



# Advance Care Planning: Aged Care Implementation Guide

2023

**Advance Care  
Planning Australia**

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## **Foreword by Associate Professor Michael Murray AM**

Providing high-quality aged care to older people in need, is a hallmark of a compassionate and inclusive society, and a fundamental human right. Recent submissions to the Aged Care Royal Commission and the Commission's Interim report have focused our attention on needs not met in this vulnerable group, highlighting our shared failure over many years. COVID-19, particularly as it has affected this sector, has been a further catalyst to undertake serious and wide-reaching aged care reforms. We, the community, with more focus that has been evident for some time, appear ready to raise our expectations of ourselves and our government with an understanding that 'quality' must encompass engagement and meaningful choice and control of decision making often felt lacking by older people especially in the latter part of their lives.

Our shared human experience underscores the importance of advance care planning as a driver of personal autonomy and dignity. Nevertheless, uptake of advance care planning in Australia remains low and it is often poorly understood and appreciated by those most likely to benefit. Compounding this is a lack of national consistency and a fragmented approach to advance care planning, with differing laws and terminology across Australia.

As a geriatrician, I've had the pleasure of working with many committed professionals in aged care. Almost all are overwhelmingly supportive of advance care planning and recognise the difference it can make for their clients and families. But, understandably, many struggle with advance care planning's apparent complexity and shy away from the process.

The Advance Care Planning Implementation Guide for Aged Care has been developed to reduce the complexity and provide aged care providers with the tools to implement advance care planning in accordance with the Aged Care Quality Standards and legal and ethical frameworks. The guide also provides guidance on the systems, processes and governance required to ensure robust implementation in aged care settings.

Advance care planning is just a small component of a broader suite of aged care reform. But it's critical we get this right. When done well, advance care planning can help people live well and on their own terms, confident their choices will be respected and implemented. To deliver on this will require all of us involved in the care of older Australians, to move beyond checking a 'tick box' on a form. Instead we will help create an environment that empowers people to have an enduring voice in the care that they receive. It is after all the standard of care we would want for our loved ones and ourselves.

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Advance Care Planning Australia delivers national advance care planning leadership, advocacy, communications, support services, prevalence audit toolkit, and education and information resources for consumers, the health and aged care workforce, and/or service providers.

Our program is focused on improving advance care planning policy and systems, community awareness, understanding and uptake, workforce capability and quality monitoring and evidence. We promote a national collaborative approach to achieving excellence in advance care planning.

ACPA acknowledges the valuable advance care planning work being undertaken by others throughout Australia. This guide has been informed by the 2017 *Advance care planning in aged care: A guide to support implementation in community and residential settings* which was developed by ACPA and the National Ageing Research Institute.

Further information regarding this guide can be obtained by contacting the Advance Care Planning Program Director at Metro South Health on phone 1300 208 582. A copy of the report is available at [advancecareplanning.org.au](http://advancecareplanning.org.au).

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### Disclaimer:

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## Advance care planning overview

Together, we are working to ensure older Australians have access to quality health and aged care that is tailored to an individual's needs and preferences, promotes dignity and respect, and enables choice and decision-making.

National quality standards and policy documents recognise the importance of advance care planning (ACP) and Advance Care Directives (ACD) in ensuring consumer choice, decision-making and preference-aligned care. Quality standards for health, aged care and multi-purpose service organisations include advance care planning related criteria, statement of outcomes, expectations, actions and/or evidence requirements. Standards emphasise that assessment and planning should identify and address the consumer's needs, goals and preferences, including advance care planning and end-of-life planning if the consumer wishes.

This guide aims to support the implementation of advance care planning and Advance Care Directives in aged care as well as compliance with relevant standards. The guide explains why advance care planning and Advance Care Directives are important, explores Advance Care Directive legislation and standards, and provides guidance for implementing and monitoring advance care planning activities and documents in aged care.

### What is advance care planning?

Advance care planning is the voluntary process of planning for future health and personal care needs. It provides a way for a person to make their values and preferences for future medical care known.

Advance care planning is not a single event but an ongoing process and conversation that should be undertaken early and revisited regularly. Revisiting these conversations is especially important when a person's health or social situation changes.

Advance care planning conversations and documentation inform future medical treatment decisions, if the person cannot make or communicate these decisions themselves. It aims to align the treatment and care they receive to their actual preferences and preferred health outcomes.

Key components of advance care planning in aged care are:

- the person thinking about what's important to them in terms of specific care, medical treatment preferences and where they wish to receive care
- the person talking about their values and preferences for future health care with others
- the person selecting and appointing a trusted substitute decision-maker
- the person documenting their preferences in a legally-binding Advance Care Directive
- if the person has diminished or no capacity, having someone (the substitute decision-maker) document the person's preferences in an advance care plan to inform care
- aged care service providers supporting advance care planning and Advance Care Directives, including establishing systems, educating the workforce, engaging with consumers, and implementing and enacting Advance Care Directives.

## What is an Advance Care Directive?

An Advance Care Directive is the national catch-all term to refer to the instruments (Directives) recognised in each jurisdiction (states or territory) under advance care directive legislation or common law.

An Advance Care Directive is a voluntary, person-led document completed and signed by a competent person describing the person's values and preferences for future medical treatment decisions, including their preferred health outcomes and care. They may include binding instructions regarding consent, refusal, or withdrawal of medical treatment. They may also be used to appoint a substitute decision-maker who can make decisions about health or personal care on the person's behalf.

Advance Care Directives only come into effect when the person loses decision-making capacity. If the loss of capacity is only temporary (e.g. delirium related to illness or treatment), the Advance Care Directive will only be in effect until the person regains decision-making capacity. Advance Care Directives are an important mechanism of informed consent for those without capacity. An Advance Care Directive is preferable to an advance care plan. Table 1 provides the names of jurisdictional Advance Care Directives.

## What is an advance care plan?

An advance care plan captures the person's beliefs, values and preferences in relation to future care decisions, but does not meet the requirements for statutory or common law recognition due to the person's diminished or lack of capacity.

If an advance care plan is made on behalf of an individual with impaired capacity, it should be created by the substitute decision-maker and/or other people who know the person well. An advance care plan made on behalf of an individual, should reflect what the person would document for themselves if they were able to do so. They are often helpful in providing information and guiding decisions for substitute decision-makers and health practitioners but are not legally binding.

These documents may be known as an 'advance care plan', 'statement of choice' or 'statement of choices – no legal capacity'.

## Other types of advance care planning documentation

Like advance care plans, other documentation may not meet the formalities or capacity requirements to be legally binding but may still inform care. These include:

- personally-written letters
- letters or documents written by a medical practitioner outlining the person's preferences, resuscitation status, or whether they should be transferred to hospital.

In some jurisdictions, medical orders are part of a state-based approach or public health policy, such as the Resuscitation Plan in NSW, the Acute Resuscitation Plan in Queensland, the Goals of Care plan in Tasmania and the 7 Steps Pathway in SA. They provide important instructions.

## What is a substitute decision-maker?

A substitute decision-maker is a person appointed or identified by law to make medical treatment decisions on behalf of a person whose decision-making capacity is impaired. Substitute decision-makers have the legal authority to make these decisions. The relevant legislation and names vary between jurisdictions (see Table 1).

Identification of the substitute decision-maker can help to reduce confusion and family conflict.

A document that appoints a substitute decision-maker to make health, medical, residential and other personal (but not financial or legal) decisions is called an Advance Care Directive.

