

# FAQ

## FREQUENTLY ASKED QUESTIONS



PODCAST



WEBINAR

## Helping Registrars Build Skills in Advance Care Planning

### What is advance care planning ("ACP")?

A process of planning for future health and personal care, **whereby the person's values and preferences are made known so that they can guide decision-making** at a future time when the person cannot make or communicate their decisions.

Working Group of the Clinical Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council. A national framework for advance care directives. Adelaide: Australian Health Ministers' Advisory Council, 2011.

Advance care planning ("ACP"):

- Is more than making decisions about death and end-of-life care
- Is about understanding both health and personal care preferences, now and in the future
- Enables people to have their say to inform decisions that need to be made when they can no longer communicate their wishes, through understanding what their values are and what they would prefer as goals or outcomes of known medical options
- Respects the rights of an individual to decide how decisions are made – which could mean that they choose not to participate
- Is preferably documented so that preferences are made known, such as in an Advance Care Directive ("ACD")

ACP empowers people to have a voice

ACP is not a 'set and forget' but a living, ongoing

A different type of discussion will be required for someone who is healthy, compared to someone with mild to moderate chronic illness, or someone with 12 months to live.

### How can I explain ACP to my registrar?

Ask them to consider these patient questions:

1. Who would you want to speak for you?
2. What would you want them to say?
3. Do they know what you would want them to say?

**Consider ACP as a type of insurance... You don't take out house insurance because you're fixating on your house burning down, but to fall back on if something goes wrong.**

#### TEACHING ACTIVITY 1: Video review

[duration: 1 minute 16 seconds]

View animation "Advance care planning: Talking about it" produced by Advance Care Planning Australia. Ask the registrar to talk through the key take-aways.

Video available at <https://www.youtube.com/watch?v=0AcjGLn9BZ8>

#### TEACHING ACTIVITY 2: Elevator pitch

The purpose of this exercise is to practise introducing advance care planning in 30 seconds by **developing a statement that is memorable, evokes emotion and is succinct.**

Initially it can be quite intimidating to think about introducing advance care planning to someone. In the beginning it can be good to have a few sentences describing what advance care planning is until you become comfortable.

Scenario: *You are in a coffee shop with a friend who is the primary carer for an elderly relative. Briefly introduce what advance care planning is to your friend, taking turns with your registrar to role play the friend and the person introducing advance care planning.*

After the role-play, discuss what came naturally, and what each of you felt you should work on.

# FAQ

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### Why is ACP important to GPs?

- It supports patient-centred care
- It Identifies who to contact to speak on behalf of the person
- It enables GPs to know, respect, and follow the person's preferences when making medical decisions
- It can reduce unnecessary or unwanted hospitalisations

### What are a GP's responsibilities with respect to ACP?

The RACGP's Position Statement on Advance Care Planning ("ACP") states that:

GPs should aim to incorporate ACP as part of routine healthcare. A conversation about ACP fits well with a GP's responsibility to ensure that the patient receives, and understands, advice on various healthcare options relevant to any current diagnosis and realistic assessment of prognosis.

The Position Rationale for this Position Statement emphasises:

- The ongoing and trusted nature of the GP-patient relationship, which can be leveraged by GPs to initiate and promote ACP
- ACP as "the embodiment of person-centred healthcare and a response to the challenges that an ageing population and modern healthcare present"
- ACP as a tool for ensuring the patient's wishes remain the focus of decisions made about their care
- ACP as a means for improving end of life care and patient/family satisfaction

RACGP. Advance care planning should be incorporated into routine general practice. <https://www.racgp.org.au/advocacy/position-statements/view-all-position-statements/clinical-and-practice-management/advance-care-planning>

This aligns with AHPRA's **Good medical practice: a code of conduct for doctors in Australia (2020)**, in particular section 4.13 "End-of-life care" which includes the following points about good medical practice when caring for patients towards the end of their life:

- (4.13.1) "Taking steps to **manage a patient's symptoms and concerns in a manner consistent with their values and wishes**";
- (4.13.8) "**Encouraging advance care planning and facilitating the appropriate documentation, such as an advance care directive (or similar)**".

### What are the benefits of ACP?

Everyone can benefit from ACP at different stages of their lives.

Advance care planning has benefits for patients, their family and loved ones, and health professionals and services:

- **PATIENTS** can state their preferences and put their plans into place, meaning that they will be more likely to receive the treatment they prefer and avoid treatment they wouldn't want to receive.
- **FAMILY/LOVED ONES** can feel more confident that decisions made in times of heightened emotions/emergency are in keeping with the wishes of the patient, minimising the possible burden on them.

