Advance Care Planning Australia
An Australian Government initiative

In collaboration with
Dementia Australia®

Advance Care Planning and Dementia

Joint Position Statement

> *"People shouldn't wait until they have a health condition to do [advance care planning]"*
>
> – Person living with dementia

Overview

An estimated **446,500 Australians are living with dementia in 2026**[1], and this number is projected to grow to over one million in the next four decades.[2] Dementia is the leading cause of death in Australia[3] and one of the most significant public health challenges facing society globally.[4]

Dementia refers to a group of complex conditions that affect a person's brain function and lead to progressive decline in cognitive and functional abilities.[5] Dementia can also affect speech, mobility, emotions, reasoning and behaviour. People can be diagnosed with dementia at any age, from childhood to older age.

Evidence highlights the value of timely diagnosis in improving management and care planning, and sustaining the person's health and wellbeing over time.[6] Dementia has a significant impact, not only on the daily lives of individuals, but also their family* and carers, health systems, and the broader community. Currently, there is no cure for dementia, therefore the provision of services and support is vital in maintaining the wellbeing of people living with dementia and those caring for them.

Early advance care planning is critical for people with dementia because it enables them to plan for their future health care if they are unable to make decisions for themselves.[7]

Advance care planning is a voluntary, person-led process that is most effective when done early, while one is well. It enables a person with decision-making capacity† to share their wishes and preferences, including cultural or spiritual considerations; to specify medical treatments they would or would not want to receive in the future, and to appoint trusted substitute decision-maker(s).[8] It may include completing legally binding documents such as an advance care directive or appointment of a substitute decision-maker(s). Each Australian state and territory has its own legislation, recognised forms, and witnessing requirements.[9]

Despite its value, awareness and engagement in advance care planning remain low. Only **one third of Australians** have engaged in some form of advance care planning, and even fewer **(6%)** have **completed a formal advance care directive.**[10] Similarly, while most individuals say they place a high value on being able to express their future wishes, only **19% have discussed** their future health care preferences with someone else, and of those, only **12%** had discussions **with a health professional**.

Advance care planning is embedded across national health and aged care quality and safety standards in Australia, and is a core component of comprehensive, person-centred care. Health professionals are expected to have appropriate knowledge and skills to support individuals to engage in advance care planning, to respect and uphold each person's right to participate in decisions about their care, and to respect their wishes and preferences when they cannot speak for themselves.

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* The term 'family' used in this document is inclusive of key supporters, chosen family, culturally recognised family, biological relatives and/or those living in the same household that a person has a close and continuing relationship with.

† 'Capacity' is a legal term that is defined in Australian state and territory legislation. A person is typically said to have capacity to make a particular decision if they can understand information relevant to the decision, retain that information in making the decision, use or weigh up relevant information in making the decision, and communicate the decision in some way.

Our position

- **Autonomy and choice must be respected.** People living with dementia have the right to participate in decisions about their health care, with support as required. They must have opportunities to explore, express and record their wishes and preferences, and have those choices respected when they are unable to communicate for themselves.

- **Early advance care planning conversations are essential.** Advance care planning conversations must be normalised as a routine component of dementia diagnosis and care delivery, initiated early, and revisited over time. Importantly, completing formal documents is not a requirement, and must not be a barrier to accessing care.

- **A supported decision-making approach must be prioritised.** A dementia diagnosis must not exclude a person from being involved in decisions about their care. Despite potential fluctuations in capacity, individuals may be able to express care preferences, with appropriate support. Health professionals and care providers have the responsibility to enable meaningful participation and provide information and resources that are clear, practical and easy to understand.

- **Substitute-decision makers have a critical role.** A substitute decision-maker will be required to make health care decisions on a person's behalf only when capacity is impaired. They may be formally appointed by the individual or identified according to law. They have a responsibility to act in accordance with any specific instructions in an existing advance care directive or, if none exist, based on the person's known values, wishes and preferences.

- **The value of documents prepared by others.** At times, there may be appropriate reasons to document wishes and preferences on behalf of a person with impaired capacity, to support good communication with family, carers, and/or different services involved in their care. These documents do not have the same legal weight as advance care directives; however, they can help keep the person's voice central in decision-making.

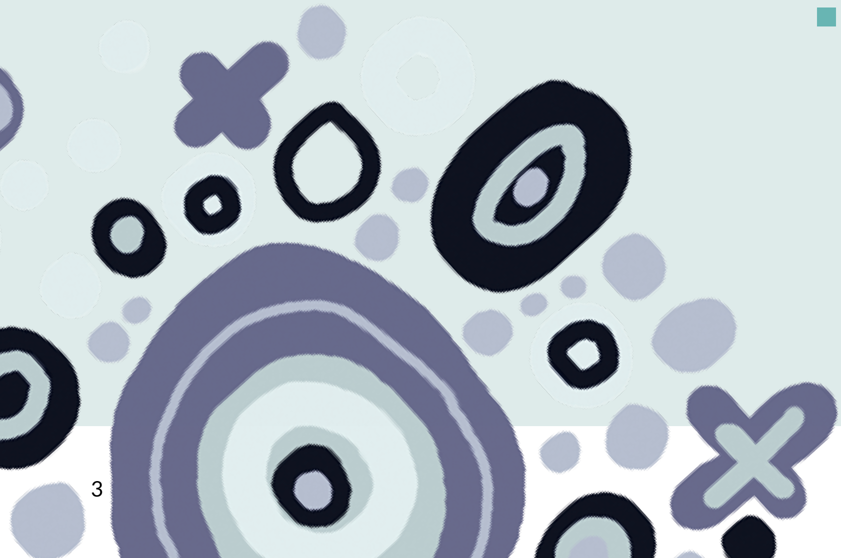
> *"The earlier advance care planning is addressed, the louder the voice of a person with dementia"*
>
> – Current carer

- **Culture, language and interpreter rights matter.** People with dementia have the right to access advance care planning information in their preferred language, with interpreter services and other supports if needed. The diverse values and lived experiences of Aboriginal and Torres Strait Islander peoples, multicultural communities, and other priority groups must be recognised and respected throughout all stages of advance care planning.