## The role of the substitute decision-maker

A substitute decision-maker is called upon to make medical treatment decisions on behalf of a person if the person loses decision-making capacity. Historically, this role was known as next of kin, but that term no longer exists.

The substitute decision-maker is expected to make the same decision they believe the person would have made. Their authority, and limits to their authority, are defined by relevant law. A substitute decision-maker can generally consent to medical treatment on the person's behalf. In some states, a substitute decision-maker can legally refuse medical treatment on behalf of the person, if the person has previously made their preferences for refusing medical treatment known.

There are three types of substitute decision-makers:

1. one chosen and appointed by the person
2. one assigned to the person by law in the absence of an appointed substitute decision-maker (default substitute decision-maker). The person who becomes the legal substitute decision-maker is the first person listed in the jurisdictions hierarchy that is available, willing, and able to make decisions on behalf of the person. They may be:
  - a. a spouse or de facto spouse
  - b. an unpaid carer
  - c. the nearest relative or a friend who has a close personal relationship with the person
3. one appointed for the person (e.g. a guardian appointed by a guardianship tribunal). If a tribunal assigns a substitute decision-maker, this appointment ranks higher than that assigned as default within the law.

A substitute decision-maker should be:

- someone the person trusts to make their medical treatment decisions
- someone who understands the person's values and preferences for care
- at least 18 years of age and available to make decisions (ideally in the same city or region)
- prepared to communicate clearly and confidently on the person's behalf when talking to doctors, other health professionals, care workers and family members.

## Advance Care Directive legislation across Australia

There is no national Advance Care Directive legislation in Australia. Each jurisdiction determines legislation or policy about Advance Care Directives. The law exists to allow people autonomy and choice in their future medical treatment decisions, including consent, withdrawal, refusal and/or substitute decision-making.

When a person has decision-making capacity, service providers should promote the use of the existing state or territory Advance Care Directive forms, rather than creating an organisation-specific advance care plan. Table 1 provides a summary of the Advance Care Directive names and other documentation used in each jurisdiction. Forms are available [www.advancecareplanning.org.au](http://www.advancecareplanning.org.au).

**Table 1:** Advance care planning documents and terms in Australia

State or territory	Advance Care Directive – preferences for care	Advance Care Directive – appointment substitute decision-maker	Other documentation
Australian Capital Territory	Health Direction	Enduring Power of Attorney	<ul style="list-style-type: none"> <li>• Advance care plan</li> <li>• Statement of Choices Resuscitation Plan</li> <li>• Goals of Care Form</li> <li>• Letters from the person</li> </ul>
New South Wales	Advance Care Directive (non-statutory)	Enduring Guardian	<ul style="list-style-type: none"> <li>• Statement of Values and Wishes Resuscitation Plan</li> <li>• Goals of Care Form</li> <li>• Letters from the person</li> </ul>
Northern Territory	Advance Personal Plan Direction under <i>Natural Death Act 1998</i> (NT) (if made before 17 March 2014)	Advance Personal Plan – Decision Maker	<ul style="list-style-type: none"> <li>• Resuscitation Plan</li> <li>• Goals of Care Form</li> <li>• Letters from the person</li> </ul>
Queensland	Advance Health Directive	Enduring Power of Attorney for personal matters	<ul style="list-style-type: none"> <li>• Statement of Choices – persons with decision-making capacity</li> <li>• Statement of Choices – persons without decision-making capacity</li> <li>• Resuscitation Plan</li> <li>• Goals of Care Form</li> <li>• Letters from the person</li> </ul>

South Australia	Advance Care Directive Anticipatory Direction (if made before 30 June 2014)	Advance Care Directive – Substitute Decision Maker Appointment  Medical Power of Attorney (if made before June 2014)  Enduring Power of Guardianship (if made before 1 June 2014)	<ul style="list-style-type: none"> <li>• Statement of Choices Resuscitation Plan</li> <li>• Letters from the person</li> <li>• 7 Step Pathway</li> </ul>
Tasmania	Advance Care Directive	Enduring Guardian	<ul style="list-style-type: none"> <li>• Resuscitation Plan</li> <li>• Goals of Care Form</li> <li>• Letters from the person</li> </ul>
Victoria	Advance Care Directive Refusal of Treatment Certificate (Competent) (if made before 12 March 2018)	Medical Treatment Decision Maker  Enduring Power of Attorney (Medical Treatment) or attorney (health care decisions) (if made before 12 March 2018)	<ul style="list-style-type: none"> <li>• Statement of Choices Resuscitation Plan</li> <li>• Goals of Care Form</li> <li>• Letters from the person</li> </ul>
Western Australia	Advance Health Directive	Enduring Guardian	<ul style="list-style-type: none"> <li>• Values and Preference Form</li> <li>• Goals of Care Form</li> <li>• Letters from the person</li> </ul>

Some jurisdictions recognise interstate Advance Care Directives and decisions, and others do not. As a provider, you must understand your state and territory’s legislation and be aware of the framework in other jurisdictions. The Advance Care Planning Australia website and [legal resources hub](#) provides useful information specific to each state and territory, including the relevant forms. The National Advance Care Planning Support Service™ 1300 208 582 is available for consumers, the health and aged care workforce, and service providers. Alternatively, check with your local Office of the Public Advocate/Guardian to find out more.

## Witnessing of advance care planning documents

Advance Care Directives for preferences of care and substitute decision-maker appointments have specific witnessing requirements. Witnessing is an important safeguard for vulnerable people. Witnessing ensures the individual to whom the directive applies was competent, understood the nature and significance of the decisions contained within the Advance Care Directive, and acted freely and voluntarily in signing the document. Witnessing requirements vary between jurisdictions, and the form usually provides details of the requirements.

There is no requirement for an advance care plan to be signed and witnessed. However, having a signed, witnessed, and dated document will strengthen its usefulness in informing care.

## **Benefits of advance care planning**

Advance care planning has benefits for the person, their family, and other people who care for them. Some of these benefits are:

- improved care, including end-of-life care
- increased likelihood that the person's preferences are known and respected
- improved psychological outcomes for surviving relatives
- reduced stress and anxiety for family members in making decisions
- fewer inappropriate transfers from residential aged care to hospital
- higher staff satisfaction for those caring for residents of aged care facilities.

## **Advance care planning standards**

Assessment and care planning in aged care should provide access to advance care planning, including the development of Advance Care Directives and end-of-life planning if the consumer wants this. Ideally, advance care planning should begin early when the person has decision-making capacity. Anyone 18 years and above can document an Advance Care Directive. The triggers for advance care planning may include a health assessment with a general practitioner, the onset of chronic or sudden illness, diagnosis of dementia, assessment for aged care services (community or residential), and as part of the health assessment for people 75+ years.

Those receiving community based aged care services might be better able to participate in advance care planning. The person's general practitioner, case managers or community health practitioners can play an important role. Residential aged care facilities should ensure advance care planning is available for residents.

## **National quality standards for aged care**

In Australia, national quality standards aim to protect the public from harm and to improve the quality of health and aged care. The National Safety and Quality Health Service Standards (NSQHS) outline the safety and quality outcomes that a health service organisation must achieve. The Aged Care Quality Standards (ACQ Standards) outline the safety and quality outcomes that an aged care provider must achieve. Multi-Purpose Services (MPSs) provide integrated health and aged care services, particularly in small regional and remote communities. MPSs must achieve the NSQHS and the MPSs Aged Care Module (currently in draft).

