



# Advance care planning

## DEMENTIA CARE

This evidence theme on advance care planning is a summary of one of the key topics identified by a scoping review of dementia research.

### Key points

- Advance care planning is a process that allows a person living with dementia to express their preferences and goals for future health care once their decision-making capacity has passed.
- Advance care planning increases the likelihood that someone with dementia will receive the end-of-life care they desire.
- It may also improve the quality of life of carers and strengthen their coping skills and decision-making abilities.
- Advance care planning has demonstrated a reduction in hospital death rates and intensive care use at the end of life for people living with dementia.

### What is advance care planning?

Advance care planning is a person-centred approach that supports people to understand and share their values, goals, and preferences for their future healthcare with their

families and care providers. [1] This may result in an advance directive: a formal document written by the person with instructions to ensure their wishes are respected. [2]

In this document, people might choose to nominate a substitute decision-maker to make decisions on their behalf if they can no longer communicate. [3]

People living with dementia gradually stop thinking about the future as their condition progresses, which reduces their ability to make decisions. [4] It is therefore especially important that the person with dementia is given opportunities to be involved in discussions around their preferences for future care as soon as possible after diagnosis and whenever their condition changes. [5]

Discussions might cover topics such as the involvement of palliative care and the use of antipsychotics. This is also the time to discuss the person's preference for comfort care versus life-sustaining therapies that extend the dying process. [6] These might include cardiopulmonary resuscitation, intravenous antibiotics, hospital and emergency transfers, and tube feeding. [2]

## Is advance care planning effective?

Several reviews describe the impact of structured approaches to advance care planning on the care received by people with advanced dementia in both community and residential care settings.

### Community setting

In community settings, individual and group education advance care planning interventions led to benefits such as:

- Increased advance care planning discussions and formal documentation, including wills and power of attorney
- Increased quality of life for the person living with dementia and their carer (one-on-one sessions only)
- Improved carer coping skills and decision-making self-efficacy [7]
- Reduced levels of hospital death and intensive care use. [8]

### Residential aged care

There is consistent evidence from residential aged care that structured approaches to conducting advance care planning, such as comprehensive staff education, lead to a range of positive end-of-life outcomes for people living with dementia. [7, 8]

With an advance care plan:

- People's wishes were more likely to be documented in their care record. [9]
- The care received at the end of life was more likely to be consistent with the care people said they wanted in their advance care plan.
- People showed a reduction in psychiatric symptoms and pain.
- People were less likely to be hospitalised. [7]

Research in residential care also shows that a large number of people with dementia are excluded from taking part in advance care planning conversations when they may have the capacity to express their wishes. [7]

## Evidence limitations

The reviews highlighted concerns about the state of the evidence for advance care planning. For example

- Few studies have examined the issue of advance care planning for people living with dementia, despite it being an important consideration for this group of people and their carers
- There is little known about when people with dementia would prefer advance care planning conversations to occur.

## What can an individual do?

- There are plenty of good quality Australian resources on advance care planning and advance directives available

online. Some provide state- or territory-specific information. See ARIIA Knowledge Hub Resources.

- Consider raising the topic of advance planning with the family of someone with dementia in your care. Involve the person with dementia in the conversation while that person can still make decisions. [3]
- Be aware that people with dementia and family carers may find it emotionally difficult to discuss end-of-life care decisions and advance care planning. If so, consider providing them with some print information on advance care planning and return to the topic at another time.

## What can the organisation do?

- Implement a systematic way of introducing advance care planning discussions which include staff, the person with dementia and family. These discussions should be returned to over time. They might include the person's medical practitioner if there has been a long-term relationship. [7]
- Invest in training staff about advance care planning and its benefits for people living with dementia and their families. See ARIIA Knowledge and Implementation Hub Resources.

## References

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