

Advance care planning in aged care: A guide to support implementation in community and residential settings





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# Acknowledgement

This guide provides information to assist aged care providers, particularly managers and senior staff, in implementing advance care planning.

Aged care organisations can play a key role in supporting conversations, providing information, discussing health issues and treatment options, recording discussions, storing and sharing plans, and referring to existing Advance Care Plans to provide care consistent with a person's preferences.

This guide was developed by Advance Care Planning Australia (ACPA) and the National Ageing Research Institute as part of the Specialist Palliative Care and Advance Care Planning Advisory Services program, an Australian Government initiative.

The guide uses the findings from a literature review, a national survey of community and residential aged care providers, a consultation with community and residential aged care staff from four states, and consultations with older people, as well as existing resources produced by Advance Care Planning Australia.

Further information can be obtained from Advance Care Planning Australia on (03) 9496 5660 or email acpa@austin.org.au

The guide is available via the resource hub: advancecareplanning.org.au/resources

#### **Recommended citation**

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# Background

This section provides an overview of advance care planning, explains why it is important, explores the role of aged care in advance care planning and discusses legislation in Australian jurisdictions.

# What is advance care planning?

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 known so that they can guide decision-making at a future time when they cannot make or communicate their decisions.

Engaging in advance care planning helps people to determine their healthcare priorities, and thereby to align their health and care preferences with the actual care they receive.

Advance care planning is not a single event but an ongoing process, which should be revisited regularly. This is especially important when a person's health or social situation changes.

Key components of advance care planning are:

- having a conversation about the person's values, beliefs and goals and how these influence preferences for care – this may include specific care and treatment preferences
- selecting and appointing a substitute decision-maker
- documenting a person's preferences in an Advance Care Directive or Advance Care Plan
- regularly reviewing and updating the plan or directive.

# What is an Advance Care Plan?

Advance Care Plans state preferences about health and personal care and preferred outcomes.

An advance care planning discussion will often result in a written plan. The plan may be made by the person or by someone else on their behalf, depending on the person's capacity to make healthcare decisions. It will take into consideration the person's perspectives and values to guide decisions about care.

If an Advance Care Plan is made on behalf of an individual with impaired capacity, it is formulated with the substitute decision-maker and/or other people who know the person well, and aims to reflect what the person would document for themselves if they were able to do so.

# What is an Advance Care Directive?

An Advance Care Directive is a type of written Advance Care Plan recognised by common law or specific legislation that is completed and signed by a competent adult. It may record the person's values, and preferences for future care, and/or include the appointment of a substitute decision-maker to make decisions about health care and personal life management. An instructional directive is a specific type of Advance Care Directive, that outlines specific treatment they would or would not like to receive and under what conditions. Each state and territory has different forms and requirements for instructional directives, so it is important to familiarise yourself with your jurisdiction's legal requirements and documents.

# Other types of written plans

Documentation of advance care planning can also be informal. It can include:

- non-statutory forms
- personally written letters
- a written plan outlining a person's values, beliefs and specific goals for care
- letters or documents written by a professional outlining the person's preferences.

# What is a substitute decision-maker?

A substitute decision-maker is a person appointed or identified by law to make decisions on behalf of a person whose decision-making capacity is impaired. Substitute decision-makers have legal authority to make these decisions; the relevant legislation varies between jurisdictions (states and territories).

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

There are three categories of substitute decision-makers. They may be:

- 1. chosen by the person
- 2. assigned to the person by law in the absence of an appointed substitute decision-maker (default substitute decision-maker)
- 3. appointed for the person (e.g. a guardian appointed by a guardianship tribunal).

# The role of the substitute decision-maker

A substitute decision-maker is called upon to make medical treatment decisions on behalf of a person who is unable to communicate their wishes. The substitute decision-maker is expected to make the same decision they believe the person would have made. Their authority and limits on their authority are defined by relevant legislation in each state and territory, but generally a substitute decision-maker can consent to medical treatment on the person's behalf if they lose capacity. In some states, they can also legally refuse medical treatment if the person has made their preferences known.

The substitute decision-maker is not necessarily the patient's next of kin. There are three types of substitute decision-makers:

- 1. A substitute decision-maker chosen by the person. Depending on the state or territory, they may be called:
  - enduring guardian
  - medical enduring power of attorney
  - an agent
  - a decision-maker.
- 2. A substitute decision-maker assigned to the person by the law in the absence of an appointed substitute decision-maker (default substitute decision-maker). States have different legislations and hierarchies for appointing a substitute decision-maker, and may allow for more than one substitute decision-maker. They may be:
  - spouse or de facto spouse
  - unpaid carer
  - nearest relative or friend who has a close personal relationship with the person.
- 3. A substitute decision-maker appointed for the person (e.g. a guardian appointed by a guardianship tribunal)

There are differences between the way a default appointment of a substitute decision-maker is made in each state or territory. Check with your local Office of the Public Advocate/Guardian to find out more. Links are provided in the resource section to help you determine the hierarchy of appointed substitute decision-makers.

When legally appointing a substitute decision-maker, they should be:

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

# Benefits of advance care planning

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

Ideally, the process of advance care planning should begin in the community before the person requires community or residential aged care services. However, evidence suggests that the uptake of advance care planning in the community is low and that the majority of older people will not have an Advance Care Plan prior to receiving community or residential aged care.

#### Community aged care

Clients receiving community aged care services under the Community Home Support Programme and Home Care Packages are likely to have chronic conditions and be frail but may still have capacity to make decisions. Community aged care providers are in a better position than hospitals or residential aged care providers to commence advance care planning with clients, as community aged care clients are less likely to have cognitive impairment and are more likely to be in a stable condition.

The implementation pathway shown in Figure 1 (see page 10), is the same in community aged care settings, but the case manager plays an important role. There is evidence that initiation rates are similar whether case managers refer community aged care clients for external advance care planning services or conduct the planning themselves (after suitable training).

Working with health professionals such as general practitioners (GPs), community aged care workers can help people undertake advance care planning and complete an Advance Care Plan or Advance Care Directive.

#### **Residential aged care**

Residential aged care providers care for many older people as their health and function declines and as they are approaching the end of their life. Advance care planning does occur in residential aged care, although many people admitted to residential aged care have cognitive impairment and may have lost decision-making capacity, which limits their ability to develop an Advance Care Plan.

However, residential aged care providers play a key role in, for example:

- identifying if a resident has an Advance Care Plan or Advance Care Directive
- identifying the resident's substitute decision-maker
- talking with residents about their values and preferences, regardless of cognitive capacity, and involving their substitute decision-maker and others such as family in the conversations
- facilitating advance care planning with residents who have decision-making capacity
- enacting the Advance Care Plan or Advance Care Directive as the need arises
- ensuring timely sharing of information with other services and healthcare providers when capacity is lost and a care or medical decision is required or if transfer of care is required.

# Legislation: states and territories and interstate recognition

There is no national advance care planning legislation in Australia. Legislation about the appointment of substitute decision-makers and Advance Care Directives are determined by each jurisdiction. As such, there are various forms and other requirements for documenting Advance Care Plans and Directives and appointing substitute decision-makers in the different states and territories.