**Table 2:** Quality standards that refer to advance care planning

Quality Standard	Standard / criteria	Items
National Safety and Quality Health Service Standards	Partnering with consumers standard	The health service organization ensures that its informed consent processes comply with legislation and best practice
		The health service organization has processes to identify: <ul style="list-style-type: none"> <li>• The capacity of a patient to make decisions about their own care</li> <li>• A substitute decision-maker if a patient does not have the capacity to make decisions for themselves</li> </ul>
		The health service organisation has processes for clinicians to partner with patients and/or their substitute decision-maker to plan, communicate, set goals, and make decisions about their current and future care
	Comprehensive care standard	Patients are supported to document clear Advance Care Directives/plans
		The health service organization has processes to ensure that current Advance Care Directives/plans: <ul style="list-style-type: none"> <li>• Can be received from patients</li> <li>• Are documented in the patient’s healthcare record</li> </ul>
Aged Care Quality Standards	Ongoing assessment and planning with consumers	Assessment and planning identified and addresses the consumer’s current needs. Goals and preferences, including advance care planning and end-of-life planning if the consumer wishes
Multi-Purpose Services Aged Care Module	Consumer dignity and choice	Support to make informed choices about their care, including taking risks to live the best life they can
RACGP Standards for general practice residential aged care	Access to care	Coordinate resident’s treatment according to Advance Care Directives, where available.  If relevant, involve the substitute-decision maker in the advance care planning/Directive discussions

## National Advance Care Directive prevalence

Despite legislation, national standards, and the known importance and benefits of advance care planning and Advance Care Directives, community understanding and uptake remain low. Unfortunately, most older people will not have an Advance Care Directive before receiving community or residential aged care.

The prevalence of older Australians aged 65+ years with an Advance Care Directive is approximately 14% (weighted, adjusted result). For those in residential aged care, approximately 38% have an Advance Care Directive and 30% have an advance care plan (unweight, adjusted result). The low prevalence of advance care planning documents indicates that consumers are under-prepared for future health care decisions and end-of-life care.

## Practical considerations for aged care service providers

Community and residential aged care staff should:

- determine whether the person has an Advance Care Directive at assessment, receipt of aged care services or admission to residential care. Be sure to determine whether it's an Advance Care Directive or advance care plan, and whether a substitute decision-maker has been legally appointed.
- record the person's substitute decision-maker and their contact details in the person's health record.
- encourage the person's participation in advance care planning if they have capacity and don't have existing documentation. It is a voluntary process.
- encourage the person's substitute decision-maker to know and understand the client's preferences. If the person no longer has decision-making capacity, the substitute decision-maker could document an advance care plan to inform care.
- ensure documents are stored in the person's health record and are easily accessible and transferable.

Aged care providers will require systems and governance to ensure robust advance care planning implementation. Multi-site organisations operating across different jurisdictions will need to account for any differences in legislation between facilities and ensure that the relevant policies reflect this.

## Advance care planning implementation

This section explains how to support advance care planning implementation within your organisation to promote compliance with quality standards. Priorities include:

- clinical governance incorporating advance care planning and Advance Care Directives
- advance care planning leaders or champions
- organisational advance care planning and Advance Care Directives policy and procedures
- support for consumers in advance care planning including information support and promotion of the National Advance Care Planning Support Service™ 1300 208 582
- staff with advance care planning capability and competency
- embedding advance care planning processes into existing models of care, including admission and assessment processes
- health records systems that include Advance Care Directives and alerts
- quality improvement processes and audits inclusive of Advance Care Directives and person experience
- ensuring an Advance Care Directive can be accessed, transferred and enacted.

Establishing, communicating, and reviewing systems and governance processes related to advance care planning can help your organisation meet its legislative requirements and quality standards obligations.

### Policies and procedures

Advance care planning policy and procedures can embed advance care planning practices into an organisation. Key recommendations for ACP policy development include:

#### General content

- Policy document should refer to legislation relevant to the state or territory where the organisation is located.
- Policy authors and approvers should ensure ACP policy documents do not use out of date terminology.
- Policy documents should include a clear statement of intent outlining why the policy was created, what the intended outcomes of the policy are, how these outcomes will be measured (e.g. ACP document on file for every consumer etc.), what the evaluation/audit processes to evaluate the success of the policy will involve, and the specific measure that would demonstrate policy success (e.g. increase of x% in ACP documents on file etc.).
- Policy documents should define the role and responsibility of staff.

## ACP content

- Policy background information should include:
  - A clear explanation of regulations and legislation relevant to the jurisdiction of the facility,
  - Descriptions of when and how an ACD is documented, stored, accessed and activated, including how the decision is made, by whom, what processes are involved, and whether this activation is temporary (e.g. in the case of delirium or unconsciousness)
  - Information to staff about how to make sure ACDs are valid and regularly reviewed for consumers; staff obligations when the person deteriorates.
- Policy documents should outline who needs to be involved in ACP (including consumers and their family and/or loved ones), and what their role in the process is.
- Detailed information should be provided in the policy with regards to how ACP is documented within the facility (e.g. forms used and where they are located, etc.). This information should include:
  - ACD storage (e.g. role of My Health Record) and access within the facility,
  - making sure all relevant parties have a copy of ACP documentation,
  - the importance of ensuring ACP documents are transferable when external facilities/health practitioners are engaged in medical decision-making.
- Where possible, links to additional sources of information relating to ACP should be included, including ways to access additional training if desired.

## Language and presentation

- Documents should use clear and easy to understand language and avoid using any jargon, clichés, and unfamiliar words and phrases.
- Documents should use clear headings and bullet points (where possible) to present information in a succinct and easily read format.
- Documents should use white space effectively to improve readability and ensure any technical words or acronyms used are clearly defined.
- At a minimum, ACP policy documents should include the following terms and their definitions:
  - Advance Care Directive/Health Directive/Health Direction/Advance Personal Plan
  - Advance care planning
  - Capacity
  - Consent
  - Inclusive decision-making
  - Substitute decision-maker (or other jurisdiction-specific terms)

## Diversity and inclusion

- Policy documents should include specific information related to engaging with consumers from diverse backgrounds, including culturally and linguistically diverse and/or Indigenous groups
- ACP policy documents should refer to, and be written to reflect the importance of respecting and discussing values and preferences of the consumer and engaging in inclusive and informed decision-making
- Documents should be written so that the focus of the ACP process remains on the consumer.

## Health record systems for advance care planning documents

Accessibility and transferability of advance care planning documents are important to ensure that care is preference-aligned. Priorities include:

- determining whether the person has an Advance Care Directive at assessment, receipt of aged care services or admission to residential care, and storing the document within their health record and add the relevant alert
- checking the person's My Health Record for any Advance Care Directive documentation
- recording the person's substitute decision-maker and their contact details within the health record
- if the person is a community aged care recipient, encouraging them to store a copy of their Advance Care Directive with them, their substitute decision-maker, their general practitioner, their treating health service or hospital, and in My Health Record
- transferring Advance Care Directives or advance care plans between relevant service providers to inform future medical treatment decision-making.

## Quality improvement and audit processes

Quality improvement activities, including audit or person experience surveys, can help to monitor advance care planning uptake and understanding.

An audit may include identifying:

- the prevalence of Advance Care Directives in client health records such as the percentage of documents stored that describe preferences of care and substitute decision-maker appointment
- the percentage of Advance Care Directives compared to advance care plans
- quality aspects of documents such as whether they are signed, dated and witnessed.

In contrast to an audit, a survey may examine clients understanding and attitudes toward advance care planning.

