

National Suicide Prevention Strategy Consultation Draft

October 2024

Dementia Australia

Dementia Australia is the peak dementia advocacy organisation in Australia.

Our organisation engages with people with dementia, their families and carers in our activities, planning, policy and decision-making, ensuring we capture the diversity of the living experience of dementia across Australia.

Our advocacy amplifies the voices of people living with dementia by sharing their stories and helping inform and inspire others. As the trusted source of information, education and support services, we advocate for positive change for people living with dementia, their families and carers, and support vital research across a range of dementia-related fields.

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Dementia prevalence in Australia

Dementia is the term used to describe the symptoms of a large group of neurocognitive conditions which cause progressive decline in a person's functioning.

Dementia is not just memory loss - symptoms can also include changes in speech, reasoning, visuospatial abilities, emotional responses, social skills and physical functioning. There are many types of dementia, including Alzheimer's disease, vascular dementia, frontotemporal dementia and Lewy body disease. Dementia is ultimately a terminal condition.

In 2024, it is estimated there are more than 421,000 people living with all forms of dementia. This figure is projected to increase to more than 812,500 by 2054.¹

¹ Dementia Australia (2024) [Dementia in Australia 2024-2054](#).

Dementia is major public health concern and a leading cause of disease burden among Australians aged 65 and over.² It is the second leading cause of death for Australians and the leading cause of death for women.³ In 2023, there were an equivalent of 15 people with dementia per 1,000 Australians.⁴

It is important to acknowledge that those experiencing cognitive decline, dementia and other mental and psychosocial issues can be younger. The misconception that dementia is a condition of old age contributes to, and exacerbates, multiple challenges experienced by younger people with a diagnosis of dementia. Overall, the experience for people with younger onset dementia – who often receive a diagnosis when they are in full-time employment and actively raising and financially supporting a family – is different from those diagnosed with dementia at a later stage of life. Loss of income, self-esteem and perceived future purpose can pose multiple physical and psychological challenges for people with younger onset dementia and their families.

Introduction

Dementia Australia welcomes the opportunity to provide feedback on the consultation draft of the National Suicide Prevention Strategy.

The draft Strategy currently makes no specific reference to dementia, despite growing evidence that individuals with dementia are at heightened risk of suicide within the first 12 months post-diagnosis.⁵ A recent UNSW study, which examined over 180,000 hospital admissions, highlights that people with dementia are particularly vulnerable to self-harm, especially within the first 12 months after diagnosis.⁶ Studies have also found suicide risk is increased in people diagnosed with dementia before the age of 65.⁷ Research shows that 10-15% of older adults experience depression, yet mental health conditions are less commonly recorded for aged care recipients as they age.⁸ Given this evidence, dementia should be explicitly recognised as a risk factor in the strategy to ensure targeted prevention and support for this group.

These findings highlight the need for dementia-specific actions to be integrated into the National Suicide Prevention Strategy.

² Australian Institute of Health and Welfare (2024) [Dementia in Australia.](#)

³ Australian Institute of Health and Welfare (2024) [Dementia in Australia.](#)

⁴ Australian Institute of Health and Welfare (2024) [Dementia in Australia.](#)

⁵ Althman D et al. (2022) Risk of Suicide After Dementia Diagnosis.

⁶ Walker, A. R., et al. (2023) Risk factors for dementia and self-harm: A linkage study.

⁷ Althman D et al. (2022) Risk of Suicide After Dementia Diagnosis.

⁸ Australian Institute of Health and Welfare (2024) Mental health in aged care.

Recommendations

- The strategy must improve awareness of dementia and dementia-related suicide risks in the broader community, among those caring for people living with dementia and in the health and social care professions
- The strategy must address stigma and social isolation for people living with dementia by supporting the co-design of dementia-friendly communities with those with lived experience, including those from diverse groups.
- The strategy must provide education and training for health and social care professionals to ensure that a dementia diagnosis, and the 12-month post diagnostic period, is recognised as a risk factor for suicide and encourage timely actions and referrals to relevant services and supports.
- The strategy must recognise the need to provide customised support for carers of people living with dementia that includes but is not limited to improving awareness of and the ability to identify signs of suicidal risk, and offers the appropriate services to support carers in their role
- The strategy must acknowledge the importance of tailored support and services for younger people with a dementia diagnosis, particularly with regard to economic security.

Stigma, social isolation and dementia

Following a diagnosis of dementia, people with dementia and their carers often experience stigma, loss of social engagement and connection. Social isolation has a reciprocal relationship with dementia: it can increase the risk of developing dementia, while a dementia diagnosis itself often leads to social isolation due to stigma and loss of social connections. People with dementia often face negative stereotypes, discrimination, and a lack of understanding about their symptoms, leading to feelings of shame, fear, and exclusion. 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.⁹

⁹ Dementia Australia (2018). Inclusion And Isolation: The Contrasting Community Attitudes to Dementia

This stigma can cause individuals to withdraw from usual social activities, avoid seeking help and become disconnected from their communities and support networks. As social isolation increases, it can contribute to feelings of loneliness, depression, and hopelessness, which are risk factors for suicide.¹⁰ Research indicates that people living with dementia may experience a heightened risk of suicidal thoughts, particularly in the early stages post-diagnosis.¹¹

Addressing this stigma and greater community awareness and can help improve public understanding and reduce social isolation and subsequently suicide among people living with dementia.

Dementia Friendly Communities

Dementia Australia supports the actions outlined in the National Suicide Prevention Strategy's objective on improving social inclusion, particularly for those at higher risk of loneliness and social exclusion.

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.

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. Ultimately, a dementia-friendly community will be friendly for everyone.