- **Health professionals in dementia care require appropriate training.** They play a central role in initiating future care planning conversations with people living with dementia. Health professionals require training, time and organisational support to develop the skills and expertise needed to support people to engage in all aspects of advance care planning in their local settings.

- **Systems must support access and visibility of documents.** Health, disability, and aged care systems have a responsibility to ensure advance care planning documents are stored, accessed and shared appropriately, including through national platforms such as My Health Record, to inform care decisions and support continuity of care across settings.

- **Robust data measures are needed.** Currently, no national scale data exist to report on advance care planning for people with dementia in Australia. Development of rigorous evidence and quality data are needed to improve monitoring of the quality of care and outcomes for people with dementia, including monitoring of equity of access and outcomes for high priority groups. This includes strengthening data capture within the National Dementia Action Plan indicators.



> *"I feel safe knowing that I have a document that will ensure I will be treated as a unique individual. It covers my values, my faith needs, my family, my health wishes and how I want to be treated should I need end of life care"*
>
> \- Person living with dementia

Why it matters

Advance care planning conversations should start early, ideally soon after a dementia diagnosis and be revisited as the condition progresses. For the individual, advance care planning supports the autonomy and the right to choose future care, provides peace of mind and sense of control, and helps avoid unwanted medical treatments. Planning can also reduce uncertainty, distress and decision-making challenges for substitute decision-makers, including family and carers, by providing clarity and guidance about the person's preferences that need to be considered at the point of care.[11]

Importantly, a dementia diagnosis alone does not determine a person's decision-making capacity and does not exclude them from doing advance care planning. People living with dementia can continue to meaningfully participate in discussions about their care and treatments choices.[12]

Supporting a person with dementia to make health care decisions requires flexibility and responsiveness. A supported decision-making approach[13] can help ensure that individuals maintain control and choice over their health care for as long as possible. Recent reforms to aged care[14] and policy and guidelines updates[15,16] have reinforced this shift, emphasising a rights-based approach to care, and the responsibility of the health, disability and aged care systems to support an individual's decision-making autonomy.

Understanding the challenges

As dementia progresses, it impacts a person's ability to understand information, consider options, and express preferences. Their capacity to make decisions may fluctuate and be affected by the type and stage of dementia, time of day, fatigue, medication, stress, or care environments. A person living with dementia may be able to make some decisions at certain times, with appropriate support, but not at other times. Over time, the condition will impact their capacity to make and communicate decisions, requiring a substitute decision-maker(s), either appointed by the person or identified by law, to make decisions on their behalf.

When a person has impaired capacity and has not previously completed any advance care planning documents, substitute decision-makers should act based on their understanding of what the person would want. Documenting care preferences on behalf of a person in these circumstances is not a requirement, and can be challenging and ethically complex, remaining an area of ongoing debate. Any documents which are created by someone else do not carry the same legal weight as advance care directives. Still, they can assist substitute decision-makers to record and communicate their understanding of the person's wishes and preferences to others.[17]

Existing structural and systemic barriers in the health, disability, and aged care sectors make priority populations less likely to access timely and appropriate support and care. Aboriginal and Torres Strait Islander people and individuals from multicultural communities living with dementia experience significantly poorer health outcomes.[18,19] A person may revert to their first language or mix languages as dementia symptoms progress, making advance care planning more challenging. They may encounter persistent cultural barriers, limited familiarity with the Australian health system, and insufficient access to culturally safe information and interpreter services.

Challenges for the workforce include limited time, inadequate training and skills, low confidence in initiating sensitive conversations, and concerns about causing undue distress to individuals and their families.[20] From the system perspective, the lack of consistent national data for advance care planning for people living with dementia limits the ability to monitor progress and outcomes, address existing gaps, or enable coordinated evaluation and service planning.

Conclusion

For people with dementia, advance care planning is essential in ensuring their voice, wishes and preferences are respected as their healthcare needs change over time. By enabling timely conversations, strengthening the role of supported decision-making, improving workforce capability and national data collection, advance care planning can enhance outcomes and quality of life for people living with dementia and those caring for them.

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In collaboration with
Dementia Australia®

☎ National Dementia Helpline 1800 100 500

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For language assistance call 131 450

About us

Dementia Australia is the peak dementia advocacy body in Australia. Our organisation engages people living with dementia, their families and carers in our activities, planning and policy, ensuring that the diversity of the living experience of dementia is captured fully. 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.

Advance Care Planning Australia is the national voice for advance care planning. It is an Australian Government initiative administered by Brisbane South Palliative Care Collaborative at Metro South Health. We work across the community, health and aged care workforce, and systems to promote awareness and engagement in advance care planning. We deliver workforce education and aim to improve systems and policies that support advance care planning nationally and across jurisdictions. Ultimately, we aim to ensure that people's preferences and wishes for future health care are known and respected.

Acknowledgements

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