Quality improvement resources and toolkits are available from Advance Care Planning Australia and ELDAC.

## Staff education and support

This section explains how to provide education and support to your staff and discusses available advance care planning educational resources.

### Why educate staff about advance care planning?

Educating and supporting staff will assist your organisation in implementing advance care planning effectively. It will help to improve staff knowledge of advance care planning and their confidence to have advance care planning conversations with clients. Improving staff confidence and knowledge of advance care planning can increase the quality and number of advance care planning conversations that take place, improve the likelihood that these conversations are appropriately documented, and increase the likelihood that people's preferences will be followed.

It is important to consider the educational needs of all levels of staff, and to ensure the education provided is suitable and accommodates different educational needs.

Staff may feel unable to engage in advance care planning with clients if they:

- are unclear about their role in advance care planning
- are unsure about the legal implications of advance care planning
- do not feel confident to introduce advance care planning conversations or discuss advance care planning with clients and their loved ones
- do not feel they have time to have advance care planning conversations with clients and their loved ones
- feel they lack the skills required to document the outcome of advance care planning conversations.

### Information to include in staff education and workshops

#### What is advance care planning?

Training should include a clear statement that describes the process of advance care planning. One possible statement could be:

Advance care planning is the process of planning for future health and personal care needs. It provides a way for a person to make their values and preferences for future medical care known. These documents are then used to help guide decision-making at a future time if and/or when the person cannot make or communicate their own decisions.

Staff must have a good understanding of advance care planning and its principles. To do so, make sure you provide staff with an overview of advance care planning, including:

- the concept of advance care planning, and how it works over time and across settings
- an overview of the fundamental principles of advance care planning (i.e. self-determination, dignity, and the avoidance of suffering)
- the benefits of advance care planning

- the language and terminology used
- how advance care planning can be integrated into routine care
- the role of the person and their substitute decision-maker.

### How to have an advance care planning conversation

Conversations about advance care planning may occur over a period of time and may involve one or many conversations.

Evidence shows that older people expect advance care planning conversations to be initiated by health professionals and care workers. The key aspects of facilitating advance care planning conversations include:

- recognising when it's the appropriate time to initiate an advance care planning conversation
- providing an appropriate environment for the conversation to occur
- acknowledging, validating, and normalising the conversation
- providing information to support the person to have future conversations
- engaging in detailed advance care planning conversations with the person and their loved ones.

Education for staff should include information about:

- when it is relevant to have an advance care planning conversation, noting that this may be different for each individual and setting
- how to identify the cues and triggers that indicate when it is appropriate or when it becomes necessary to initiate the conversation
- how to talk about advance care planning with the person and their loved ones to ensure it is normalised and presented in a non-threatening and optional manner
- suggested conversation starters to provide staff with ways to initiate advance care planning discussions with clients and their support network
- what resources are available that can be given to the person and their loved ones to help them to become more prepared

### Communication skills

Effective communication is essential and requires:

- considering the appropriateness of the environment
- being aware of the body language of the person and their family or loved ones
- using clear, easy to understand spoken language
- adjusting your style to meet the needs of the person if their spoken language is not English, or if they have difficulty communicating in English
- using active listening
- responding to the emotional cues of the person and their family or loved ones.

The type of communication style used in advance care planning discussions will depend on:

- the person's disease progression
- how much advance care planning discussion has already occurred
- the person's cultural and language background

### Advance care planning documents and enactment

Education for staff should include information about:

- the documentation used within your organisation – this should include Advance Care Directives, advance care plans (including those made on behalf of a non-competent person), and medically initiated clinical care plans or medical orders
- what to do if a person is admitted into your organisation with an existing Advance Care Directive, including how to ensure it is current and stored correctly
- how to complete advance care planning documents
- where advance care planning documents should be stored
- how to access and transfer advance care planning documents
- how to enact Advance Care Directives to inform care and medical treatment decisions.

### Education resources

Advance Care Planning Australia provides free e-learning modules for aged care workers and health professionals. These e-learning modules can be accessed from [learning.advancecareplanning.org.au](https://learning.advancecareplanning.org.au). Advance Care Planning Australia also provides educational webinars and [video resources](#).

### E-learning and online education programs

Advance Care Planning Australia online learning modules currently available include:

- Module – Advance care planning introduction
- Module – Advance care planning conversations
- Module – Advance care planning decision-making – the legal implications
- Module – Advance care planning implementation
- Module – Advance care planning in the primary care setting
- Module – Advance care planning and dementia
- Module – Advance care planning and Aged care
- Module – Advance care planning and Cultural diversity
- Module – Advanced communication skills and advance care planning
- Module - Advance care planning and volunteers
- Module - Advance care planning for substitute decision-makers

## Consumer engagement

This section highlights the diversity of people receiving aged care services and explains how to engage them in advance care planning conversations.

Advance care planning conversations should be a part of routine care in community and residential aged care services. It is beneficial to introduce the concept of advance care planning when a person is medically stable, rather than waiting for a crisis.

Conversations about advance care planning should be introduced early and revisited at regular intervals, or when there is a change in the person's health status. Conversations should focus on the importance of future health care planning, consent, and the identification of a suitable substitute decision-maker. Conversations can include the person, their substitute decision-maker, other family members or loved ones, and relevant healthcare or aged care workers.

Information resources and support are available from the National Advance Care Planning Support Service™ 1300 208 582 or [www.advancecareplanning.org.au](http://www.advancecareplanning.org.au).

## Education and information support

There is a wide variation in people's understanding and knowledge about advance care planning. As such, an important part of advance care planning includes providing education, information resources, and support to people and their support network (families/loved ones, etc.) to increase the uptake of advance care planning.

As part of this process, you should provide information to consumers about:

- what advance care planning is, with a focus on future health care planning, consent, and identification of a substitute decision-maker, making sure to recognise advance care planning is a voluntary process
- the benefits of advance care planning and receiving preference-aligned care
- what is involved in the advance care planning process, including that these conversations and documents can be revisited and revised at any time
- what a substitute decision-maker is and what their role is
- how to document preferences (i.e. what documentation is used within your organisation based on the state or territory laws – e.g. an Advance Care Directive, advance care plan, statement of choices, Advance Health Directive)
- who should have a copy of the plan and the best place to store the plan
- the circumstances that activate an Advance Care Directive
- what will happen if the plan is activated
- what happens if a person regains capacity after a plan is activated.

The information provided to consumers should be easy to understand, with clear and simple terms and no use of jargon. If possible, having this information available in multiple languages may also benefit consumers whose first language is not English. See [video resources](#).

There is no right or wrong time to provide education and information about advance care planning. Times when advance care planning information can be provided include:

- on assessment for aged care services
- on admission into the service/aged care facility
- at resident and family meetings or groups sessions
- if there is any change in the person's medical condition
- during GP visits or during regular client assessments.

## **Barriers to having advance care planning conversations**

Some barriers may impact whether a person will engage in advance care planning conversations. These barriers include:

- The person does not understand the concept of advance care planning and the importance of future health care planning.
- The person may perceive advance care planning to be focused on death and dying, rather than preferences and preferred health outcomes.
- The person may not want to talk about being seriously unwell or death.
- It is seen as a 'taboo' topic for some people.
- The person may be in denial about their illness, health status, or a possible loss of capacity.
- The person may not want to discuss advance care planning because of cultural or religious reasons.
- There may be many other things happening at the time (e.g. admission into residential aged care, medical issues).
- The person may not know how to raise the topic with their healthcare professional, aged care worker, GP or family.

