Aged Care Research & Industry Innovation Australia

Evidence Theme

Advance Care Planning

PALLIATIVE CARE & END OF LIFE

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

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.
- It is important for people receiving aged care to discuss and document their wishes for end-of-life care, and many desire to do so. However, only a small proportion of Australians in aged care get this opportunity.
- People in aged care with advance care plans in place appear to 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.
- Successful implementation of advance care planning programs in aged care largely depends on staff training and their knowledge, skills, and confidence level.
- 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 (ACP) 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. [1, 2] ACP aims to ensure people receive the type and intensity of care they desire, especially if they can no longer 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 appointing a substitute decision-maker (can be known as a 'proxy' or 'surrogate' decision-maker or 'lasting power of attorney'). [5]

Advance care planning is particularly relevant to aged care settings where older age, frailty, serious illness, multimorbidity, and cognitive impairment often reduce people's abilities to make or communicate their preferences. [5] However, we know that only a very small proportion of people in aged care are offered the opportunity to 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 is 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. A person may have comparatively less consistent contact with nurses, where all the care providers are rarely present simultaneously in the person's home to foster shared communication. [8] It is also up to the home care provider to determine if and how staff are trained to approach 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 twenty reviews discussing advance care planning in aged care settings. [3-6, 9-24]

A more specific evidence theme is available on Advance Care Planning for people living with dementia.

The effects of ACP on aged care residents

Various approaches have been studied to increase Advance Care Planning in residential aged care. These include formal education or training programs for aged care staff, [3, 14] including train-the-trainer approaches, [14] written information provision on end-of-life care options directed at residents and substitute decision-makers, [14] and the introduction of a new ACP process or protocol in the facility, usually in the form of a medical treatment order. [3] All approaches to increasing ACP implementation demonstrated flow-on benefits for residential aged care residents. [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 [13, 14]
- Less likely to experience an unwanted hospitalisation [3, 13] with hospitalisation rates reduced by 9%-26% [3]
- Hospitalised for fewer days when hospitalisation was unavoidable, thereby reducing the costs of care [3, 13]
- Less likely to die in a hospital and more likely to die in their residential aged care facility [3, 13], 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 consistent with their wishes, [3, 14] although this was not always the case. [3] For example, one review found that ACP 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, ACP interventions do not significantly influence family satisfaction with end-of-life care. [14]

When should ACP discussions take place?

ACP discussions should not be restricted to the final days of life. [16] Instead, people should be offered ACP discussions as early as possible in the disease trajectory when cognitive problems first arise. [4, 16, 17, 20, 22] Most older people preferred early ACP, believing they needed time and information to make end-of-life care decisions. [20, 22] However, studies also reported that older people preferred delaying end-of-life discussions to the point where the disease was debilitating or terminal, precipitating the need to make plans. [22] This was because some older people felt that ACP discussions were overly negative, caused unnecessary upset, or they felt unprepared to talk about it. [22] Early discussions were also seen to possibly damage the hope that older people often brought to patient-physician relationships and were seen by family members as having the potential to limit the continuity of care and support. [22]

Other times that ACP may take place include:

- When unforeseen medical scenarios occur, or family members decide to limit or withdraw life-sustaining treatments. [16, 22] Life-sustaining treatment differed across studies, where some included the exploration of one medical intervention (i.e. tube feeding, resuscitation) whilst others defined it as hospitalisation (i.e. surgery). [16]
- Revisiting ACP on admission to RACF. [11]
- When there is a change in health status or experiences of advanced illness. [11]
- If the older person is near the end of life. [11]
- Routine practice for Residential Aged Care Facility (RACF) residents and families across their time within the facility. [4, 23]

Mode of delivery

The reported mode of delivery ranged from face-to-face discussions supported by written information to the use of remote Information and Communication Technologies (ICT) (i.e. Internet and mobile networks). [10, 17] In choosing whichever mode of delivery, ACP should take place within a private environment and ensure that discussions are not undertaken in communal areas. [17]

The use of ICT was proposed during the COVID-19 pandemic and the enforcement of social distancing regulations and visitation restrictions to RACF. [10, 17] ICT is a convenient way of delivering ACP and has been reported to increase the frequency of family-professional interaction and provide the ability to speak concurrently with more relatives. [10] However, ICT may present challenges, such as difficulties understanding and monitoring emotions and non-verbal communication cues compared to face-to-face interactions. [10] The review found that the lack

of non-verbal communication and the inability of relatives to be present with their loved ones eroded the trust and relationship between staff, family caregivers, and substitute decision-makers. [10]

Content of ACP discussions

ACP content must have clear instructions for care preferences at the end of life; [18] however, there were no specifications on the structure or characteristics of end-of-life discussions. [16, 19] Main discussion topics may include one or a combination of the following topics:

