



Standing Committee on Education and Inclusion Inquiry into Loneliness and Social Isolation in the ACT

A Dementia Australia Submission

February 13, 2024

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About 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 the Australian Capital Territory

In 2024 it is estimated there are more than 6,000 people living with all forms of dementia in the Australia Capital Territory. This figure is projected to increase to almost 12,300 by 2054.^v

Dementia as a disability

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 broader community.

The impacts of loneliness and social isolation on mental and physical well-being

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.^{viii} 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.^{ix} 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. ^x

‘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...’ ^{xi}

Dementia-related stigma and social isolation and loneliness

Dementia Australia surveys over the last decade reveal that a lack of awareness and understanding about dementia persists in the Australian community. A 2018 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.^{xii}

Limited knowledge and understanding about dementia can have widespread repercussions. Most significantly, poor dementia literacy results in people with dementia, their family members and carers, experiencing stigma and discrimination in a wide range of settings from home, community 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 affiliate or stigma-by-association (directed at family members or carers of the person living with dementia). Knowledge, understanding and beliefs about dementia 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 and discrimination.^{xiii}

For the person living with dementia, the impacts of stigma can be significant and wide-ranging from discouraging help-seeking behaviour to anxiety, depression and negative impacts on physical health, identity and self-worth. Australian and international studies have shown that these impacts can in turn result in reduced social engagement with family, friends and the broader community, and disengagement and social isolation.^{xiv}

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^{xv} 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.

Living with dementia and the ongoing impacts of COVID-19

The COVID-19 pandemic has compounded the nexus of stigma, discrimination and social isolation experienced by people living with dementia and those supporting them. Dementia Australia research has highlighted the decline in cognitive, emotional and physical wellbeing for people living with dementia, with evidence that in some cases this decline was likely to be irreversible.^{xvi}

At the time of the 2020 release of a discussion paper exploring the effects of Covid-19, Dementia Australia CEO Maree McCabe noted that the pandemic had affected people living with dementia, their families and carers in a multitude of ways:

“People impacted by dementia already experience lower levels of social engagement, inclusion and connectedness within their communities. This, coupled with the restrictions enforced through the COVID-19 pandemic, has meant that people living with dementia, their families and carers are even more vulnerable to adverse mental health outcomes.”^{xvii}

These findings are supported by the burgeoning body of international literature looking at the damaging, ongoing physical and psychosocial impacts of the COVID-19 pandemic, including the exacerbation of social isolation and the associated risks of adverse physical and mental health outcomes for people living with dementia, their families and carers.^{xviii}

Protective factors to mitigate social isolation and loneliness

An inclusive society allows for participation, respect and shared decision-making. It is about equity of access and ensuring that all people feel safe and supported to meaningfully participate in and contribute to society.

“The ability to be able to access the community and be involved in community groups and organisations. Being valued still, as a person, being respected and included. Being asked for my opinion and input.” Person living with dementia ^{xix}

Inclusion means to me that I have the exact same rights as anyone else in society. That there are allowances and alterations, if required, in my society and environment to live alongside all other human beings. That people without disabilities value my rights to be able to live a normal life, as they do. That I have the same access to services as they do. That I should never have to explain why I need to be treated as everyone else.” Person living with dementia

“Being accepted, no matter what.” Former carer

“From a dementia perspective, inclusion means giving (better) recognition and acceptance of cognitive disability throughout societal structures, rules and behaviours, and making adjustments to support continuing participation in "life" and in the community.” Former carer

A community underpinned by respect for all individuals, including people living with dementia, their families and carers, is key to mitigating social isolation and loneliness. A genuinely inclusive community commits to valuing all people as equal, regardless of their abilities, and being pro-active in anticipating and providing the appropriate services and supports to meet their needs. This can include everything from building enabling physical environments through dementia-friendly design, to the provision of high quality home and residential dementia care to advocacy, the provision of information and support for carers and family members.