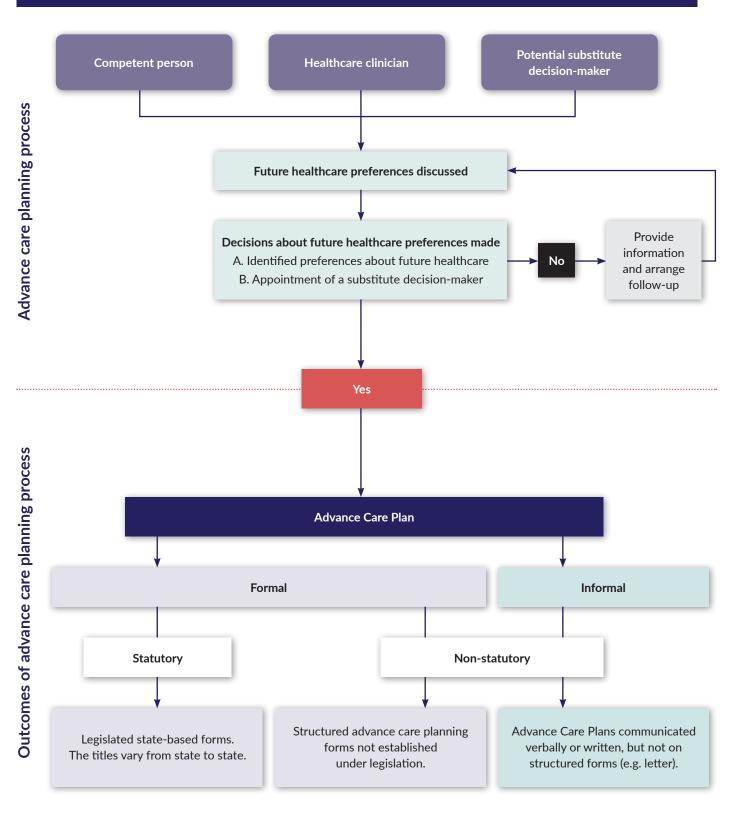
Some jurisdictions recognise interstate advance care planning and others do not. As a provider, it is important that you understand your state or territory's legislation, and are aware of the framework in other jurisdictions (see Table 1 on page 11).

#### Interstate recognition of Advance Care Directives - preferences for care

The Northern Territory (NT) and South Australia (SA) recognise interstate Advance Personal Plans and Advance Care Directives, respectively. NT currently recognises all other statutory documents, however the substitute decision-maker needs to work within the requirements of NT. SA currently recognises all interstate statutory documents and forms that are recognised under common law.

From March 2018, Victoria will recognise interstate advance care planning documents as Values Directives. The Western Australia (WA) State Administrative Tribunal can make an order to recognise interstate directives. Queensland recognises interstate directives if the provisions/ scope align with Queensland legislation. The Australian Capital Territory (ACT), New South Wales (NSW) and Tasmania do not recognise statutory documents from interstate and therefore these documents are recognised as common law documents that inform decision-making.

# Advance care planning implementation



**Figure 1:** Advance Care Planning Implementation Pathway. Source: Advance Care Planning Australia, 2017.

State or territory	Statutory preferences	Statutory decision- maker	Non-statutory documents	Other documentation		
Australian Capital Territory	Health Direction	Enduring Power of Attorney	<ul> <li>Advance Care Directive</li> <li>Advance Care Plan</li> <li>Statement of Choices</li> </ul>	<ul> <li>Resuscitation Plan</li> <li>Goals of Care Form</li> <li>Letters from the person</li> </ul>		
New South Wales	N/A	Enduring Guardian	<ul> <li>Advance Care Directive</li> <li>Advance Care Plan</li> <li>Statement of Values and Wishes</li> </ul>	<ul> <li>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</i> 1998 (NT) (if made before 17 March 2014)	Advance Personal Plan - Decision Maker	<ul> <li>Advance Care Directive</li> <li>Advance Care Plan</li> </ul>	<ul> <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> <li>Statement of Choices – persons with decision- making capacity</li> <li>Statement of Choices – persons without decision-making capacity</li> </ul>	<ul> <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 30 June 2014) Enduring Power of Guardianship (if made before 1 July 2014)	<ul> <li>Advance Care Plan</li> <li>Statement of Choices</li> </ul>	<ul> <li>Resuscitation Plan</li> <li>Letters from the person</li> <li>7 Step Pathway</li> </ul>		
Tasmania	N/A	Enduring Guardian	<ul> <li>Advance Care Directive</li> <li>Advance Care Plan</li> </ul>	<ul> <li>Resuscitation Plan</li> <li>Goals of Care Form</li> <li>Letters from the person</li> </ul>		

Table 1: A	Advance care pla	nning docum	entation a	nd terms	s in Aus	tralia (	conti	nued)	
<b>.</b>	<b>-</b>	<b>.</b>						- · ·	

State or territory	Statutory preferences	Statutory decision- maker	Non-statutory documents	Other documentation
Victoria	Advance CareDirective (thismay include aninstructionaldirective and/or avalues directive)Refusal ofTreatmentCertificate(Competent) ifmade before 12March 2018Refusal ofTreatmentCertificate (Non-Competent) if madebefore 12 March2018	Medical Treatment Decision Maker. Enduring Power of Attorney (Medical Treatment) or attorney (health care decisions) if made before 12 March 2018	<ul> <li>Advance Care Plan</li> <li>Statement of Choices</li> </ul>	<ul> <li>Resuscitation Plan</li> <li>Goals of Care Form</li> <li>Letters from the person</li> </ul>
Western Australia	Advance Health Directive	Enduring Guardian	<ul> <li>Advance Care Directive</li> <li>Advance Care Plan</li> <li>Statement of Choices</li> </ul>	<ul> <li>Resuscitation Plan</li> <li>Goals of Care Form</li> <li>Letters from the person</li> </ul>

# Non-statutory Advance Care Plans

A non-statutory Advance Care Plan is a written document outlining a person's values, goals and preferences for care, made by a person with decision-making capacity. There are no formal requirements for non-statutory Advance Care Plans.

Written Advance Care Plans can include personally written letters, or other types of written documents outlining a person's values, beliefs and specific goals for care.

# **Clinical care plans**

Clinical care plans or medical orders are documents completed by a doctor that outline the plan of care for emergency treatment of severe clinical deterioration. Such plans may include not for resuscitation (NFR) orders, and other treatment limitations. They may also include decisions about transfer to hospital.

In some jurisdictions, medical orders are part of a state-based approach or policy. They include 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.

# Witnessing of documents

Statutory Advance Care Directives and substitute decision-maker appointments have specific witnessing requirements. They vary between jurisdictions.

Although there is no requirement for a non-statutory Advance Care Plan to be documented, signed and witnessed, having a signed, witnessed and dated document will strengthen its validity as a true representation of a person's preferences.

# Legislation: practical considerations

At intake or admission, community and aged care staff should determine whether the person has an Advance Care Plan or Advance Care Directive and under which jurisdiction it was completed. This includes documents outlining preferences for care as well as legally appointed substitute decision-makers.

Community and aged care organisations must have knowledge of the legislation in their state or territory.

The Advance Care Planning Australia website provides useful information specific to each state or territory, including the legal implications, requirements and forms (advancecareplanning. org.au/resources/advance-care-planning-in-my-state). Further information can be obtained from the relevant state or territory government.