*Also shown to improve family satisfaction with the care their loved ones receive and avoid conflict, for example where family members might disagree about what the right decision for the patient is.*

- **THE TREATING TEAM** is better able to direct their attention to appropriate care when the patient has participated in advance care planning while they are still well.

# FAQ

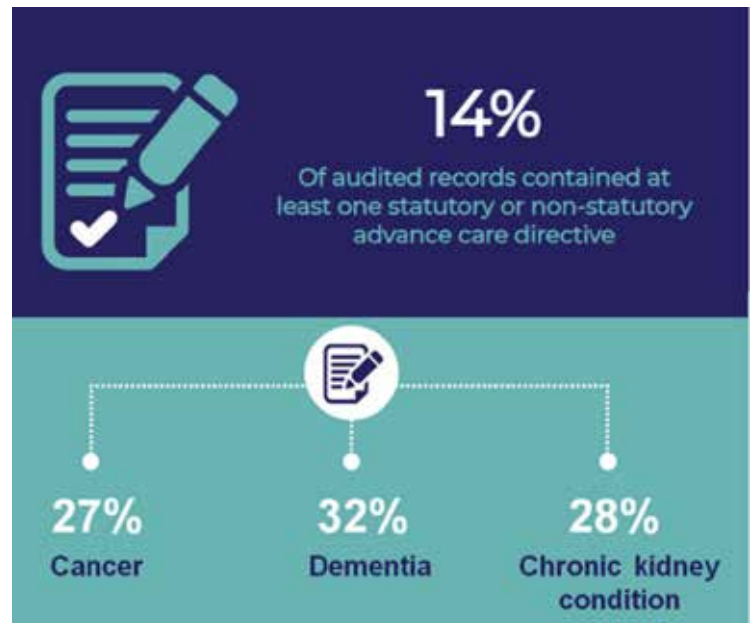
## FREQUENTLY ASKED QUESTIONS

### What percentage of Australians over the age of 65 have an advance care directive in their records?

Despite robust legislation and policy in this area, there is limited uptake of Advance Care Directives.

In a 2019 national prevalence study of 4187 Australians aged 65+ years, only 14% had an Advance Care Directive ("ACD").

- These results are likely to be a lot lower when considering all patients (e.g. not 65+ years)
- Overall, low prevalence rates indicate advance care planning is not part of routine organisational systems or care for the older person in Australia
- Only 7-9% of older Australians with an ACD reported wanting life prolonging treatments. Primary care services need to ensure adequate access to palliative care and end-of-life care



### What are some of the conflicting pressures on decision making in situations where a patient has impaired decision making capacity?

*What are the clinical parameters that will tell me that this patient is at the end of their life?*

*My job is to save lives isn't it?*

*What's the legal situation if I don't give treatment? Maybe I'd better keep trying to keep him alive.*

*What is the protocol in this situation? What did the textbook say? What did the consultant do the last time this happened?*

*My belief is that life is sacrosanct*

*His children are saying that we should let him go. But his wife is saying that we must keep him alive. What do I do?*

*What's this bit of paper – an Advance Care Directive? And what's this plan? And who is this person calling themselves a medical power of attorney? Who do I listen to?*

*I don't know how to tell them this bad news. I need to give them hope. Maybe I'll give them one more round of treatment...*

**What would this patient have wanted if they had been conscious?**



# FAQ

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It is well known that decision-making in situations where a patient has impaired decision-making capacity, such as in end-of-life situations, can be difficult for doctors (particularly registrars) because they are often faced with a confusing array of competing thoughts which can make decision making inconsistent.

Decisions often have to be made in urgent and emotional situations.

Decisions often have to be made with very little information about the wishes of a patient, who may be unconscious or delirious.

There is often confusion about legal and ethical responsibilities.

The basis of decision making can be unclear to some:

- Varying from being based on noble impulses to preserve life at all costs
- To confusion about what the patient would have wanted ("substituted judgement decision making")
- Versus what is thought to be best for the patient ("best interests decision making").

Decision-making may be affected or dominated by:

- The individual values of the doctor or relatives
- Protocols or best practice
- Fear (in decisions made with a legally-defensive mindset)
- Reluctance to enter difficult discussions with the patient and the family about death and dying when it might be easier just to offer another round of treatment.

