

What is advance care planning?

Advance care planning supports health professionals to understand and respect a person's healthcare preferences if the person ever becomes seriously ill and unable to communicate for themselves.

Ideally, advance care planning will result in a written advance care directive (appointing a substitute decision-maker and values or instructional directive), to help ensure the person's preferences are respected. An advance care directive is only used when the person loses capacity to make or express their preferences.

Benefits of advance care planning

Advance care planning benefits the person, their family, carers, health professionals and associated organisations.

- It helps to ensure people receive care that is consistent with their beliefs, values and preferences.
- It improves end-of-life care, satisfaction with the care provided¹ and communication with healthcare professionals².
- Families of people who have done advance care planning experience less distress, and are less conflicted about the decisions they make for, and about, their loved ones.³
- For healthcare professionals and organisations, it may reduce non-beneficial transfers to acute care and unwanted interventions.⁴



How can a speech pathologist participate in advance care planning?

Advance care planning requires a team effort. Speech pathologists can:

- ask a person if they have an advance care planning document such as an advance care directive
- explore a person's values and priorities with them regarding swallowing management, food and fluid preferences, and the type of care they would and would not like to receive (such as percutaneous endoscopic gastrostomy or nasogastric feeding, and eating and drinking with known risk)
- support conversations with the person and their substitute decision maker/s about their preferences and encourage them to speak with their doctor
- provide blank copies of advance care planning documents and encourage a person to discuss advance care planning with their loved ones and their doctor.

When should advance care planning be introduced?

Advance care planning conversations should be routine and occur as part of a person's ongoing health care plan.

Better outcomes are experienced when advance care planning is introduced early as part of ongoing care rather than in reaction to a decline in condition or a crisis situation.

When the advance care planning conversation is initiated, the person should be medically stable, comfortable and ideally accompanied by their substitute decision-maker(s), and/or a family/carer.

Triggers for advance care planning conversations can include:

- when a person has been diagnosed with a communication impairment or swallowing disorder resulting from cancer, stroke, or a progressive neurological condition such as Motor neurone or Parkinson's disease
- if you would not be surprised if the person were to die within twelve months
- a 75+ health assessment
- when an older person receives their flu or COVID vaccination
- when there is a diagnosis of a life-limiting illness or organ failure indicating a poor prognosis
- when there is a diagnosis of early dementia or disease which could result in loss of capacity
- if there are changes in care arrangements (e.g. admission to a residential aged care facility)
- when a person or family member asks about current or future treatment goals.

Other triggers for initiating this conversation can be found at advancecareplanning.org.au.

How can speech pathologists help with advance care planning?

Be open

- Find out more about advance care planning and the requirements relevant to your state/territory.
- Encourage people to think and talk about their beliefs, values and preferences regarding their current and future health care.
- Explain that they may like to select a substitute decision-maker(s). This should be someone who is not a paid carer or healthcare provider.

Ideally, substitute decision-makers will need to be:

- available (live in the same city or region) or readily contactable
- over the age of 18 years
- prepared to advocate and make decisions clearly and confidently on a person's behalf when talking to doctors, other health professionals and family members if needed.

Be ready

- Undertake training in advance care planning to increase knowledge and improve skills.
- Talk about the person's beliefs, values and life goals regarding health care options.

Be heard

- Discuss with other relevant healthcare professionals, family, friends and/or carers.
- Encourage people to write an advance care directive or use a form relevant to their state/territory law. See advancecareplanning.org.au.
- Encourage them to store their advance care directive appropriately.
- Encourage them to review their advance care directive every year or if there is a change in their health or personal situation.

References

1. Brazil K, Carter G, Cardwell C, et al. (2018). Effectiveness of advance care planning with family carers in dementia nursing homes: a paired cluster randomized controlled trial. *Palliative Medicine*, 32(3), 603–612. doi.org/10.1177/0269216317722413
2. Jimenez G, Tan W, Virk A, et al. (2018). Overview of systematic reviews of advance care planning: summary of evidence and global lessons. *Journal of Pain and Symptom Management*, 56(3), 436–459. doi.org/10.1016/j.jpainsymman.2018.05.016
3. McMahan R, Tellez I, and Sudore R. (2021). Deconstructing the complexities of advance care planning outcomes: what do we know and where do we go? A scoping review. *Journal of the American Geriatrics Society*, 69(1), 234–244. doi.org/10.1111/jgs.16801
4. Brinkman-Stoppelenburg A, Rietjens J, and van der Heide A. (2014). The effects of advance care planning on end-of-life care: a systematic review. *Palliative Medicine*, 28(8), 1000–1025. doi.org/10.1177/0269216314526272

The law and advance care planning

Health professionals are obliged to review and consider documents. Different states and territories in Australia have different laws regarding advance care planning. There are also common law decisions in advance care planning. See advancecareplanning.org.au for information.

Depending on the state/territory:

- A Substitute Decision-Maker may be legally appointed and also known as an Attorney (through an Enduring Power of Attorney), Enduring Guardian, Decision-Maker or Medical Treatment Decision-Maker.
- An Advance Care Directive may also be called an Advance Health Directive, Health Direction or Advance Personal Plan.

Where should advance care directives be kept?

Advance care directives may be stored with the:

- person
- substitute decision-maker(s)
- GP/local doctor
- specialist(s)
- residential aged care home or specialist disability accommodation
- hospital.

Encourage and help people to store them in My Health Record at adh.gov.info/ACP.

Conversation starters

- I try to talk to all my patients about how they would want to be cared for if they become more unwell or were suddenly unable to make their own healthcare decisions. Have you ever thought about this?
- I am pleased to see you have made some changes to manage your condition. If you became very sick again and needed extra help to speak or swallow, have you thought about the treatment that you would or would not want?

For more examples visit the conversation starter page at advancecareplanning.org.au.

Where can I get more information?

Advance Care Planning Australia

 advancecareplanning.org.au

 National Advance Care Planning Support Service:
1300 208 582

 learning.advancecareplanning.org.au

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This publication is general in nature and people should seek appropriate professional advice about their specific circumstances, including advance care planning legislation in their State or Territory.