“An inclusive community: * Does everything that it can to respect all its citizens, gives them full access to resources, and promotes equal treatment and opportunity; * Works to eliminate all forms of discrimination; * Engages all its citizens in decision-making processes that affect their lives; and * Values diversity.” Carer

A critical priority in mitigating isolation and loneliness for people living with dementia, their families and carers is for aged care providers and the ACT Government to facilitate ongoing mental health and aged care support services.

Benefits of addressing social isolation and loneliness

Two in three people with a diagnosis of dementia in Australia live in the community and over two thirds of aged care residents have moderate to severe cognitive impairment.^{xx}

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.

Addressing social isolation and loneliness will improve the health and wellbeing of the ACT community, better support people living with dementia, their families and carers, and have a positive impact on the economy.

“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

Social health, inclusivity and dementia-friendly communities

The concept of social health in relation to dementia has become increasingly significant in recent decades. The social health lens focuses attention on improving health and wellbeing by supporting the current capacities of a person living with dementia, encouraging new skills and abilities and promoting social engagement. Recognition of the importance of social health has led to the development of a wide range of initiatives and programs aimed at promoting social engagement and connectivity for people living with dementia, their family members and carers. One of the most significant of these is the Dementia-Friendly Communities movement. 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. 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.^{xxi}

Creating dementia-friendly communities improves access to social activities and opportunities for engagement including employment and volunteering. 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.

“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

By treating others as you would want to be treated yourself!" Person living with dementia

Addressing the impacts of social isolation and loneliness across the ACT

Promoting an inclusive and dementia-friendly community is not simply about providing more funding. It is about collaboration within and across governments, sectors, communities, businesses and organisations. When people in the community come together, they create a more inclusive and welcoming place for everyone to live. There are a number of priority areas and issues that must be addressed to reduce social isolation and promote an inclusive, dementia-friendly community in the ACT and these include:

- innovative thinking in relation to supporting people living with dementia to live well in the community, underpinned by the understanding of dignity of risk;
- inclusion, participation and supported decision-making for people living with dementia;
- training and building the capacity of the health, disability and aged care workforce to understand dementia and acquire the necessary skills, knowledge and capacity to deliver high quality dementia care;
 - involving carers, families and advocates as partners in care and supporting them with decision-making and care planning;
- creating and delivering meaningful activities for people living with dementia to engage with or participate in;
- building supportive environments that are dementia-friendly and create a sense of homeliness and familiarity, and encourage participation;
- developing feedback and complaints systems that take the concerns of people living with dementia seriously and facilitate their involvement; and
- building a culture that encourages an understanding of dementia and how respond appropriately to the needs of the person living with dementia, their families and carers.

A holistic and person-centred approach, including clear, accessible and effective communication with every individual, is fundamental to improve inclusivity and recognise the human rights of people living with dementia. Existing structures, frameworks and policies, and transparency, accountability, greater collaboration and awareness raising activities can contribute to positive change, but a fundamental shift in community attitude is also required.

"Where we accept all people for who and what they bring to their community." Person living with dementia

This shift in attitude requires education to dispel the myths and misconceptions about dementia that contribute to the exclusion and social isolation of people living with dementia, their families and carers. Public health awareness and information campaigns that target the

community and build a broader understanding of dementia will be important in this context. Mainstream media and social media platforms are key sources of information (and misinformation) about dementia, so harnessing these channels to communicate accurate information about dementia will contribute to changing attitudes and perceptions.

“Education first and foremost. Eradication of fear and stigma through learning encourages increased awareness, inclusion and lack of fear. I think we all want to be seen as the good guys and we benefit from helping. Everyone feels connected after performing a helpful act.”
Former carer

Developing community dementia education and the provision of accurate information creates supportive environments for people to discuss dementia, gain an understanding of how to meaningfully engage with and support people living with dementia, their families and carers.