### How can I help my registrar identify triggers for advance care planning?

The below graphic includes prompts your registrar can use in identifying triggers for an ACP discussion with their patient.

#### DECISION-MAKING CAPACITY

A person who has the capacity to be involved must always be involved in a decision-making process about their health condition and treatment options, unless they choose not to be. The assessment of capacity is not always straightforward.

A person must be able to:

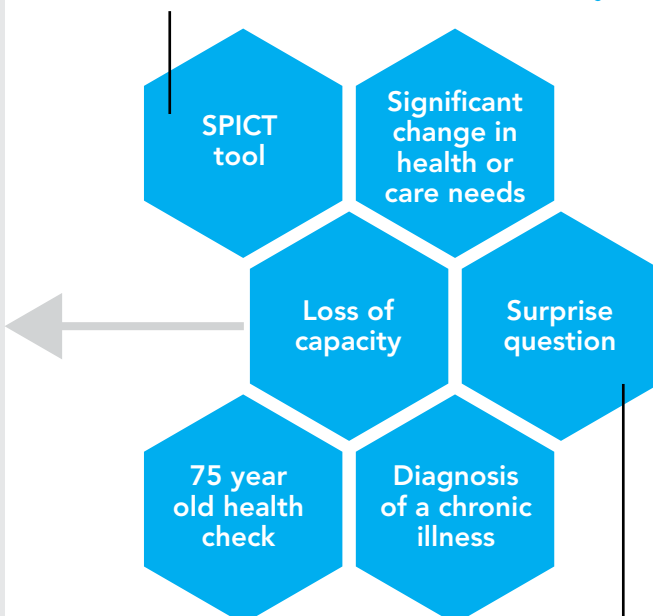
- Understand the information provided
- Understand the information as it relates to them
- Consider the possible choices in terms of personal values/preferences
- Make a decision and provide a rationale for the decision
- Be able to communicate their decision.

An Advance Care Directive ("ACD") is only enacted in the instance that a patient has lost capacity or competence, and cannot make a medical treatment decision.

It is important to note that the terms 'capacity' and 'competence' are often used interchangeably, although they can be differentiated. Competence is a legal term and is presumed (it must be proven otherwise). Capacity is a clinical/functional term that is task-specific and can fluctuate.

Some states have further defined the criteria for capacity in their own legislation.

*Helps identify people needing well-coordinated care planning using six general indicators of deteriorating health or increasing care needs (including trigger events like hospital/care home admission): <https://www.spict.org.uk/>*



*e.g.: Would you be surprised if this patient died in the next six months?*



# FAQ

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### SPICT TOOL

The Support and Palliative Care Indicators Tool (SPICT) can also assist with identifying triggers for an ACP discussion and help identify people needing well-coordinated care planning using 6 general indicators of deteriorating health or increasing care needs (including trigger events like hospital/care home admission): <https://www.spict.org.uk/>

### How is decision-making capacity defined?

An adult is presumed to have decision-making capacity unless there is evidence to the contrary.

#### Decision-making capacity is task-specific.

Components of decision-making capacity include:

1. The ability to understand information
2. The appreciation of the relevance of that information to the situation
3. The ability to reason or weigh up the risks and benefits
4. The ability to express a choice

### SUBSTITUTED JUDGEMENT DECISION-MAKING STANDARD

If a patient has impaired decision-making capacity, all parties - substitute decision-makers, family members, carers, doctors, and other health practitioners caring for the patient - must try to make decisions **which they genuinely believe that the patient would have made for themselves** if they still had decision-making capacity.

#### Everyone should decide as if "in the patient's shoes".

In accordance with this fundamental principle, when making decisions for an individual, all parties should consider:

1. What they know of the individual's values and preferences
2. What they have been told by the individual in the past
3. What the individual may have documented including wishes documented in their ACD

### Who can participate in advance care planning?

ANYONE can participate in the ACP discussions. Even those with insufficient decision-making capacity can express their values and preferences; however, these values and preferences would contribute to a non-binding "goals of care" plan. This is distinct from an advanced care directive (ACD) which can only be completed by people with decision-making capacity due to the legally binding nature of the relevant forms.

#### Statutory Advance Care Directives include:

- The person's values and preferences (values directive)
- (Depending on the Australian jurisdiction) consent for, withdrawal or refusal of treatment instructions (instructional directive)
- Appointment of a substitute decision-maker – this might be on a dedicated form (e.g. enduring guardian) or a combined form (e.g. South Australian Advance Care Directive).