- Advance Care Planning advisory service: 1300 208 582, 9am-5pm, M-F (AEST)
- Advance Care Planning Australia website: advancecareplanning.org.au
- Advance Care Planning documents relevant to each state/territory: advancecareplanning.org.au/resources/advance-care-planning-in-my-state
- Advance Care Planning Australia legal factsheets for providers and consumers: advancecareplanning.org.au/resources
- Advance Care Planning Australia Learning e-learning Module Three: Advance care planning decision-making the legal implications: learning.advancecareplanning.org.au
- Office of the Public Advocate or equivalent in each state or territory:
  - ACT (Public Trustee and Guardian): (02) 6207 9800
  - NSW (Public Guardian): (02) 8688 6070
  - NT (Office of the Public Guardian): 1800 810 979
  - Queensland (Office of the Public Advocate): (07) 3224 7424
  - SA (Office of the Public Advocate): (08) 8342 8200; Country SA: 1800 066 969
  - Tasmania (Office of the Public Guardian): (03) 6165 3444
  - Victoria (Office of the Public Advocate): 1300 309 337
  - WA (Office of the Public Advocate): 1300 858 455
- State or territory government websites:
  - ACT: health.act.gov.au/public-information/consumers/advance-care-planning
  - NSW: health.nsw.gov.au/patients/acp/Pages/default.aspx
  - **NT:** nt.gov.au/law/rights/advance-personal-plan
  - **Queensland:** qld.gov.au/law/legal-mediation-and-justice-of-the-peace/power-of-attorneyand-making-decisions-for-others/advance-health-directive
  - SA: sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/ health+topics/health+conditions+prevention+and+treatment/end+of+life/ advance+care+directive
  - **Tasmania:** dhhs.tas.gov.au/palliativecare/advance\_care\_planning\_for\_healthy\_dying
  - **Victoria:** health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/ advance-care-planning
  - WA: healthywa.wa.gov.au/Articles/A\_E/Advance-care-planning

# **Systems and governance**

# This section explains how to support advance care planning implementation within your organisation.

Robust systems and governance will support your staff to implement advance care planning in the context of person-centred practice. Embedding advance care planning into your organisation's everyday practice will improve access to quality advance care planning. This includes:

- developing policies and procedures
- identifying leaders or champions within each of your teams/sites
- embedding the process into existing models of care, including admission and assessment processes
- linking to quality improvement processes
- building the capability of staff.

Establishing, communicating and reviewing systems and governance processes can help your organisation meet its accreditation obligations and legislative requirements.

# How to incorporate advance care planning into governance

Identify and appoint advance care planning leaders or champions and establish reporting structures within the organisation. Develop an organisation-wide work plan for implementing and monitoring advance care planning, including:

- reviewing or developing policies and procedures that are endorsed and communicated by management and clinical leaders
- integrating advance care planning reporting into existing reporting arrangements such as management meetings, board meetings, quality of care committee meetings, mortality audits, staff meetings, care coordination and family conferences
- aligning with existing clinical/care protocols such as palliative care guidelines
- implementing systems to monitor and measure activity to facilitate continuous improvement and demonstrate adherence to existing quality processes and accreditation standards.

# **Policies and procedures**

Develop an organisation-wide, evidence-based advance care planning policy that is available to all staff.

#### **Background context**

Explain the context for the policy, including:

- the Australian definition of advance care planning per the Australian Commission of Quality and Safety in Health Care (2017) is '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'.
- an overview of the legislation that relates to advance care planning in your state or territory.
- the benefits and evidence for implementing advance care planning.
- links with the residential standards (1.1–1.3; 1.6–1.8; 2.1–2.4; 3.1–3.9) and home care standards (2.2–2.4).
- organisational resources and other resources for staff such as the ACPA website and advisory service.
- policy on how and by whom external assistance is sought and utilised should be developed by services.

- The Australian Commission of Quality and Safety in Health Care. The National Consensus Statement: Essential elements for safe and high-quality end-of-life care (cited 2017 [accessed Nov 2016]).
- Australian Aged Care Quality Agency Accreditation Standards Fact Sheet: aacqa.gov.au/providers/residential-aged-care/resources/brocah0011accreditationstandardsfa ctsheetenglishv14.1.pdf
- Australian Aged Care Quality Agency Home Care Common Standards Fact Sheet: aacqa.gov.au/providers/home-care/processes-and-resources/resources-specifically-forhome-care/fact-sheets/homecarecommonstandardsv14\_0.pdf
- Australian Aged Care Quality Agency Quality review guidelines: aacqa.gov.au/publications/ publications-providers-and-surveyors/QualityReviewguidelines.pdf
- Advance Care Planning Australia: advancecareplanning.org.au

## The role and responsibility of team members

Embed advance care planning into recruitment strategies and processes. This can be achieved by including it in relevant job descriptions, interview questions and performance reviews.

- Emphasise that it is a job requirement to support each person's values, goals and preferences. Prompt staff to consider what strategies they would employ to ensure they do not impose their own values onto the process.
- Outline the role of each team member in advance care planning, including:
  - executive, clinical leaders, management, nursing staff, allied health, care coordinators, case managers, support workers, administration staff and GPs
  - after-hours nursing staff and locum GPs.
- Emphasise the nature of team work and create a shared understanding of everyone's role in the process.
- Embed advance care planning into routine care and make it the shared responsibility of all staff.

### Building the capability of staff

Education builds the competence and confidence of staff to initiate and revisit the process of advance care planning. Include a statement on how the organisation will support staff to access education and training on advance care planning.

Inhouse education sessions can be tailored to your organisation's policies and procedures. They can include:

- the evidence for implementing advance care planning
- relevant legislation
- how advance care planning sits with other organisational processes such as not-forresuscitation (NFR) orders, goals of care, Wills and financial powers of attorney
- the correct forms which to use, who can complete them, how to complete them, and who can sign them
- processes for storing, retrieving, communicating and transferring information.

Provide effective communication skills development. This can include training on how to:

- initiate advance care planning conversations
- revisit existing plans to ensure they continue to reflect the person's values and preferences
- respect diversity.

Develop a system to track who is attending education, evaluate progress and promote a competency framework. Types of education can include:

- inhouse workforce development sessions
- accessing external specialised face-to-face training programs
- specialised webinars
- specialised online training.

It is important to implement systems to identify and support clinical champions who model good practice. Consider using mentoring and supervision, team meetings, case conferences and observation of discussions to foster ongoing skill development within your broader team.

# System to alert, store, retrieve and progress advance care planning documentation

Accessibility is a key component of successful advance care planning. Organisational policy needs to include systems for consistently guiding staff to record, store and retrieve existing advance care planning documentation at the time of a person's admission to your service, discharge and/ or transfer to a health service or another aged care provider.

There will be differences in systems used by community aged care and residential aged care providers. For example, community aged care providers may need to store Advance Care Plans for clients on My Health Record.

Some community services encourage the person to keep their documentation in a colourful folder on the fridge or another easily identifiable place. Residential aged care services may also store the Advance Care Plan on the resident's file.

The following methods underpin alerting, storage and retrieval:

- Place an alert on the person's electronic or hard file to indicate they have an Advance Care Plan.
- Ensure all staff know how to obtain a copy of the Advance Care Plan.
- Ensure all staff including after-hours staff have access to the plans and the procedures should they need guidance on the person's wishes and preferences.
- Determine the best avenues for sharing documents with the person's family and carers and other health providers in your area. This can include:
  - supporting people to upload their Advance Care Plan onto My Health Record (particularly relevant for community aged care service providers)
  - talking with the person about where to safely store the plan in their home
  - sending the plan to the local hospital for filing on the person's medical record
  - sending the plan with the person on transfer to hospital
  - sending the plan to the person's GP practice.

- Initiate the process of advance care planning if the person does not have a documented Advance Care Plan at the time of admission. This could include a prompt to staff to:
  - briefly introduce the concept of advance care planning at admission
  - provide the option to engage in the conversation or bring up at a later time.
- Review existing Advance Care Plans. This could include:
  - creating an alert that reminds staff to consider updating or reviewing Advance Care Plans at appropriate time intervals
  - creating alerts to remind staff to revisit the plan with an individual if their health status changes, such as on discharge from hospital care; upon a new diagnosis, or worsening, of a life-limiting medical condition; during an over-75 medical assessment; if at risk of losing capacity; if at risk of or experiencing social isolation.
- Activate an Advance Care Plan if a person loses capacity. Develop a clear guide for staff that outlines the process. This could include:
  - referring to the GP to assess for capacity
  - contacting the person's nominated substitute decision-maker
  - asking the GP to develop a clinical care plan in case of sudden deterioration.
- Source and store the required forms and consumer information brochures to give to the person and the family. This should include information in languages other than English.

