Aged Care Research & Industry Innovation Australia

Evidence Theme

Advance Care Planning

PALLIATIVE CARE & END OF LIFE

This evidence theme on advance care planning in aged care is a summary of one of the key topics identified by a scoping review of the palliative care research. It looks at the evidence for advance care planning in general while a more specific evidence theme is available on Advance Care Planning for people with dementia is available via the ARIIA website.

Key points

- Advance care planning is a process that enables a person to communicate and discuss their preferences for future medical treatment and care with their family and care providers to come to a shared understanding. This is important if a person is no longer able to speak for themselves.
- Aged care services can provide an opportunity for people to discuss and document their wishes for end-of-life care, and many people desire to do so. However, only a small proportion of Australians in aged care appear to complete this process.
- People in aged care with advance care plans in place may be less likely to experience a burdensome transfer to a hospital or emergency department near the end of their life, die in hospital, or be given medical treatments that are inconsistent with their expressed wishes.
- Training and education initiatives can improve aged care staff knowledge about advance care planning as well as their skills and confidence in initiating these conversations with those in their care.
- Aged care services can promote advance care planning through policies that clarify staff roles and embed processes into routine care. Standardised forms and processes for storing, accessing and sharing documentation across care settings are also important considerations.

What is advance care planning?

Advance care planning is a process that enables a person to communicate and discuss their wishes for future medical treatment and care with family and care providers. [1, 2] The purpose of advance care planning is to ensure people receive the type and intensity of care they desire, especially if they are no longer able to make decisions or let their preferences be known. [3] The decisions reached during an advance care planning discussion might be documented in an advance directive. [4] The process might also lead to the appointment of a substitute decision-maker (also called a 'proxy' or 'surrogate' decision-maker, or 'lasting power of attorney'). [5]

Advance care planning is particularly relevant in aged care settings where older age, frailty, serious illness, multimorbidity, and cognitive impairment are common. [5] However, we know that only a very small proportion of people in aged care engage in advance care planning, despite most expressing a willingness to do so. [6, 7] In Australia, the estimated number of people in residential aged care with an advance care plan in place is somewhere between 0.2 and 14 per cent. [5]

Whose role is it to initiate advance care planning conversations?

In the residential aged care setting, the topic of advance care planning might be introduced to residents and their families by registered nurses, visiting general practitioners, or the facility's clinical manager. The process is less clear in the home care setting where a person may have relatively less consistent contact with nurses and general practitioners and the responsibility of raising the opportunity for advance care planning may be less defined. [8] It is also up to the home care agency to determine if and how staff are trained to raise advance care planning, methods for documenting conversations, and mechanisms for sharing the client's wishes across the wider interprofessional care team. [8]

What do we know about Advance Care Planning in aged care?

We identified eight systematic reviews discussing advance care planning in aged care settings. [3-6, 9-12] Three reviews focused on the effects of advance care planning on aged care residents. [3, 9, 11] The remaining five reviews examined factors that encourage or discourage advance care planning activities or participation in residential aged care. [4-6, 10, 12]

The effects of advance care planning on aged care residents

A range of different approaches to increasing advance care planning in residential aged care have been studied. These include formal education or training programs for aged care staff, [3, 11] including train-the-trainer approaches, [11] written information provision on end-of-life care options directed at residents and substitute decision-makers, [11] and the introduction of a new advance care planning process or protocol in the facility, usually in the form of a medical treatment order. [3] All approaches to increasing advance care planning implementation demonstrated flow-on benefits for people living in residential aged care. [3] In improving staff knowledge and resident and family awareness of advance care planning, and in improving care planning processes, residents were:

- Significantly more likely to have their end-of-life care preferences documented [9, 11]
- Less likely to experience an unwanted hospitalisation [3, 9] with hospitalisation rates reduced by 9%-26% [3]
- Hospitalised for less days when hospitalisation was unavoidable, thereby reducing the costs of care [3, 9]
- Less likely to die in hospital and more likely to die in their residential aged care facility, [3, 9] which was often their preferred place of death. [3] Deaths in the care home increased by between 29% and 40% in one review. [3]
- More likely to be given medical treatments that were consistent with their personal wishes, [3, 11] although this was not always the case. [3] For example, one review found that advance care planning was 100 per cent effective in reducing unwanted cardiopulmonary resuscitation but much less effective in reducing the rate of antibiotics administration at the end of life. [3]