### What does advance care planning look like in practice?

- Identifying triggers and starting the conversation
- Appointing a substitute decision-maker ("SDM")
- Documenting the patient's values and preferences
- Documenting specific medical treatment instructions



# FAQ

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### What are some of the practicalities registrars need to be aware of regarding advance care planning?

- There is no specific MBS item for ACP conversations, so these need to be billed against another item - taking into account the length of consultation needed.
- While Telehealth can be used for ACP, audio-visual witnessing is not available.
- Storage of completed ACP documentation is important - copies need to be
  - Kept on the patient's electronic file, and
  - Provided to the patient, SDM, and other members of the healthcare team.
- Advance Care Directive forms differ by state/territory, below are links to different forms for each state and territory:
  - [Australian Capital Territory - Advance care planning](#)
  - [New South Wales - Advance care directive](#)
  - [Northern Territory - Advance personal Plan](#)
  - [Queensland - Advance care directive](#)
  - [Tasmania - Advance care directive](#)
  - [Victoria - Advance care directive](#)
  - [Western Australia - Advance health directive](#)
- Terminology differs by state/territory
  - Each state and territory has their own terminology, however the term "advance care directive" is used nationally as a catch-all term to refer to the instruments which are recognised in each jurisdiction under advance care directive legislation or common law.
  - "Substitute Decision-Maker" is used nationally as a catch-all term to refer to an alternative decision-maker, if the person is no longer able to make their own decisions; however, legal documentation requires a different term for this individual according to state/territory.

TABLE 1. TERMINOLOGY

Jurisdiction	Statutory document preference for care	Statutory appointment: Substitute Decision Maker
<b>Australian Capital Territory</b>	Health Direction	Enduring Power of Attorney
<b>New South Wales</b>	Advance Care Directive (common law)	Enduring Guardian
<b>Northern Territory</b>	Advance Personal Plan	Decision Maker
<b>Queensland</b>	Advance Health Directive	Enduring Power of Attorney
<b>South Australia</b>	Advance Care Directive	Substitute Decision Maker
<b>Tasmania</b>	Advance Care Directive (common law)	Enduring Guardianship
<b>Victoria</b>	Advance Care Directive	Medical Treatment Decision Maker
<b>Western Australia</b>	Advance Health Directive	Enduring Guardian

### What ACP supports are available to registrars and the GP team?

- Nurses and allied health can assist with instigating and developing the ACP, including it as a part of routine conversations e.g. 75-year-old health check, care plans.
- ACPA's Support Service offers advice and referrals both online and via telephone to help them understand where their knowledge and skills are and supporting them to develop skills in areas they find challenging e.g. legal issues

# FAQ

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### How can I assist my registrar in developing well written Advance Care Directives that can be enacted?

Ensure the registrar:

- Is aware of the correct terminology
- Lists the correct details for the substitute decision-maker ("SDM"), noting that this needs to be a person who can be trusted to follow through on the patient's wishes (making it a difficult role for loved ones)
- Clearly outlines the patient's values and preferences, focusing not only on what is NOT wanted but also on positive values such as love for family
- Describe the perceived impact of acute and chronic health issues on the individual
- Clearly delineates instructions regarding medical treatments that will and will not be in keeping with the patient's wishes, considering these in both a short-term and long-term situation

**A medical team can only act on an ACD if they know about it: ensure the patient is aware they can share their plan by uploading it to their My Health Record**

<https://www.digitalhealth.gov.au/initiatives-and-programs/my-health-record/whats-inside/advance-care-planning>

### Resources



GPSA webinars



GPSA guides



GPSA teaching plans



GPSA FAQs

All GPSA resources are available [here](#)

Advance Care Planning Australia (ACPA) offers a free national advisory service for health professionals and consumers to answer all queries related to advance care planning. Their website also provides key information and forms, with free online learning modules that can be completed to advance learning about ACP and specialist areas.

- Advance Care Planning Australia [website](#)
- Advance Care Planning Australia [YouTube channel](#)
- Advance Care Planning [Learning website](#) (11 modules, with one specific to general practice accredited for RACGP and ACRRM CPD points)
- [Free National Advance Care Planning Support Service](#) [1300 208 582 9am - 5pm (AEST) Monday to Friday] and referral service
- [Advance Care Planning Australia Newsletter](#) - subscribe to receive updates on ACP and stay on top any relevant legal changes
- [How to upload advance care planning documents to My Health Record](#)