“There must be strong education programs specifically aimed at sectors within the community such as employers, board members, children, the aged, specific cultural groups, etc. This education should include showcasing the value to the community that is provided by some disabled members of community but this must not imply that only the disabled who can demonstrate worth to the community are worthy of support and protection.” Carer

“It’s really important to keep up the momentum of the disability sector gains in community understanding and acceptance and now focus on dementia being firstly a disability caused by a degenerative brain disease and not a diagnosis overshadowing / excluding by the old definition of dementia not be able to be changed in any way shape or form.” Person living with dementia

Priorities for a territory-wide strategy to address social isolation and loneliness in the ACT

“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

An inclusive ACT community that supports people living with dementia and their families and carers to remain connected, must have a focus on acknowledging and celebrating social, cultural and ethnic diversity and making people feel valued, integrated and included rather than discriminated against and isolated.

In 2023, Canberra was accredited as an ‘Advanced Welcoming City’, one of only two Australian cities - and 38 worldwide - to achieve this classification. One of the key criteria for accreditation was the category of social and cultural inclusion. This criterion aligns broadly with the equally strong emphasis on creating a welcoming, inclusive and socially connected environment for people living with dementia, their families and carers, that underpins the dementia-friendly communities approach.

The ‘Welcoming City’ model provides a useful template for the ACT in setting out how to create the kind of territory-wide, inclusive community that would support and encourage the participation of all its citizens, and contribute to reducing loneliness and social isolation. There are many ways this can be achieved. A crucial first step is the inclusion of people living

with dementia, family members and carers in policy development and program design objectives aimed at combatting social isolation and loneliness. They must be empowered to not only speak up if they experience the adverse effects of loneliness, but to contribute ideas on how to mitigate social isolation and promote and encourage a more inclusive society. This requires the leadership of governments in acknowledging the value of living experience perspectives in shaping policy formation and service provision and in creating supportive environments for people living with dementia.

“Stand up for unrighteousness. Advocate for inclusion. Employ people with a disability. Give them a voice - encourage them to speak up!!! Report inappropriate behaviour!!! Empower them.” Person living with dementia

“Have them first, their representatives second involved across all community life - beginning with full representation on all bodies and ideally using basic principles of co-design to re-engineer the community. Inclusion comes from within the community, not by a dictate or directive from outside.” Person living with dementia

Half the Story, our guide to meaningful consultation with people living with dementia, families, and carers, is a valuable resource in this context. It provides information, tips, and strategies for community groups, service providers, businesses and other organisations to identify opportunities and develop solutions in consultation with people impacted by dementia.

Some examples of a genuinely inclusive and consultative approach include:

- people living with dementia sitting on project specific working groups and/or steering committees;
- people living with dementia being consulted with about policy, programs, and/or service redesign that have a direct impact on them;
- people living with dementia being listened to and having their ideas taken seriously by decision-makers when they provide feedback, share insights, or provide guidance;
- seeing people living with dementia as equals and engaging with them from this perspective;
- promoting supportive and positive images, stories and contributions of people living with dementia, particularly in policy and program development;
- introducing dementia awareness training in school based programs; and
- not excluding people from consultation processes based on their dementia.

Inclusivity and dementia-friendly initiatives in action in the ACT

The following examples are three **Dementia Australia Community Engagement Program**-funded 'grass roots' ACT projects that represent the kind of inclusive and collaborative initiatives that make a significant difference in reducing isolation and loneliness, and promoting social engagement and connection for people living with dementia, and their family members and carers.

COTA ACT

This project is expanding the successful COTA ACT Get IT program (a digital mentoring program which assists older people to gain confidence and better use their mobile devices) to develop specific dementia-friendly training for mentors, resources and practices. This will support people living with dementia and their care partners, by assisting them to feel confident using their mobile devices, particularly in regard to safety, support and mindfulness and remain connected with their community. Appropriate resources will be developed in collaboration with participants to promote to other people living with dementia and their carers.