Barriers to advance care planning discussions can be managed by giving the person useful resources and information about advance care planning such as culturally appropriate information, and by initiating advance care planning conversations when a person is medically stable. Advance care planning conversations can be revisited on other occasions. Generally, multiple conversations are required for quality advance care planning to allow time for thinking and talking about values and preferences.

## **Diverse populations**

Australia has a large population with different needs, religions, beliefs and health. These differences may influence the way advance care planning conversations take place, the way individuals communicate, or the specific preferences and values of the person producing the advance care plan. Because of this, the advance care planning process may include additional steps to those listed above for people with diverse backgrounds.

## Culturally and linguistically diverse people

With over 300 languages spoken at home, over 100 religions, and nearly 200 countries of origin represented, Australia has a rich cultural diversity. These diverse backgrounds bring with them diverse values, some of which may affect an individual's willingness to engage in advance care planning conversations.

Historically, advance care planning has been built on the fundamentals of self-determination and patient autonomy. These principles may conflict with other traditional values such as familial decision-making and non-disclosure present in some cultures. However, these differences in decision-making fundamentals do not prevent people of all cultural backgrounds from engaging in advance care planning.

Adopting an approach of 'cultural humility' may work best in introducing advance care planning. Adopting cultural humility includes:

- avoiding making cultural assumptions
- asking the person how they would like decisions made if they are unable to do so themselves
- asking the person who they would want to be involved in making such decisions.

By avoiding assumptions, the staff member can approach advance care planning conversations openly and respectfully. People may prefer not to document an Advance Care Directive; however, these conversations are valuable in their own right.

A person's preferred language is another factor to consider when facilitating advance care planning conversations. This may include:

- using interpreters when appropriate in advance care planning conversations
- providing resources and information in languages other than English as required.

## Aboriginal and Torres Strait Islander people

Aboriginal and/or Torres Strait Islander people may not engage in discussions about future medical care and advance care planning. Some may consider discussions about becoming sick or injured, or what will happen towards the end of their life, as 'family business' that is not to be discussed with others. Some Aboriginal and Torres Strait Islanders may not feel comfortable producing 'official paperwork' or filling out forms. As such, there are important considerations when engaging in advance care planning discussions with Indigenous people.

- When introducing advance care planning to an Aboriginal and/or Torres Strait Islander person, allow adequate time to provide an appropriate and clear explanation of the benefits to the individual, the family and community.
- Many Aboriginal and/or Torres Strait Islander people have a strong connection to country. They may be distressed if they need to move into care away from their community. Documenting their wish to stay on country may be an important aspect of their Advance Care Directive.
- Family harmony may be a strong driving force for deciding whether to engage in advance care planning. Family dynamics might mean the person wants to include specific individuals in the advance care planning process, or that they do not wish to engage in advance care

planning at all because it may create problems within the family.

- There will be variation in people's knowledge of and willingness to engage in advance care planning, as there is in any population. At all times, avoid making assumptions based on cultural background.

### **Lesbian, gay, bisexual, transgender, intersex, and queer (LGBTIQ+) people**

People identifying as LGBTIQ+ may have special needs that should be considered when discussing advance care planning. Depending on their circumstances, they may not be in close contact with their family, may have no children, or may have children who do not respect their life decisions or acknowledge their partner. These issues can all impact on their willingness to engage in advance care planning. However, their partner or the person they want to make medical decisions on their behalf may not be recognised as their default substitute decision-maker according to relevant state and/or territory laws. As such, encouraging them to appoint a substitute decision-maker as well as documenting their treatment preferences may be helpful.

### **Living alone and without family**

People without family who live alone may experience social isolation and uncertainty about how they may be treated if they become ill or require medical care. Documenting treatment preferences in an Advance Care Directive and making a formal appointment of a substitute decision-maker may provide some reassurance to the person that their preferences will be followed. Some people may need help in determining who they want to act as their substitute decision-maker.

### **Living with dementia**

'Dementia' describes a collection of symptoms caused by disorders affecting the brain that result in a progressive decline in a person's functioning. The likelihood that an Advance Care Directive will be enacted at some point is much higher for individuals living with dementia or other forms of cognitive decline than for most others.

The progressive nature of dementia makes it essential to discuss future health and personal care needs as early as possible with the person and their family to ensure that their preferences will be known and respected.

Ideally, advance care planning conversations would have begun before the diagnosis of dementia. If this has not occurred, it is highly recommended that advance care planning conversations occur in the early stages of dementia when the person can still meaningfully participate in the conversations.

A person's capacity to make informed decisions becomes less likely as their symptoms of dementia progress. This progression may hinder their ability to participate in reviewing their Advance Care Directive. Advance care planning discussions should, therefore, cover a wide range of issues including end of life, preferences for health and personal care, lifestyle issues such as living arrangements, social engagement, financial planning and wills.

Having a diagnosis of dementia does not preclude someone from engaging in advance care planning. Capacity to complete an Advance Care Directive is presumed unless demonstrated otherwise. Even when a person lacks capacity, they should still be supported to be involved in medical decision-making to the best of their abilities.

## Living with an intellectual disability

People living with intellectual disabilities often have opinions about the extent and nature of the care they wish to receive if they become unwell. These people should be supported to participate in decision-making to the best of their abilities. However, the extent to which they can take part in these activities will depend on the degree of their disability. The extent of their intellectual impairment will also determine their ability to produce an Advance Care Directive or advance care plan.

Research shows that people living with intellectual disability have twice as many health problems as the general population. There is also evidence that when health professionals and relatives doubt whether the person can understand information related to their health care, they might withhold potentially upsetting information from the person. Withholding information from a person impacts their ability to make informed decisions about their health care and restricts their ability to participate in advance care planning discussions. However, most individuals with mild or moderate intellectual disability want to be involved in their medical decision-making and should be given that opportunity.

## Mental health

People living with long-term mental health conditions are at higher risk of developing physical health conditions than the general population. Living with a mental illness does not preclude someone from participating in advance care planning.

A key consideration for people living with mental illness is capacity:

- They do not necessarily lack capacity because they live with mental illness.
- Capacity is presumed, so unless demonstrated otherwise, it is assumed that the person has the capacity to take part in advance care planning.
- Capacity may fluctuate. If someone has previously been demonstrated to lack capacity, it does not mean they currently lack capacity.

It is important to involve people living with mental health conditions in all decisions about their assessment, treatment, and recovery, to the best of their ability. A key part of this process is to support them to make or participate in those decisions, and to respect their views and preferences.

Ideally, advance care planning will occur early in their illness progression.

There are differences between the types of choices a person living with mental illness can make about their mental healthcare and other types of healthcare (e.g. surgery, end-of-life care). The types of choices a person living with a mental illness can make will vary in different jurisdictions.

## A multidisciplinary approach

This section highlights the importance of a multidisciplinary approach to advance care planning and outlines the role of key practitioners within the health system.

Other healthcare professionals and services can support aged care providers when working with older people to engage in advance care planning. They should be considered part of a multidisciplinary approach to the process.

### General practitioners

General practitioners often have long term and trusted relationships with their patients. A person's GP is most likely to have a record of the person's health history, be able to discuss the prognosis of medical conditions with them and provide advice on any future treatment considerations. As such, they are essential to include in the advance care planning process.