# Quality improvement and audit processes

Embed reporting on advance care planning implementation into your organisation's systems and processes. Audits are a useful way to inform the quality improvement cycle and measure progress in a number of ways.

#### Governance

This includes auditing how advance care planning has been embedded into:

- organisational structure
- job descriptions and recruitment and performance development processes
- reporting in management, board and staff meetings
- usual models of care (e.g. prompts on care planning documentation, inclusion in case conferences, team meetings).

#### **Policies**

This includes:

- having an organisational policy
- tracking the number of people aware of and accessing the policy
- reviewing the policy.

#### **Building capability**

This includes auditing:

- the number and types of education sessions offered to staff and clients/residents and their families
- the number of staff and clients/residents accessing education
- evaluating people's confidence in and understanding of the process.

#### Systems and documentation

This includes auditing:

- whether the organisation has an alert system that is being used appropriately
- the number of people whose Advance Care Plan is valid, accessible, recognised and activated appropriately
- whether there is written evidence of advance care planning conversations; a record of advance care planning documents that have been completed correctly, signed and witnessed; and evidence of implementation
- mortality and morbidity reviews that monitor advance care planning processes and outcomes
- adherence to preferences (e.g. transfer to hospital that was not wanted).

- Australian Aged Care Quality Agency Accreditation Standards Fact Sheet: aacqa.gov.au/providers/residential-aged-care/resources/brocah0011accreditationstandardsfa ctsheetenglishv14.1.pdf
- Australian Aged Care Quality Agency Home Care Common Standards Fact Sheet: aacqa.gov.au/providers/home-care/processes-and-resources/resources-specifically-forhome-care/fact-sheets/homecarecommonstandardsv14\_0.pdf
- Australian Aged Care Quality Agency Quality review guidelines: aacqa.gov.au/publications/ publications-providers-and-surveyors/QualityReviewguidelines.pdf
- Advance Care Planning Australia Learning e-learning Module Four Advance care planning implementation: learning.advancecareplanning.org.au

# **Staff education and support**

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

# Why educate staff about advance care planning?

Educating staff will help to improve their knowledge and their confidence to have advance care planning conversations. This is likely to increase the quality and number of advance care planning conversations, improve documentation of the conversations and increase the likelihood that people's preferences will be followed.

It is important to consider the education needs of all levels of staff. Ensure that the education provided is suitable and takes into account different needs.

Some barriers to effective advance care planning implementation can include the fact that staff may:

- be unclear about their role in advance care planning
- be unsure about the legal implications of advance care planning
- not feel confident to introduce advance care planning conversations or discuss advance care planning
- not feel they have time to have advance care planning conversations
- feel they lack the skills required to document the outcome of conversations.

Educating and supporting staff will assist your organisation to effectively implement advance care planning.

# Information to include in staff education

#### What is advance care planning?

Advance care planning is an ongoing process that needs to be person-centred. It focuses on the person's goals, values, beliefs and health preferences, not on those of the staff, healthcare system or organisation.

It is important that staff have a good understanding of advance care planning and its principles. 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
- the principles of advance care planning
- 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.

#### Resources

- Advance Care Planning Australia webinar What is advance care planning?: advancecareplanning.org.au/education-and-training
- Advance Care Planning Australia Learning e-learning Module One Advance care planning introduction: learning.advancecareplanning.org.au
- Advance Care Planning Australia (this website has resources that can be included in an introductory workshop for health and care workers): advancecareplanning.org.au/for-healthand-care-workers
- Advance Care Planning Australia webinars and videos: advancecareplanning.org.au/educationand-training

#### How to have an advance care planning conversation

Conversations about advance care planning may occur over a period of time, and entail 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 is the appropriate time to initiate an advance care planning conversation
- providing an appropriate environment for the conversation
- acknowledging, validating and normalising the conversation
- providing information to support the person to have future conversations
- engaging in more detailed advance care planning conversations.

Education for staff therefore includes information on:

- when it is relevant to have an advance care planning conversation, noting that this may be different for each individual and in different settings
- how to identify the cues and triggers for initiating the conversation
- how to talk about advance care planning with the person and their family to ensure it is normalised, and presented in a non-threatening and optional manner
- resources that can be given to the person and their family to help them to become more prepared.

#### Resources

- Advance Care Planning Australia webinar: Advance care planning how to: advancecareplanning.org.au/education-and-training
- Advance Care Planning Australia Learning e-learning Module Two Advance care planning conversations: learning.advancecareplanning.org.au
- Dying to Talk has a discussion starter resource that helps people think about what is important to them; it is useful in having an advance care planning conversation: dyingtotalk.org.au
- Advance care planning: have the conversation. A strategy for Victorian health services 2014–2018 provides example phrases that can be used during the conversation: health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/advance-care-planning/acp-strategy
- Videos displaying examples of successful and unsuccessful advance care planning conversations are available on the Victorian Department of Health website: health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/advance-careplanning/acp-resources
- Advance Care Planning Australia webinars and videos: advancecareplanning.org.au/educationand-training

#### **Communication skills**

Effective communication is essential when having an advance care planning conversation, to ensure that advance care planning is normalised. Effective communication requires considering:

- the appropriateness of the environment
- body language
- spoken language
- active listening
- responding to emotional cues.

The type of communication style used will depend on:

- the person's disease progression
- how much advance care planning discussion has already taken place
- the person's cultural and language background
- the person's preferences for information, including how much they would like to know about their situation and likely future.

- Advance Care Planning Australia Learning e-learning Module Two Advance care planning conversations: learning.advancecareplanning.org.au
- Advance Care Planning Australia Learning e-learning Module Nine Advanced communication (due for release early 2018)

#### Advance care planning documentation

After having a conversation with someone about their preferences, it is important to effectively and accurately document them. This increases the likelihood of the person's preferences being known and respected.

The documentation used will depend on your state or territory. Provide staff with education and information about:

- the documentation that is used within your organisation this should include Advance Care Directives, Advance Care Plans (including those made on behalf on a non-competent person), and medically initiated clinical care plans
- what to do if a person is admitted into your organisation with an existing Advance Care Plan
- how to complete the documentation
- where the documentation should be stored
- how to access the documentation.

## Legislation related to advance care planning

Refer to the first section of this guide for more information. Advance care planning legislation varies throughout Australia. It is important to provide staff with education and information about the specific legal requirements for your state or territory, including the correct documentation.

- Advance Care Planning Australia legal factsheets for providers and consumers: advancecareplanning.org.au/resources
- Advance Care Planning Australia Learning e-learning Module Three Advance care planning decision-making the legal implications: learning.advancecareplanning.org.au
- Advance Care Planning Australia webinars and videos: advancecareplanning.org.au/educationand-training

# Advance care planning and dementia

The capacity of people living with dementia to make an Advance Care Plan will depend on their diagnosis and the progression of the condition.

Capacity is presumed and may fluctuate over time. Just because a person is living with a diagnosis of dementia or has previously been deemed to lack capacity, it does not mean that they do not currently have capacity. Ensure staff know what steps to follow if they consider a person may no longer have capacity to be actively involved in the advance care planning process. This may include referral to a GP for a capacity assessment.

Even if the person lacks capacity, it is important that they are given support to enable them to participate in advance care planning conversations as much as possible.