Community Home Australia

The community garden at Club Kalina will be developed for hosting purposeful living activities. Developing a dedicated disability friendly garden, including raised plant stands and stable seating, will encourage and support people living with dementia and carers to participate in all the activities offered within the local community in an open and shared space. Community garden members are proactively involved in the selecting and planning activities including the choice of plants, seating and menu development for community BBQs using produce from the garden.

Capital Region Community Services

The INVOLVE Seniors Social Group will incorporate the Dementia Café in its program with the objective of improving the skills of staff across CRCS to create safe and inclusive dementia-friendly environments. The training of Café, Community Centre, transport and care workers will allow the organisation to hold regular café social events for individuals living with dementia and their families. An Advisory Group will be formed comprised of people living with dementia and carers and will work with an experienced co-design facilitator to support the appropriate inclusive and consultative approaches are considered.

Giving people with dementia a stronger voice, through advocacy organisations and mechanisms such as Dementia Alliance International (DAI) and Dementia Australia can also make a powerful contribution to mitigating social isolation and loneliness. These organisations are equipped to help people better understand dementia, its progressive nature and how needs of people living with the condition and those supporting them can be best met.

Conclusion

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 meet the mental, physical and emotional health needs of people living with dementia, their families and carers within the ACT community to mitigate the negative impacts many have experienced. The extent to which an inclusive society is realised in practice depends not only on the willingness of the ACT 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 ACT Government, to ensure people living with dementia are treated with the same dignity, respect and rights as everyone else.

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 challenges in relation to social isolation and loneliness that people living with dementia, their families and carers face. We welcome the opportunity for further consultation to explore these issues in more detail to ensure that the needs and concerns of people living with dementia, their families and carers are addressed.

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

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

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^{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/>

^{vii} Dementia Friends & Dementia Friendly Communities Program. Exploratory report, Kantar Consultants, 2019

^{viii} Cacioppo, J. T., & Cacioppo, S. (2018). The growing problem of loneliness. *The Lancet*, 391(10119), 426.

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- ^{xv} Centre for Change Governance and NATSEM. (2021). National Caring for Others and Yourself: The 2021 Carer Wellbeing Survey, University of Canberra, https://www.carersaustralia.com.au/wp-content/uploads/2021/10/211011_Carer-Wellbeing-Survey_Final.pdf
- ^{xvi} Dementia Australia. (2020). One day the support was gone. The mental health impact of COVID-19 on people living with dementia, their families and carers.
- ^{xvii} McCabe, Maree, Media Release, One Day the Support Was Gone, <https://www.dementia.org.au/about-us/media-centre/media-releases/new-discussion-paper-highlights-mental-health-impacts-covid-19>
- ^{xviii} Muntant, A & Giménez-Llort, L. (2020) Impact of Social Isolation on the Behavioral, Functional Profiles, and Hippocampal Atrophy Asymmetry in Dementia in Times of Coronavirus Pandemic (COVID-19): A Translational Neuroscience Approach. *Frontiers in Psychiatry*. 11: 572583. Azevedo, L. et al. (2021) *Journal of Alzheimer's Disease*; 81(2): 607-617
- ^{xix} All quotes provided by people living with dementia and carers have been gathered from a 2020, Dementia Australia 2020 surveyed of Dementia Advocates (that is, people living with dementia, families and carers who work with Dementia Australia to elevate the voices of those impacted by dementia) about their experiences to better understand the impact of COVID-19. Combined with analysis of qualitative and quantitative primary research conducted by the research team at the University of Sydney between July and October 2020, and data obtained from the National Dementia Helpline, it is clear that COVID-19 has had fundamental and lasting mental health impacts for people living with dementia, their families and carers.
- ^{xx} Australian Institute of Health and Welfare (2022) Dementia in Australia, AIHW, Australian Government. AIHW suggests that more than half of all aged care residents have dementia: Australian Institute of Health and Welfare (2022) Dementia in Australia, AIHW, Australian Government, accessed 20 January 2020.
- ^{xxi} Alzheimer's Disease International (2019). Dementia Friendly Communities: Key Principles, 4