According to one review, advance care planning interventions do not significantly influence family satisfaction with end-of-life care. [11]

Facilitating factors for advance care planning uptake

A range of factors can support the implementation of an advance care planning program in an aged care setting. At the individual level, these factors include:

- Having aged care staff with the knowledge, skills, and confidence to initiate advance care planning discussions. [4, 5, 9, 12] Advance care planning relies on good conversation skills, knowing how to raise and discuss end-of-life care choices, and how to document an individual's wishes. [4]
- Having written, easy-to-read information on advance care planning at hand to give to aged care recipients and their families to increase their understanding of what it entails and its potential benefits. This includes information on related issues such as the legal status of advance directives and the role of substitute decision makers. [4, 5]
- Positive staff attitudes towards advance care planning, including belief in its benefits and seeing themselves as having a role in the process. [10, 12]
- Staff approaches that address psychosocial and spiritual needs at the end of life in addition to its clinical and physical aspects. [12]
- The involvement of family and the multidisciplinary team in advance care planning discussions, perhaps through multidisciplinary care conferences. [12]

Organisational structures also play a part in facilitating these processes. Advance care planning is more likely to be implemented if the organisation:

- Encourages staff to view these discussions as part of their role [12] and gives them the time to undertake advance care planning with care recipients [5]
- Embeds advance care planning into routine or standard care in the residential aged care facility. [4]
- Has advance care planning policies in place, along with standardised forms and systematic processes for storing and retrieving advance care plans [4, 5]
- Is equipped with a central electronic registry that supports easy access to and transfer of advance care planning documents across care settings. [5]

In the end, advance care planning is a voluntary activity and individuals can choose to be involved or not. The reasons why some people choose not to document their wishes for future care will be highly individualistic but may include:

- Family or personal unwillingness to think about death [4, 5]
- Being part of a culture that considers death a taboo topic [10]
- Having complete trust in the decisions and actions of health professionals, [6]
- A desire to receive all available care on offer if and when the need arises. [5]
- An assumption that their preferences for end-of-life care are already known by their loved ones, even if they have never discussed them directly. [6]

Personally motivating factors for someone to proceed with advance care planning include wanting to take the burden of decision making off family members, not trusting family to enact wishes, or not having a substitute decision maker. [6]

Overall, the quality of the studies on which these reviews are based was considered low with small numbers of participants and varying approaches which were not always well described. [3-6, 9, 11] As the types of advance care planning interventions tested varied across the studies (e.g., educating staff versus introducing a new procedure) and there are few studies that directly compare advance care planning with other approaches, it is difficult to know which advance care planning approach might be considered the best. [3] Future studies are needed that examine the essential components of the most successful interventions. [11] We also note a lack of studies on advance care planning conducted with home care clients and diverse groups such as culturally and linguistically diverse, LGBTQI+, and Aboriginal and Torres Strait Islander populations. [5]

What can an individual do?

- Introduce advance care planning to individuals and their families as a way of increasing the agency and autonomy of older people.
- Initiate conversations based on cues from the individual, rather than letting advance care planning be a process-driven activity.
- Allow advance care planning discussions to occur over time. It may take several conversations for people to arrive at a plan they are happy with.
- Revisit documented plans regularly to give people the opportunity to make changes to them.
- Be aware of barriers that might make it difficult for someone to understand what advance care planning is or to get involved in advance care planning discussions. These might include problems with the language used (i.e., English) or its terminology, or the presence of hearing, visual, or cognitive impairments. Adjust how information is conveyed accordingly wherever possible by increasing font sizes, using amplification, or involving language interpreters.

What can the organisation do?

- Train home care and residential aged care staff to initiate and deliver advance care planning discussions with those to whom they provide care.
- Have an advance care planning implementation strategy. Integrate advance care planning discussions into routine practice as part of a structured program supported by policy, standardised forms, and clear processes for storing and accessing documents when needed.
- Make clear to staff the organisation's expectations in terms of roles and responsibilities for advance care planning, including the amount of time staff can give to the process.

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ARIIA was established as an independent, not-for-profit organisation, set up to lead the advancement of the aged care workforce capability by promoting and facilitating innovation and research to improve the quality of aged care for all Australians.

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