#### Resources

- Advance Care Planning Australia Learning e-learning Module Six Advance care planning and dementia: learning.advancecareplanning.org.au
- Dementia Australia provides general information about planning ahead: dementia.org.au

## Advance care planning, person-centred care and diversity

People come from diverse backgrounds and have a variety of beliefs and healthcare preferences.

Some populations may have special considerations. These include:

- people from culturally and linguistically diverse backgrounds
- Aboriginal and Torres Strait Islander people
- Lesbian, gay, bisexual, trans, and/or intersex (LGBTI) people
- people living alone, or who are socially isolated, and those with no family
- people living with a disability
- people experiencing mental health problems.

#### Resources

The following resources provide information and education on advance care planning for diverse populations:

- Advance Care Planning Australia webinar We're all different: advancecareplanning.org.au/ education-and-training
- Start2Talk provides general information about planning ahead, and includes information for multicultural and Aboriginal health workers: dementia.org.au/planning-ahead
- Advance Care Planning Australia Learning e-learning Module Eight Advance care planning and cultural diversity: learning.advancecareplanning.org.au
- My Aged Care resource LGBTI advance care planning: agedcare.health.gov.au/sites/g/files/ net1426/f/documents/06\_2017/lgbti\_-\_advance\_care\_plan\_factsheet\_-\_print\_version.pdf

- Advance Care Planning Australia Medical Director speaks about advance care planning in the LGBTI community in this radio episode: www.advancecareplanning.org.au/whats-on/ article/2018/01/18/preparing-for-ageing-in-the-lgbti-community
- Palliative Care Australia provides a discussion starter for Aboriginal and Torres Strait Islander people: dyingtotalk.org.au
- Taking control of your health journey is an introduction to advance care planning for Aboriginal and Torres Strait Islander people: advancecareplanning.org.au/docs/default-source/ acpa-resource-library/acpa-publications/taking-control-of-your-health-journey.pdf?sfvrsn=12
- Advance Care Planning Australia provides bilingual resources in a range of languages. These include resources for the individual, the substitute decision-maker and care workers: advancecareplanning.org.au/resources – see other languages
- ACPtalk provides information and discussion starters for having advance care planning conversations with people from various religious faiths and cultures: acptalk.com.au.

# Format of education

Education and support can be provided in a number of formats, including e-learning, webinars, seminars and workshops, inhouse learning and mentoring. Different formats may be suitable for different staff, depending on their level of experience and learning needs, and their availability to attend education sessions.

#### E-learning and online education programs

Advance Care Planning Australia has developed nine e-learning modules for aged care workers and health professionals on advance care planning.

#### Module One – Advance care planning introduction:

- defines advance care planning
- describes the components of advance care planning
- identifies the benefits of advance care planning
- describes how organisations can support advance care planning.
- Module Two Advance care planning conversations:
  - describes the roles in advance care planning discussions
  - outlines opportunities and barriers to discussing advance care planning
  - explains how to have a discussion about decision-making
  - discusses skills and strategies required for effective communication.
- Module Three Advance care planning decision-making the legal implications:
  - describes the legal process for developing Advance Care Plans
  - explains how to determine the substitute decision-maker.
- Module Four Advance care planning implementation:
  - discusses the elements required for successful implementation
  - describes strategies to assist implementation
  - explains how to understand your role in implementing advance care planning.

- Module Five Advance care planning in the primary care setting:
  - discusses advance care planning in the primary health care setting.
- Module Six Advance care planning and dementia:
  - provides an introduction to dementia in Australia
  - describes strategies to improve the uptake of advance care planning for people with dementia
  - describe specific communication strategies for advance care planning with people with dementia
  - describes various roles when discussing future care for people with dementia.
- Module Seven Aged care (available from early 2018)
- Module Eight Cultural diversity
  - Identify what comprises culture
  - Describe the role of cultural diversity in ethical reasoning
  - Describe strategies for sensitively introducing advance care planning concepts
  - Describe why stereotyping can be harmful
- Module Nine Advanced communication (available from early 2018).

These e-learning modules can be accessed from the Advance Care Planning Australia Learning learning.advancecareplanning.org.au

#### Seminars and workshops

Advance Care Planning Australia provides a range of workshops and seminars throughout Australia to all health professionals and care workers working in aged care (see advancecareplanning.org.au/education-and-training).

#### Webinars

Advance Care Planning Australia has developed a series of webinars to help aged care professionals understand the fundamentals of advance care planning. These webinars cover the following topics:

#### 1. What is Advance Care Planning?

- Learn about the principles of advance care planning.
- Discover how advance care planning can benefit your clients.
- Explore ways you can integrate advance care planning into care.

#### 2. Advance Care Planning - how to

- Understand how to recognise when an advance care planning discussion is relevant.
- Be able to talk about advance care planning in general terms with your clients.
- Know where to access further resources.
- 3. Grief, trauma and loss
  - Understand the impact of changing health on people and their families.
  - Assist people to cope with loss and provide referral to support services.

#### 4. We're all different

- Recognise that people have different beliefs and values.
- Learn conversational tools to discover the ways people differ.
- Gain information about different cultural perspectives.

#### 5. George wants resuscitation

- Appreciate that people have choices about the care they want.
- Learn to assist a person to make choices and to be comfortable with their decisions.

#### 6. Jane does not want to go to hospital

- Recognise that people may not all want the same level of care.
- Know where to refer people for assistance.
- Understand your role and responsibilities when assisting people with choices.

#### 7. Marjorie is breathless

- Learn about ways to make people more comfortable.
- Understand patient choices.
- Recognise other team members' roles.

#### 8. Do you think dad is dying?

- Learn to recognise when end-of-life care is needed.
- Learn to be able to assist and provide direction to support services.

#### 9. Advance Care Planning in Primary Care

- Enhance the knowledge, skills and confidence of the primary care workforce to promote, initiate and continue discussions regarding future health preferences in routine care.

#### 10. Advance care planning and the law

- Understand how the law supports advance care planning nationally

These webinar recordings can be accessed from Advance Care Planning Australia website: advancecareplanning.org.au/education-and-training

#### Inhouse learning

Team meetings, case conferences or supervision meetings can provide a platform to deliver advance care planning education and support to staff. If your organisation has a staff member experienced in advance care planning, they may be able to facilitate education sessions with other staff.

Group education with all staff can facilitate discussion about issues specific to your organisation. The resources listed earlier can be used during these inhouse learning sessions.

#### **Mentoring system**

A mentoring system – where senior or more experienced staff provide support and supervision to junior or less experienced staff on having advance care planning conversations – can provide ongoing professional development for staff. This mentoring may occur during team meetings, case conferences or supervision meetings. Junior or less-experienced staff can also observe their mentor having advance care planning conversations to assist in developing their skills.

## **Allocated time**

Create a regular time slot for advance care planning education within your organisation's education calendar. The frequency of advance care planning education will depend on your program, the length of each education session and the format that you use for education.

Incorporate advance care planning education and training into staff orientation programs.

# **Consumer engagement**

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

The advance care planning conversation should be 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 situation.

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. The advance care planning conversations should include the person, their substitute decision-maker, other family members and relevant healthcare or aged care workers.

# Education and support for the person and their family

There is wide variation in people's understanding and knowledge about advance care planning. Provide education, resources and support to people and their families to increase the uptake of advance care planning.

Provide information about:

- what advance care planning is
- the benefits of advance care planning
- what is involved in the process, including that it can be revisited and revised at any time
- what a substitute decision-maker is and their role
- 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 Plan, Advance Care Directive, statement of choices, advance health directive)
- who should have a copy of their plan and the best place to store the plan
- the circumstances that activate an Advance Care Plan
- what will happen if the plan is activated.