- Prognosis [10, 16]
- Care preferences and goals (i.e. hydration) [10, 15, 16, 24]
- Treatment goals (i.e. use of antibiotics) [10, 15, 16, 24]
- Life-sustaining treatments (i.e. resuscitation, sedation) [15, 16, 24]
- Euthanasia [16]
- Risks and benefits of invasive treatments (i.e. artificial feeding tubes, intubation) [16]
- Withdrawal from treatments [16]
- Hospitalisation [16]
- Support during bereavement [10]
- Options within palliation [16]
- Advanced directives [15, 16, 24]
- Psychological- spiritual- and existential- problems [16]
- Explaining the medical conditions, risks and benefits of treatment [15]
- Documenting the older person's insights about the disease [15]
- Referral, enrolment, and length of stay in a specialised palliative care, hospice, care, or other types of aged care setting – considering the context of the situation, such as the level of care needed and timeframe (i.e. within the last week before death). [21]
- Document family member's preferences in communicating about medical conditions, their insights into the disease, and the configuration of family relationships in the older person's care. [15, 24]
- Evidence that assessment and documentation have been completed regarding the carer's needs, family's expectations and preferences, and preferred place of care. [15, 24]

Despite changes in communication pathways during the COVID-19 pandemic (i.e. Information and Communications Technology), remote conversations about ACP remained the same with the addition of more anticipatory-type conversations about intensive care unit admissions, ventilation, resuscitation, and hospital admissions at end-of-life. [10] During the pandemic, topics related to COVID-19 were prominent compared to pre-pandemic, where ACP discussions focused on more holistic care planning. [10] Conversations tended to take on a more linear form that discussed singular topics, for example, an older person's wishes not to be admitted to hospital due to fears of COVID-19 infection. [10]

For older people living with dementia, ACP should be continuous, and discussion topics should consider their preferences and circumstances. [18, 19] It is important to note that ACP may be difficult for older people living with dementia and the complexity of having a substitute decision-maker may complicate the process.

Facilitating factors for ACP uptake

Many factors can support implementing an ACP 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 ACP discussions. [4, 5, 9, 13] ACP 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 ACP available 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]

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

- Give staff the time to undertake ACP with care recipients. [5]
- Embeds ACP into routine or standard care in the residential aged care facility. [4]
- Has ACP 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 ACP documents across care settings. [5]

Ultimately, ACP is voluntary, and individuals can choose to be involved. [9] 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]
- 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 is that their loved ones already know their end-of-life care preferences, even if they have never discussed them directly. [6]
- Postpone making end-of-life decisions until they were much older or in worse health. [9]
- A reluctance to think about and discuss end-of-life care, some older people prefer living a day at a time. [9]

- COVID-19 prevented families from physically visiting care homes, especially for older people who depended on substitute decision-makers (i.e. people living with dementia). [12]
- Decreased clinical routines and visits from external service staff (i.e. specialist palliative care team, General Practitioners). [12]
- Staff had increased responsibilities related to death exposure, which emotionally impacted them, deprioritising their ACP discussions. [12]
- Staff fear of infecting other residents leads to minimal care planning discussions. [12]

Personally motivating factors for someone to proceed with ACP include wanting to take the burden of decision-making off family members, not trusting the 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 participant numbers and varying approaches, which were not always well described. [3-6, 13, 14] As the types of ACP interventions tested varied across the studies (e.g., educating staff versus introducing a new procedure) and few studies directly compare ACP with other approaches, it is not easy to identify which of the ACP approaches might be considered the best. [3] Future studies are needed to examine essential components of the most successful ACP interventions. [14] We also note a lack of studies on ACP conducted with home care clients and diverse groups such as culturally and linguistically diverse, LGBTQI+, and Aboriginal and Torres Strait Islander populations. [5]

Limitations

The results have informed this evidence theme of a scoping review intended to map the published research in this area. Our findings reflect the current state of the evidence, which we note is limited in breadth and quality.

What can an individual do?

- To involve the older person's GP or Nurse Practitioner in discussing diagnosis and prognosis as they approach the end of life (Aged Care Quality Standards, Actions 5.7.1). [25]
- Introduce ACP to individuals and their families as a way to plan for a 'good death.'
- Initiate conversations based on cues from the individual rather than letting ACP be a process-driven activity.
- Allow ACP discussions to occur over time and revisit the documented plan if someone's health and cognitive capacity changes.
- Be aware of barriers that might make it difficult for someone to understand ACP or get involved in ACP discussions. These might include problems with the language used (i.e. English) or its terminology or the presence of hearing, visual, or cognitive impairments. Make adjustments, such as increasing font sizes, using amplification, or involving language interpreters.
- Assist in reviewing ACP documentation regularly to ensure that it accurately reflects the older person's current goals, needs, and preferences in accordance with the Aged Care Quality Standards, Actions 5.7.2.[26]
- Provide decision-making support for older people with fluctuating cognitive capacity. For example, engaging with a substitute decision-maker for older people living with dementia. (See the priority topic on Dementia Care) (Aged Care Quality Standards Actions 5.7.2). [25]

What can the organisation do?

- Train home and residential aged care staff to initiate and deliver advance care planning discussions with clients and residents.
- Have an ACP 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 regarding roles and responsibilities for ACP, including how much time staff can give to the ACP process.

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