Steps to consider:

- If the person has an Advance Care Directive, make sure their nominated GP has a copy of the most recent version of the plan.
- If the person has an Advance Care Directive but their condition appears to have deteriorated since it was made, you could recommend to the person and/or their family that they ask their GP whether their plan needs to be updated.
- If the person does not have an Advance Care Directive, talk first with them about the concept. If they wish to consider advance care planning further, take steps to help them connect with their nominated GP to discuss advance care planning. This might include making written contact with their GP on their behalf to advise them that their patient is seeking to develop an Advance Care Directive, and asking that they discuss the medical considerations of advance care planning with their patient at their next appointment.

### Health services

Health services include hospitals (public and private), primary healthcare organisations, community and aged care providers, specialist services, ambulance services and palliative care services. One or more of these services may have developed, stored, or enacted a person's Advance Care Directive. Consider how to share an Advance Care Directive amongst relevant health services to help ensure the person receives treatment in line with their preferences and preferred health outcomes. Steps to consider:

- Contact health services (in particular, hospitals and the ambulance service) and ask how to transfer advance care planning information to them. Health services will often have their own local advance care planning policy and processes. As an aged care provider, familiarise yourself with the processes of local health services, and provide advance care planning documents efficiently and securely as needed.
- Consider contacting additional services regularly involved with your clients to determine whether and how to provide them with Advance Care Directives.

- When an Advance Care Directive is updated, make sure the updated document is provided to all relevant external health services to ensure that they have the most recent document. It may help to keep a record of all relevant parties that require a copy of the document in the client's file.

## **Palliative care and palliative care services**

Specialist palliative care services are provided by hospitals as well as community-based palliative care services. Their range of services and resources may vary between and within states and territories. Ideally, advance care planning will have taken place before the person is referred to palliative care.

Steps to consider:

- Become familiar with hospital and community palliative care service providers operating in your region and establish a relationship with them to understand the services they provide. This might include direct support or consultancy about advance care planning discussions.
- Staff should understand referral processes and how to share an Advance Care Directive with palliative care services efficiently, in the event they start providing palliative care to one of your residents or clients.
- Some aged care organisations employ specialist palliative care nurse practitioners to provide palliative care support to their community and residential care clients. If this role exists within your organisation, determine the necessary steps to work effectively as a team to support the implementation of the person's values, preferences and wishes for end-of-life care. This could include tailoring documentation and communication procedures related to initiating, reviewing and enacting Advance Care Directives.

## **Aged Care Assessment Team and Aged Care Assessment Service**

Aged Care Assessment Teams (ACAT) and, in Victoria, the Aged Care Assessment Service (ACAS) are assessment services that determine a person's need for access to Commonwealth-funded aged care programs or the entry-level Commonwealth Home Support Program. They do not provide ongoing support in the care of older people.

Ideally, the advance care planning process is facilitated by those closely involved with the person's care. ACAT/ACAS would recommend that the person and their family discuss advance care planning with their GP and/or other ongoing service providers where appropriate.

If ACAT/ACAS has recently completed a comprehensive assessment of the person, it is worthwhile referring to this information to gain additional insight into the person's goals, values and wishes to assist with advance care planning discussions.

## Advance care planning: Step-by-step

This section outlines the advance care planning process. It gives information and practical tips on developing, documenting, reviewing and enacting Advance Care Directives.

The key components of advance care planning are:

1. Having a conversation about the person's values, beliefs, goals and how these influence preferences for care. This conversation may include specific care and treatment preferences, including preferences not to receive certain types of care or treatment, and what they consider acceptable and unacceptable health outcomes.
2. Selecting, preparing, and appointing a substitute decision-maker.
3. Documenting the person's preferences in an Advance Care Directive.
4. For those with diminished or no decision-making capacity, having the substitute decision-maker document the person's preferences in an advance care plan.
5. Regularly reviewing and updating an Advance Care Directive or advance care plan.
6. Sharing the Advance Care Directive or advance care plan with all relevant parties and making sure any updated documents are effectively communicated to these parties if and when these documents are revised.
7. Activating an Advance Care Directive if the person loses decision-making capacity and aligning medical treatment decision with their preferences.

The extent to which the person can be involved in the advance care planning process will be determined by a range of issues, particularly their cognitive capacity, diagnosis and stage of disease progression.

While the capacity to make decisions is assumed unless an assessment indicates otherwise, many residents of aged care facilities have some degree of cognitive impairment. People who are competent to make decisions can be fully involved in advance care planning if they choose to be. A person who does not have the capacity to make decisions should be involved to the best of their abilities, along with their potential substitute decision-maker and healthcare team.

## Advance care planning process

### Develop and document

WHO IS INVOLVED?	WHEN SHOULD IT HAPPEN?	HOW DO YOU DO IT?
<ul style="list-style-type: none"><li>• The person</li><li>• The substitute decision-maker</li><li>• Person's family and/or loved ones</li><li>• Clinicians involved in care</li></ul>	<ul style="list-style-type: none"><li>• When the person has decision-making capacity</li><li>• When the person has had time to adjust to changes in condition or prognosis</li></ul>	<ul style="list-style-type: none"><li>• Initiate the advance care planning conversation</li><li>• Reflect and discuss the plan</li><li>• Record and document preferences</li></ul>

### How you do it – initiate the conversation

- introduce the topic
- help the person think about what their preferences are
- talk about their values, explore goals, and include any cultural or religious values
- explore the person's experience of healthcare decision-making
- explore their understanding of their medical conditions and prognosis
- use leading questions to initiate the conversation

### Example conversation starters and leading questions:

- 'Would you like to talk about what to expect or what to prepare for as your illness worsens?'
- 'Have you ever thought about your preferences regarding future medical care?'
- 'What things are important for you to be able to enjoy your life?'
- 'When you look at the future, what do you hope for?'
- 'Is there anything that you worry might happen if you were very ill?'
- 'Do you have spiritual or cultural beliefs that you would like the healthcare team to know about, and that might influence the type of care you wish to receive?'
- 'Do you have any thoughts about how you would like to be cared for if you became very sick?'
- 'If you cannot, or choose not to, participate in healthcare decisions, how would you want decisions regarding your medical treatment to be made?'
- 'What have you been told about your health/illness?'
- 'What do you understand about your health/illness?'

- ‘Do you feel you have a good understanding of your illness and what treatment is appropriate?’
- ‘What further information do you need about your health/illness?’
- ‘How are you going since you were discharged from hospital?’

### How you do it – reflect and discuss the plan

- clarify the person’s concerns and expectations related to their health and care needs
- discuss their understanding of their condition and possible care or treatments
- clarify their understanding of their health goals, preferences, and values
- be clear about the purpose of advance care planning
- provide written information for the person and others present to take away
- describe the important outcomes of advance care planning, including:
  - the appointment of a substitute decision-maker
  - documentation of values and preferences
  - describe the role of the substitute decision-maker and how to identify and appoint one
  - if a substitute decision-maker has already been identified, involve them in all advance care planning conversations
- check with the person about their understanding of advance care planning and a substitute decision-maker’s role
- summarise and suggest documenting preferences, making sure to address the following:
  - explain that the Advance Care Directive they produce belongs to them and that they will keep the original document
  - encourage them to provide a copy of their Advance Care Directive to their substitute decision-maker once it is documented
  - encourage the person to also provide a copy of their Advance Care Directive to other loved ones, their GP, other treating clinicians and their local hospital
- let the person know that their Advance Care Directive will be kept in their health record or My Health Record and how it will be used
- ensure the person knows they can change and add to their Advance Care Directive at any time and let them know how to do so.