The information should be easy to understand, with clear and simple terms.

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

- on admission into the service/aged care facility
- at resident and family meetings
- if there is any change in the person's medical condition
- during GP visits
- during regular assessments
- with guest speakers, at information sessions for people and their families
- during National Advance Care Planning Week.

#### Resources

- Advance Care Planning Australia has developed a fact sheet explaining advance care planning: advancecareplanning.org.au/docs/default-source/acpa-resource-library/acpa-fact-sheets/ acp\_fact\_sheets\_for\_patients\_and\_familys\_version-4\_july17.pdf?sfvrsn=6
- Advance Care Planning Australia provides written and audio resources in a range of languages: advancecareplanning.org.au see 'Other Languages'
- The Advance Care Planning Advisory Service 1300 208 582 is open Monday to Friday, 9am to 5pm (AEST)
- National Advance Care Planning Week: advancecareplanning.org.au/acpweek

# Having the conversation

An advance care planning conversation can be held over a period of time and a number of sessions with the person.

The staff member should feel confident having the discussion and be able to normalise the topic. Ideally they should also have rapport with the person and feel comfortable answering any questions.

Try to choose a private, quiet space, to allow adequate time and give the conversation your full attention. If adequate time is not available, perhaps just start with an introduction. It is also important to consider a range of factors – such as cultural or religious background – that may influence how best to approach the topic.

# Barriers to having the conversation

There are some barriers that may affect a person engaging in advance care planning. These include:

- They do not understand the concept of advance care planning.
- They may perceive it to be focused on death and dying.
  - They may not want to talk about death.
  - It is seen as a 'taboo' topic for some people.
  - They may be in denial.
- The person may not want to discuss advance care planning due to 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.

These barriers can be managed by giving the person useful resources and information, such as culturally appropriate information, and by initiating the conversation when a person is medically stable. Conversation starters can be useful to help the person raise the topic with family.

# Developing an Advance Care Plan

It is valuable for people to write their preferences down. This will make it easier for the substitute decision-maker, healthcare professionals and aged care workers to ensure that the person's preferences are respected when needed.

You can help a person to develop an Advance Care Plan by following these five steps:

- **Step 1.** Prompt the person to think about their beliefs, values and preferences for current and future health and personal care.
- **Step 2.** Facilitate conversations about their beliefs, values and preferences for current and future health and personal care.
- **Step 3.** Assist them to choose and prepare an appropriate substitute decision-maker.
- **Step 4.** Assist them to write down their plan and share it with others.
- **Step 5.** Review their plan with them regularly or when there is a change in their health status.

More information and tips on each of these steps can be found on the Advance Care Planning Australia website – www.advancecareplanning.org.au/individuals/how-to-make-your-plan

#### Resources

- Advance Care Planning Australia has developed a number of fact sheets explaining advance care planning: advancecareplanning.org.au/docs/default-source/acpa-resource-library/acpafact-sheets/acp\_fact\_sheets\_for\_patients\_and\_familys\_version-4\_july17.pdf?sfvrsn=6 or advancecareplanning.org.au/resources
- Palliative Care Australia has a discussion starter kit to help people work out what's right for them: dyingtotalk.org.au/discussion-starter/

# **Diverse populations**

Australia has a large population with different needs, religions, beliefs and health. Some people may have requirements in addition to those listed above.

#### Culturally and linguistically diverse people

With over 300 languages spoken in homes, over 100 religions and nearly 200 countries of origin represented, Australia has a rich cultural diversity. With these diverse backgrounds come diverse values, some of which may affect an individual's propensity to engage in advance care planning conversations.

Traditionally, advance care planning is built on the fundamentals of truth telling and patient autonomy and this may conflict with traditional values of familial decision-making and nondisclosure expressed by some cultures. But people of all cultural backgrounds may engage in advance care planning. Adopting an approach of 'cultural humility' may work best in introducing advance care planning. This 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 involved in making such decisions.

Avoiding assumptions allows the staff member to approach the advance care planning conversation in the best way.

A person's preferred language is another factor to consider.

- Use interpreters when appropriate in advance care planning conversations
- Provide resources and information in languages other than English as required

#### Resources

- Advance Care Planning Australia has written and audio resources in a number of languages: advancecareplanning.org.au 'Other Languages'
- Advance Care Planning Australia Learning eLearning Module Eight engaging people from a culturally diverse background in advance care planning: learning.advancecareplanning.org.au

### Aboriginal and Torres Strait Islander people

Many Aboriginal and/or Torres Strait Islander people do 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. Also, they might not feel comfortable getting involved with official paperwork or filling out forms.

- 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 and 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 Plan.
- Family harmony may be a strong driving force for deciding whether to engage in advance care planning.

There will be variation in people's knowledge of and willingness to engage in advance care planning. Avoid making assumptions based on cultural background.

- Palliative Care Australia has a discussion starter for Aboriginal and Torres Strait Islanders: dyingtotalk.org.au/download/6994/
- Taking control of your health journey is an introduction to advance care planning for Aboriginal and Torres Strait Islander people: advancecareplanning.org.au/docs/default-source/ acpa-resource-library/acpa-publications/taking-control-of-your-health-journey.pdf?sfvrsn=12

## Lesbian, gay, bisexual, transgender and intersex (LGBTI) people

People identifying as LGBTI people may have special needs that should be considered when discussing advance care planning. 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 partner.

Their partner or the person they want to make medical decisions on their behalf may not be recognised as their substitute decision-maker. Thus, encourage appointing a substitute decision-maker as well as documenting their treatment preferences may be helpful.

#### Resources

- My Aged Care LGBTI advance care planning: agedcare.health.gov.au/sites/g/files/ net1426/f/documents/06\_2017/lgbti\_-\_advance\_care\_plan\_factsheet\_-\_print\_version.pdf
- Advance Care Planning Australia Medical Director speaks about advance care planning in the LGBTI community in this radio episode: advancecareplanning.org.au/whats-on/ article/2018/01/18/preparing-for-ageing-in-the-lgbti-community

#### 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 Plan and formal appointment of a substitute decision-maker may provide some reassurance that their preferences will be followed.

#### Resources

Advance Care Planning Australia has a number of fact sheets information explaining advance care planning: advancecareplanning.org.au/docs/default-source/acpa-resource-library/acpafact-sheets/acp\_fact\_sheets\_for\_patients\_and\_familys\_version-4\_july17.pdf?sfvrsn=6

## 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. For individuals living with dementia, or other forms of cognitive decline, the likelihood that an Advance Care Plan will be enacted is much higher.

Due to the progressive nature of dementia, discussing future health and personal care needs early with the person and their family is essential to ensure that their preferences will be known and respected.

Ideally, advance care planning conversations would have begun before the diagnosis of dementia. However, if that has not occurred, it is highly recommended that conversations occur in the early stages of dementia when the person is still able to meaningfully participate in the conversation. A person's ability to make informed decisions becomes less likely as their symptoms of dementia progress and this may hinder their opportunity to participate in reviewing their Advance Care Plan. With this in mind, advance care planning should 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 Plan 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.

#### Resources

- Dementia Australia has a large range of resources including the Start2Talk website: dementia.org.au/planning-ahead
- The Cognitive Decline Partnership Centre has resources for implementing advance care planning in community and home care settings: sydney.edu.au/medicine/cdpc/resources/ advance-planning.php

# 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 should they become unwell. They should be supported to participate in decision-making to the best of their abilities. However, it is not expected they would be able to complete an Advance Care Directive.

