues raised in our submission will assist the Committee members to understand the complex challenges in relation to social isolation and loneliness faced by people living with dementia, their families and carers. We welcome the opportunity for further consultation to explore these issues in more detail to ensure that the needs and concerns of our stakeholders are comprehensively addressed.

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iii Dementia Australia (2023) Dementia Prevalence Data 2024-2054, commissioned research undertaken by the Australian Institute of Health and Welfare

iv Dementia Australia (2023) Dementia Prevalence Data 2024-2054, commissioned research undertaken by the Australian Institute of Health and Welfare

[v] Dementia Australia (2023) Dementia Prevalence Data 2024-2054, commissioned research undertaken by the Australian Institute of Health and Welfare. Source for all figures relating to younger onset dementia.

[vi] [vi] Former CEO of Alzheimer's Switzerland Birgitta Martensen's account of her recent diagnosis includes the most recent and compelling example of this. https://www.alzint.org/news-events/news/my-life-with-alzheimers-disease-living-better-with-a-diagnosis/

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