### Example conversation starters and leading questions:

- ‘What concerns you about your illness?’
- ‘What would be most important to you if you were very ill?’
- ‘Is there a point during your illness where you would consider stopping treatments and changing the focus of your care to focus on your comfort rather than the management or

cure of your illness? If so, when would this occur?’

- ‘Are there any specific treatments that you would definitely not want to receive?’
- ‘If you were to become unwell (or unwell again) would you want your treatment to be different? For example, would you want to go to hospital?’
- ‘What health goals do you have now and in the future?’
- ‘How do you think your current and future health will affect your chance of achieving your health goals?’
- ‘It is important to let your loved ones know about your preferences for the future. This includes letting them know who you have chosen as your substitute decision-maker and that you have documented your advance care plan. Is this something you are comfortable doing?’
- the appointment of a substitute decision-maker
- documentation of values and preferences.
- ‘Is there a specific person that you would like doctors to speak to about your medical care?’
- ‘Does this person know that you have chosen them for the role?’
- ‘Does the person you have chosen know what your preferences for future care are?’

### How you do it – record and document preferences

- use plain language when documenting
- if possible, document the conversation with the person present and use their own words
- document the person’s values, preferred outcomes, and medical treatment preferences
- ideally, document the reasoning behind decisions to provide context for future decision-making
- identify a substitute decision-maker in the documentation
- if the person chooses to, use the relevant legislated forms to document their preferences
- give the original advance care planning documents to the person
- with the person’s consent, provide a copy of the Advance Care Directive to the substitute decision-maker or ask the person to give their substitute decision-maker a copy
- place an Advance Care Directive alert in the person’s physical and/or electronic resident/client health record
- with the person’s consent, ensure that other treating clinicians, GP, residential aged care facility and other relevant family members are provided with copies of the Advance Care Directive.

## Review the Advance Care Directive

WHO IS INVOLVED?	WHEN SHOULD IT HAPPEN?	HOW DO YOU DO IT?
<ul style="list-style-type: none"><li>• The person</li><li>• The substitute decision-maker</li><li>• Person's family and/or loved ones</li><li>• Clinicians involved in care</li></ul>	<ul style="list-style-type: none"><li>• Whenever a person decides to refine their goals for care</li><li>• When there is a change in a person's condition</li><li>• When hospitalisation occurs</li><li>• When experiencing an unstable phase of illness</li></ul>	<ul style="list-style-type: none"><li>• Clarify the reason for the document review</li><li>• Use the existing plan to guide discussions</li><li>• Identify and address any gaps in knowledge or understanding</li><li>• Document and date any change</li><li>• Circulate the revised document to all relevant parties with instructions to void the previous version</li></ul>

### How you do it

- clarify what prompted the review
- use the existing Advance Care Directive to guide discussions
- ask the person about any changes to their health since the advance care plan was originally created and whether this will change anything in their Advance Care Directive
- identify gaps in the person's understanding of their current health status and provide relevant information to address these gaps
- if the person wishes to, help them revise their Advance Care Directive and confirm the changes with them, making sure any changes are clearly dated
- give the person their revised advance care planning document and, with their consent, help them to provide copies of the revised advance care planning document to their substitute decision-maker, loved ones, treating team and other relevant services with instructions to void previous versions. If this is not possible, ask them to provide copies to their substitute decision-maker and other relevant parties
- update the advance care planning alerts and documents in their resident/client health record, whether physical or electronic.

## Activate the Advance Care Directive

WHO IS INVOLVED?	WHEN SHOULD IT HAPPEN?	HOW DO YOU DO IT?
<ul style="list-style-type: none"><li>• All internal and external clinicians and carers linked to the person's care</li><li>• The person's substitute decision-maker</li><li>• The person's family and/or loved ones</li></ul>	<ul style="list-style-type: none"><li>• When a person can't be involved directly in decision-making about care or treatment because of a lack of capacity or inability to communicate</li></ul>	<ul style="list-style-type: none"><li>• Locate the Advance Care Directive or plan if one exists</li><li>• Identify and contact the substitute decision-maker</li><li>• Discuss and interpret the Advance Care Directive or plan with the substitute decision-maker</li></ul>

### How you do it

- access the person's health record and locate their Advance Care Directive in a timely manner
- check to see if an Advance Care Directive (legally binding) or advance care plan (not legally binding but informs care) exists elsewhere (copies may be with their GP, local hospital and/or other care facilities, eHealth records, or with their substitute decision-maker or loved ones)
- look for an Advance Care Directive across multiple formats. It could exist as a statutory form or structured, signed and dated form
- identify and contact the substitute decision-maker to inform them that the Advance Care Directive is being activated, and the reasons why it is being activated at this time
- involve the person as much as possible in conversations and decision-making processes even if they do not have the legal capacity to make specific decisions
- interpret and include the person's expressed values and preferences in their clinical care and medical treatment plan
- the medical practitioner should decide what medical treatment is to be offered based on the person's expressed values and preferences
- in the case that a person does not have a substitute decision-maker and the Advance Care Directive is clear and unambiguous, the medical practitioner is required to make and document a decision consistent with the Advance Care Directive
- follow instructional Advance Care Directives, dependent on legislation

## Resources and support materials

### General ACPA resources

- Advance Care Planning Australia website: [www.advancecareplanning.org.au](http://www.advancecareplanning.org.au)
- National Advance Care Planning Support Service™: 1300 208 582, 9am–5pm, Mon–Fri (AEST)
- End of Life Directions for Aged Care (ELDAC): [www.eldac.com.au](http://www.eldac.com.au)

### Quality Standards

- Aged Care Quality Standards:
  - [agedcarequality.gov.au/providers/standards](http://agedcarequality.gov.au/providers/standards)
  - [safetyandquality.gov.au/publications-and-resources](http://safetyandquality.gov.au/publications-and-resources)
- Charter of Aged Care Rights: [agedcarequality.gov.au/consumer/consumer-rights](http://agedcarequality.gov.au/consumer/consumer-rights)
- National Safety and Quality Health Service Standards – Multi-purpose service aged care module: [safetyandquality.gov.au/standards/nsqhs-standards](http://safetyandquality.gov.au/standards/nsqhs-standards)

### Legal resources and forms

- Advance Care Planning Australia legal hub – create your plan
- Advance Care Planning Australia Learning e-learning Module – Advance care planning decision-making – the legal implications: [learning.advancecareplanning.org.au](http://learning.advancecareplanning.org.au)

State or territory	Authority	Phone	Website
Australian Capital Territory	Public Trustee and Guardian	(02) 6207 9800	<a href="http://health.act.gov.au/public-information/consumers/advance-care-planning">health.act.gov.au/public-information/consumers/advance-care-planning</a>
New South Wales	Public Guardian	(02) 8688 6070	<a href="http://health.nsw.gov.au/patients/acp/Pages/default.aspx">health.nsw.gov.au/patients/acp/Pages/default.aspx</a>
Northern Territory	Office of the Public Guardian	1800 810 979	<a href="http://nt.gov.au/law/rights/advance-personal-plan">nt.gov.au/law/rights/advance-personal-plan</a>
Queensland	Office of the Public Guardian	1300 653 187	<a href="http://qld.gov.au/health/support/end-of-life/advance-care-planning">qld.gov.au/health/support/end-of-life/advance-care-planning</a>
South Australia	Office of the Public Advocate	(08) 8342 8200 Country SA: 1800 066 969	<a href="https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/conditions/end+of+life+care/advance+care+directive">https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/conditions/end+of+life+care/advance+care+directive</a>
Tasmania	Office of the Public	(03) 6165 3444	<a href="https://www.health.tas.gov.au/health-topics/palliative-care/about-palliative-">https://www.health.tas.gov.au/health-topics/palliative-care/about-palliative-</a>