It has been documented that people living with intellectual disability have twice as many health problems as the general population. Research has shown that when there is doubt as to whether the person has the ability to understand the information, health professionals and relatives might withhold potentially upsetting information from the person. However, most individuals with mild or moderate intellectual disability want to be involved in their medical decision-making and should be given that opportunity.

#### Resource

Contact the Advance Care Planning Advisory Service for information about having advance care planning conversations with people living with an intellectual disability: 1300 208 582, Monday to Friday, 9am to 5pm (AEST).

# Mental health

People living with long-term mental health conditions are at higher risk than the general population of developing physical health conditions. 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.

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

Involve people living with mental health conditions in all decisions about their assessment, treatment and recovery, to the best of their ability. Support them to make, or participate in, those decisions, and respect their views and preferences.

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

There are differences between what you can decide about your mental healthcare and what you can decide about other types of healthcare (e.g. surgery, end-of-life care). This varies in different jurisdictions. For clarification, contact the Advance Care Planning Australia Advisory Service on 1300 208 582.

- Dementia Australia website Start2Talk has general information about planning: dementia.org.au/planning-ahead
- Advance Care Planning Australia Learning has an online e-learning module to help start conversations and involve people living with dementia: learning.advancecareplanning.org.au
- NSW health have a two part resource that will help support people with mental illness, their families and carers, and health professionals with the complex issues which might arise around Advance Care Planning for End of Life. The Introductory Guide will help support people with mental illness, their families and carers. This is also available in eleven community languages. The Comprehensive Guide will help support health professionals: www.health.nsw.gov.au/patients/acp/Pages/comprehensive-guide.aspx
- Advance Care Planning Australia legal resources: advancecareplanning.org.au

# Involving other healthcare services and professionals

This section highlights the importance of a multidisciplinary approach to advance care planning and the role of key people 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 as a part of a multidisciplinary approach to the process.

# **General practitioners**

A person's GP is often the foundation of their health care and someone they trust. A person's GP would ideally have a record of the person's health history, be able to discuss the prognosis of medical conditions with them, and advise 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 Plan, ensure their nominated GP is provided with a copy.
- If the person has an Advance Care Plan, but their condition appears to have deteriorated since it was made, you could recommend to the person and/or their family to ask their GP whether the plan needs to be updated.
- If the person does not have an Advance Care Plan, talk first with them about the concept. If they wish to consider advance care planning further, take steps to help them to connect with their nominated GP for this purpose. This could include making written contact with their GP on their behalf to advise them that their patient is seeking to develop an Advance Care Plan, and requesting that they discuss the medical considerations of advance care planning with their patient during their next appointment. When contacting the GP, advance care planning resources that may be helpful to them could be provided.

# **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. Consider how to share an Advance Care Plan with relevant health services to help ensure the person receives treatment in line with their wishes. Sharing this information should only occur with the person's consent.

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 as needed.
- Consider contacting additional services regularly involved with your clients, to determine whether and how to provide them with Advance Care Plans/Advance Care Directives.

### 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.

Steps to consider:

- Become familiar with hospital and community palliative care service providers that operate in your region and establish a relationship with them to understand the services they provide. This might include some direct support or consultancy about advance care planning discussions. It is important to understand referral processes and how to efficiently share an Advance Care Plan with palliative care services, should 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 Plans.

#### Resources

- palliAGED (Palliative Care Aged Care Evidence): palliaged.com.au
- Palliative Care Australia: palliativecare.org.au
- Linkages project resources include videos, case studies and a manual, available on Advance Care Planning Australia resource hub: advancecareplanning.org.au/resources

# Aged Care Assessment Team and Aged Care Assessment Service

Aged Care Assessment Teams (ACAT) and, in Victoria, the Aged Care Assessment Service (ACAS) are mainly assessment services for access to Commonwealth-funded aged care programs requiring a delegate decision under the *Aged Care Act 1997* (Cwlth) or for access to the entry level Commonwealth Home Support Program. They do not provide ongoing support in the care of older people.

The advance care planning process is ideally 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, consider referring to this information to gain some 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 Plans.

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 may include specific care and treatment preferences.
- 2. Selecting, preparing and appointing a substitute decision-maker.
- 3. Documenting the person's preferences in an Advance Care Directive or Advance Care Plan.
- 4. Regularly reviewing and updating an Advance Care Directive or Advance Care Plan.
- 5. Sharing the Advance Care Directive or Advance Care Plan.

These components are addressed in these steps:

- 1. develop and document
- 2. review
- 3. activate.

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 capacity to make decisions is assumed unless assessed otherwise, many residents of aged care facilities have cognitive impairment. People who are competent to make decisions can be fully involved in planning if they choose to be. A person who does not have 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

#### 1. Develop and document

#### When

Ideally this should take place when the person has capacity to take part in decision-making and has had time to adjust to changes in their condition or prognosis. This might not be possible in instances where decisions take place in the context of serious medical illness.

#### Who

Advance care planning should be discussed between the person, substitute decision-maker, family and doctors involved in the person's care (e.g. GP and any specialists).

### Action point 1: Initiate the advance care planning conversation

#### How

- Introduce the topic. Example questions include:
  - '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?'
- Help them to think about their values. Talk about their values, explore goals, and include any cultural or religious values. You may find resources such as the My Values and Advance Care Planning Australia websites helpful. Example questions include:
  - '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 about happening if you were very ill?'
  - 'Do you have spiritual or cultural beliefs that you would like the healthcare team to know about?'
- Explore the person's experience of healthcare decision-making. Example questions include:
  - '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?'
- Explore their understanding of their medical conditions and prognosis. Example questions include:
  - 'What do you understand about your illness?'
  - 'Do you feel you have a good understanding of your illness and what can be done?'
  - 'What have you been told about your illness?'
  - 'What further information do you need?'
- Use triggers to initiate the conversation, (e.g. 'How are you going since you were discharged from hospital?').

# Action point 2: reflection and discussion

#### How

- Clarify the person's concerns and expectations. Example questions include:
  - 'What concerns you about your illness?'
  - 'What would be most important to you if you were very ill?'
- Discuss their understanding of their condition and possible care or treatments that they would or would not want in the future. Example questions include:
  - 'Is there a point during your illness where you would consider stopping treatments and changing the focus of your care to supportive care? 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 again would you want your treatment to be different?
     For example, would you want to go to hospital?'

- Clarify their understanding of their health goals, preferences and their values. Example questions include:
  - '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?'
- Be clear about the purpose of advance care planning and provide written information for the person and others present to take away. Example questions include:
  - 'It is important to let family 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 okay with you?'
- Describe the important outcomes of advance care planning:
  - 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 a substitute decision-maker. If a substitute decision-maker has already been identified, aim to involve them in all conversations. Example questions include:
  - '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 who you have chosen know what your preferences for future care are?'
- Check back with the person about their understanding of advance care planning and the role of a substitute decision-maker.
- Summarise and suggest documenting preferences.
  - Explain that the Advance Care Plan belongs to them and they will keep the original documentation.
  - Encourage them to provide a copy of the Advance Care Plan to their substitute decisionmaker once it is documented.
  - Encourage the person to also provide a copy of the Advance Care Plan to family members, their GP, other treating clinicians and their local hospital.
  - Let the person know that a record of the conversation and/or Advance Care Plan will be kept in their medical record or My Health Record and how it will be used.
- Ensure that the person is aware that they can change and make additions to their Advance Care Plan at any time.