People living with dementia have described their priority areas as:

1. Increasing community awareness and understanding about dementia
2. Improving access to social activities and opportunities for engagement including volunteering
3. Employment opportunities or support to remain employed
4. Access to appropriate health and care services to support them to continue to live at home for as long as possible
5. Access to affordable and convenient transportation options
6. Improved physical environments including appropriate signage, lighting and colours

There is no single, ideal model of a dementia-friendly community. No two suburbs or towns are alike, and each area will have strategic priorities and plans specific to their region that will shape how they respond to local needs. The sorts of initiatives that take priority will inevitably reflect:

¹⁰ Australian Institute of Health and Welfare (2023) Australia's Welfare, Chapter 2: Social isolation, loneliness and wellbeing

¹¹ Althman D et al. (2022) Risk of Suicide After Dementia Diagnosis.

- 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.

The Strategy identifies actions around including people with lived and living experience in designing, delivering, governing and evaluating suicide prevention activities and it is essential that people living with dementia are included in the development of dementia-friendly initiatives.

Dementia Australia has developed a comprehensive guide to meaningful engagement with people living with dementia, families and carers called **Half the Story**. Meaningful engagement means seeking out, affirming, and ratifying the voices of people living with dementia, families, and carers to understand the full story.

Diagnostic and post-diagnostic services and supports

Timely post-diagnostic support is essential for people living with dementia, as research indicates a heightened risk of suicide within the first year following diagnosis.¹² This heightened risk is often driven by feelings of loss, anxiety, and uncertainty that accompany the diagnosis.

Ensuring timely referrals and interventions during this period can significantly impact the well-being and safety of people newly diagnosed with dementia. Recent studies suggest that early involvement of support services at the time of or soon after diagnoses of MCI or dementia may help mitigate risk of suicide attempts.¹³ Health care professionals play a vital role in providing and referring to timely post-diagnostic support.

Dementia Australia supports the Strategy's action to build capacity and capability of key workforces and recommends ongoing education for health professionals in relation to the specific challenges facing people living with dementia to ensure they are referred to appropriate services and supports in a timely manner.

¹² Kong JW, Park JY (2022) Understanding Suicide Risk in People with Dementia and Family Caregivers in South Korea: A Systematic Review.

¹³ Günak MM et al., (2021) Risk of suicide attempt in patients with recent diagnosis of mild cognitive impairment or dementia.

Younger onset dementia

People with younger onset dementia face unique circumstances. Often people with younger onset dementia must retire prematurely, which can have significant financial consequence, especially if they are the primary earners for their families. These individuals may still be responsible for paying off mortgages, supporting children, and maintaining other financial obligations, heightening their vulnerability. Additionally, research has shown that individuals diagnosed with dementia at a younger age are at higher risk of suicide.¹⁴

“I went from a valuable contributor to society to having no value at all ... so there’s this whole question of, “OK, is your life over, is it still worth living?’. ”
Person living with dementia

Dementia Australia supports the Strategy’s objective on economic security, and corresponding actions for improving equitable access to meaningful and secure employment. However, it is essential that dementia-specific supports are addressed to ensure the continued employment of individuals with younger onset dementia and their financial security. These supports should focus on abilities rather than disabilities, recognise that earlier diagnosis can allow people to stay in the workforce longer, and provide education about dementia as a disability. Employers must also ensure that the workplace is safe for individuals with dementia and offer support to promote their continued employment. In cases where retirement is unavoidable, a respectful and dignified process for handling medical retirement should be established to protect the dignity of these employees.

Support for carers

Supporting carers of people living with dementia is essential. Carers of people living with dementia often face emotional, physical and financial issues, which can lead to mental health challenges such as anxiety, depression, and burnout. Research highlights that carers of people with dementia have higher levels of psychological distress compared to other types of carers, with some studies showing that up to 1 in 3 carers of people living with dementia experience clinical depression.¹⁵ This may increase the risk of suicidal ideation among carers. Research by O’Dwyer et al. (2016) found that 17% of dementia carers reported contemplating suicide, highlighting the need for targeted mental health support and suicide prevention interventions.

¹⁴ Alothman D et al. (2022) Risk of Suicide After Dementia Diagnosis.

¹⁵ Huang SS. (2022) Depression among caregivers of patients with dementia: Associative factors and management approaches.

Ensuring that carers have access to mental health services, peer support, respite care, and resources to help manage their caring responsibilities could reduce the risk of suicide while also improving the quality of care for the person they care for.

Mental health support should be integrated into dementia care strategies to protect both the carers and the people they care for.

As a result of heightened risk of suicide of those recently diagnosed with dementia, Dementia Australia recommends, specific, tailored support for carers of people living with dementia to improve their awareness and ability to identify risks and signs of suicidal ideation

Conclusion

Dementia Australia supports the Draft National Suicide Prevention Strategy, recognising the positive changes its actions aim to bring, including improving the quality of aged care services, improving the preventative health system, enabling a capable and integrated workforce, addressing loneliness and social exclusion, supporting carers and improving economic security. However, it is essential to acknowledge that dementia itself is a risk factor for suicide, particularly in the 12-month post-diagnostic period, and that people living with dementia, their carers, and those with younger onset dementia are particularly vulnerable. To address these needs, we recommend incorporating dementia-specific actions into the strategy, including improving community awareness of dementia-related suicide risks, addressing stigma, and promoting the co-design of dementia-friendly communities. It is also vital to provide targeted education for health care professionals to recognise dementia as a suicide risk factor and to offer tailored support for carers, younger people with dementia and diverse groups.

We welcome the opportunity for further consultation.