	Guardian		<a href="#">care/planning-and-decisions-about-end-life</a>
Victoria	Office of the Public Advocate	1300 309 337	<a href="https://www.health.vic.gov.au/patient-care/advance-care-planning-forms">https://www.health.vic.gov.au/patient-care/advance-care-planning-forms</a>
Western Australia	Office of the Public Advocate	1300 858 455	<a href="https://healthywa.wa.gov.au/Articles/A_E/Advance-care-planning">healthywa.wa.gov.au/Articles/A E/Advance-care-planning</a>

### Policy and implementation

- Advance Care Planning Australia: [Content and quality assessment of ACP policies in Australian health and residential aged care services](#)

### Staff education and support services

- Advance Care Planning Australia [eLearning](#)
- Advance Care Planning Australia [YouTube channel](#)

### Communication skills and conversation starters

- Advance Care Planning Australia [conversation starters](#)
- Palliative Care Australia has a [discussion starter kit](#)

## Glossary

Term	Definition
Advance Care Directive	<p>A written advance care planning document completed and signed by a competent adult (i.e. voluntarily, person-driven document). In Australia, Advance Care Directives are recognised either by specific legislation (statutory Advance Care Directive) or by common law (non-statutory Advance Care Directive). Advance Care Directives can record the person's preferences for future care, and/or record the appointment of a substitute decision-maker to make decisions about the person's health care.</p>
Non-statutory Advance Care Directive (Common Law Advance Care Directive)	<p>Common law (non-statutory) Advance Care Directive is a structured document that is completed and signed by a competent adult and that is not a legislated statutory document. This includes:</p> <ul style="list-style-type: none"> <li>▪ A document completed and signed by a competent person in a jurisdiction which does not have legislation authorising an Advance Care Directive regarding preferences for care (that is, New South Wales).</li> <li>▪ An instruction or directive completed and signed by a competent person, in a jurisdiction with advance care planning legislation, but where the document does not comply with the requirements set out in this legislation and is recognised instead by common law.</li> </ul>
Statutory Advance Care Directive	<p>A structured document that focuses on an individual's values and preferences for future health and medical treatment decisions, completed and signed by a competent person, using a statutory form and/or meets formalities within relevant legislation.</p>
Advance care plan	<p>Documents that capture an individual's beliefs, values and preferences in relation to future care decisions, but which do not meet the requirements for statutory or common law recognition due to the person's lack of competency, insufficient decision-making capacity or lack of formalities (such as inadequate person identification, signature and date).</p>
Advance care planning (ACP)	<p>Advance care planning is a process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known.</p>

Term	Definition
Advance care planning documentation	The collective term for documentation related to advance care planning completed by the person, a health professional and/or someone else. This includes Advance Care Directives, advance care plans, goals of care, statement of choices (competent or non-competent), and other informal advance care planning forms.
Advance care planning documents (ACP Documents)	A catch all term to include documents that results from advance care planning. This includes Advance Care Directives and advance care plans.
Advance Care Directive legislation	A catch all term to refer to jurisdictional legislation that promotes advance care planning and Advance Care Directives. Legislation, including, but not limited to Advance Care Directives, advance personal planning, guardianship and administration, and medical treatment decisions.
Aged care	<p>Aged care means care of one or more of the following types:</p> <ul style="list-style-type: none"> <li>▪ residential care</li> <li>▪ home care</li> <li>▪ flexible care.</li> </ul>
Aged care service	<p>The Australian Government subsidises approved aged care providers to deliver aged care services. Aged Care services include:</p> <ul style="list-style-type: none"> <li>▪ entry level support at home</li> <li>▪ a higher level of support for older Australians who are able to keep living at home with assistance</li> <li>▪ care options and accommodation for older Australians who are unable to live independently at home</li> </ul>
Capacity	<p>The ability to make a decision for oneself.</p> <p>Decision-making capacity can be assessed by trained professionals, and its assessment depends on the type and complexity of the decision to be made.</p> <p>Capacity assessment does not assess whether the decision is considered “good” or “bad” by others such as clinicians or family, but rather considers the person’s ability to make a decision and comprehend its implications.</p> <p>Generally, when a person has capacity to make a particular decision they can do all of the following:</p> <ul style="list-style-type: none"> <li>▪ understand and believe the facts involved in making the</li> </ul>

Term	Definition
	<p>decision</p> <ul style="list-style-type: none"> <li>▪ understand the main choices</li> <li>▪ weigh up the consequences of the choices</li> <li>▪ understand how the consequences affect them</li> <li>▪ make their decision freely and voluntarily</li> <li>▪ communicate their decision</li> </ul> <p>By default, people are assumed to have capacity, unless there is evidence to the contrary.</p>
Competency	<p>Competency is a legal term used to describe the mental ability required for an adult to perform a specific task. Competency is recognised in legislation and in common law as a requirement for completing a legal document that prescribes future actions and decisions, such as a will or an ACP Document.</p> <p>A person is deemed to be either competent or not competent - there are no shades of grey. Competency must be assumed unless there is evidence to suggest otherwise.</p>
Decision-making	
Contemporaneous decision-making	<p>A contemporaneous decision refers to a decision made in the present time. Individuals with competency and capacity may make contemporaneous decisions about their care and these may differ from those decisions recorded in an ACP Document. Contemporaneous decisions should be respected foremost.</p>
Shared decision-making	<p>A consultation process in which a clinician and a patient jointly participate in making a health decision, having discussed the options, and their benefits and harms, and having considered the patient's values, preferences and circumstances.</p>
Substitute decision-making	<p>Decisions made by a nominated decision maker on behalf of the individual is substitute decision-making. A substitute decision seeks to replicate the decision it is thought the person would have made.</p>
Supported decision-making	<p>Supported decision-making encompasses a range of processes to support individuals to understand and consider their options about health or social care. Ultimately, it is the individual that makes the decision.</p>
Medical order	<p>A medically-driven document (usually completed by a doctor) that outlines the plan of care in relation to emergency treatment or severe clinical deterioration. Medical orders may include 'not for resuscitation' orders and other treatment limitations, as well</p>

Term	Definition
	<p>as decisions regarding transfer to hospital. In some jurisdictions, medical orders are part of a state- or territory-based approach. Common names for medical orders include 'Resuscitation Plan' and 'Goals of Care'. Medical orders may or may not include reference to a person's known preferences.</p>
My Health Record	<p>The secure online summary of a consumer's health information, managed by the System Operator of the national My Health Record system (the Australian Digital Health Agency). Clinicians are able to share health clinical documents to a consumer's My Health Record, according to the consumer's access controls. These may include information on medical history and treatments, diagnoses, medicines and allergies.</p>
Policy (organisational)	<p>An organisational document that outlines the agreed-upon decision making processes related to the specific topic of the policy and describes the way that work in the organisation should be carried out.</p>
Substitute decision-maker	<p>Substitute decision-maker is a person appointed or identified by law to make substitute healthcare decision(s) on behalf of a person whose decision-making is impaired. A substitute decision-maker may be appointed by the person, appointed for (on behalf of) the person, or identified as the default decision-maker within legislation. Substitute decision-makers listed in Advance Care Directives are statutory appointments. Substitute decision-makers listed in advance care plans are not legally binding.</p>

Terminology consistent with the [National framework for advance care planning documents](#).

**Advance Care  
Planning Australia**  
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