# Action point 3: recording and documentation

#### How

- Use clear language when documenting. If possible document 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 any decisions made.
- A template developed by health services or peak bodies can be used to document (see the Advance Care Planning Australia website) or use a letter format.
- Identify a substitute decision-maker in the documentation.
- If the person chooses to, use the relevant legislated forms to appoint a legally appointed substitute decision-maker and/or complete an Advance Care Directive.
- Give the original advance care planning documents to the person.
- With the person's consent, provide a copy of the Advance Care Plan to the substitute decision-maker. If this is not possible, ask the person to make sure they give their substitute decision-maker a copy of the Advance Care Plan.
- Place an Advance Care Plan alert in the person's physical and/or electronic resident/client record.
- With the person's consent, ensure that other treating clinicians, including their GP or residential aged care facility and other relevant family members, are provided with copies of the Advance Care Plan.

### 2. Review the Advance Care Plan/Directive

#### When

A review of an Advance Care Plan can happen whenever a person decides to refine their goals for care during the course of their illness. Triggers for review could include a change in a person's condition, hospitalisation or an unstable phase of illness.

#### Who

The plan should be reviewed with the person, their substitute decision-maker, their family and clinicians involved in their care.

#### How

- Clarify what prompted the review.
- Use the existing Advance Care Plan to guide discussions.
- Ask the person about any current changes to their condition and whether this will change anything in their Advance Care Plan.
- Identify any gaps in the person's understanding of their condition and provide them with relevant information to address this.

- If the person wishes to, help them to revise their Advance Care Plan and confirm the changes with them. Make sure to clearly date any changes in the documentation.
- Give the person their revised plan and, with their consent, help them to provide copies to their substitute decision-maker, family, treating team and other 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 record, physical or electronic.

### 3. Activate the Advance Care Plan/Directive

#### When

This step is prompted 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.

#### Who

This step relates to all clinicians and carers linked to the person's care, both internal and external to the health service, in collaboration with the nominated substitute decision-maker and/or family.

#### How

- Access the person's resident/client record and locate their Advance Care Plan in a timely manner.
- Check to see if an Advance Care Plan exists elsewhere (copies may be with their GP, local hospital and other care facilities, eHealth records, with their substitute decision-maker or family).
- Look for an Advance Care Plan across multiple formats. It could exist as a standard form, a letter, an advance directive or in another format.
- Identify and contact the substitute decision-maker.
- Involve the person as much as possible 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 make a decision about what medical treatment is to be offered.
- In the case that a person does not have a substitute decision-maker and the Advance Care Plan is clear and unambiguous, the medical practitioner will document a decision consistent with the Advance Care Plan in the medical record.
- Follow instructional advance care directives, dependent on legislation.

Refer to the following section 'Activating the Advance Care Plan' for more information.

#### Resources

- My Values website: myvalues.org.au
- My Health Record: myhealthrecord.gov.au
- Advance Care Planning Australia: advancecareplanning.org.au
- ACPtalk conversational starter questions for advance care planning and discussion scripts: acptalk.com.au/tmp/acp-discussion-scripts.pdf
- The advance care planning conversation: A 5-step general practice guide although targeted at general practice, the guide is also helpful for aged care staff: advancecareplanning.org. au/docs/default-source/DA-Resource-Library/linkages-project/5-5-step-general-planningconversation.pdf
- Advance Care Planning Australia Learning has e-learning modules and workshops: learning.advancecareplanning.org.au

# **Activating an Advance Care Plan**

This section discusses activating Advance Care Plans, including substitute decision-makers and decision-making capacity. It provides practical steps and explains what to do if there is no Advance Care Plan.

# Enacting an Advance Care Directive or Advance Care Plan

An Advance Care Plan is only activated when someone is unable to make a medical decision because they have been demonstrated to lack capacity or are unable to communicate. The steps include:

- 1. locating the Advance Care Plan or directive if one exists, and determining validity.
- 2. identifying and contacting the substitute decision-maker
- 3. discussing and interpreting the Advance Care Plan with the substitute decision-maker.

Aged-care staff should ensure they have a clear understanding of substitute decision-makers, advance care and instructional directives and decision-making capacity.

# Advance Care Plans and instructional directives

An advance care directive is a type of written advance care plan recognised by common law or specific legislation that is completed and signed by a competent adult. It may record the person's values, and preferences for future care, and/or include the appointment of a substitute decision-maker to make decisions about health care and personal life management. An Instructional directive is a specific type of advance care directive, that outlines specific treatment they would or would not like to receive and under what conditions. Each state and territory has different forms and requirements for instructional directives, so it is important to familiarise yourself with your jurisdiction's legal requirements and documents.

# Other types of written plans

Documentation of advance care planning can occur in other ways. It can include:

- non-statutory forms
- personally written letters
- a written plan outlining a person's values, beliefs and specific goals for care
- letters or documents written by a professional outlining the person's preferences.

# **Decision-making and capacity**

Capacity to participate in medical decision-making is presumed unless demonstrated otherwise. If the person has capacity, they will participate in decision-making directly. Loss of capacity is a trigger to act on an Advance Care Plan or directive.

The assessment of capacity in the context of advance care planning should take place as close as possible to the time the decision is required. A person with capacity should:

- know the decision facing them
- know the possible options
- know the reasonably foreseeable outcomes of the options available
- be able to understand the information, retain the information to the extent necessary, use or weigh the information, and communicate the decision.

A person should not be considered to be lacking capacity if they make a decision that, in the medical treating team's opinion, is unwise or against their best interest. However, this may prompt a formal assessment of capacity or a second opinion.

A person who has been demonstrated to lack capacity should still be involved in their medical decision-making to the best of their abilities. While they lack capacity they may still be competent to express a view about what they want. Competence can fluctuate over time and for different levels of decision-making; it is 'function specific'.

# Step-by-step enactment of an Advance Care Plan

#### 1. Locate the Advance Care Plan or directive if one exists.

Advance Care Plans should be in a central location that is easily accessible to all staff members, to ensure the plans can be quickly enacted. See the 'Systems and governance' section for tips on how to centralise and store Advance Care Plans within your organisation.

Legally binding Advance Care Plans will be on forms that meet all legislative requirements (a prescribed statutory form or a form substantially similar). Other Advance Care Plans may be on standardised forms (considered non-statutory), letters or in another format. Instructional directives may take precedence over the legislated substitute decision-maker.

#### 2. Identify and contact the substitute decision-maker.

The substitute decision-maker may not be currently with the person or involved in their day-today care. The person may not have appointed a substitute decision-maker.

The procedure to identify the substitute decision-maker varies according to the state or territory, so it is important to understand the identification process.

The resources at the end of this section will help you to identify the substitute decision-maker in your state or territory.

#### 3. Discuss and interpret the Advance Care Plan with the substitute decision-maker.

The person (to the best of their ability), their substitute decision-maker and the medical treatment team should discuss the person's expressed values and preferences in the context of the clinical care and medical treatment plan.

The Advance Care Plan cannot advocate for treatment that in the medical team's opinion is not appropriate, is not indicated or is unlikely to be of benefit.

If the Advance Care Plan is a statutory document and the treatment decisions are applicable to the situation it must be followed. As legislation varies, see the resource section for links to state and territory government information.

# What to do if there is no Advance Care Plan and a decision is needed

The uptake of advance care planning is relatively low in both community and residential aged care. There are a number of possible scenarios:

- 1. The person has capacity and is able to communicate. In this situation, the person is fully involved in decisions about treatment. Health providers would need to obtain informed consent before providing treatment.
- 2. The person is unable to communicate their preferences or lacks capacity. In this situation, the treating team should make every effort to identify and contact the substitute decision-maker. If there is no Advance Care Plan, records should be examined to determine if the person has previously provided indications about their values and preferences, and this should be used to guide treatment. The substitute decision-maker, family, GP and carers should be engaged to give insight into the person's values and preferences, which should be used to guide treatment. Consent for treatment should be obtained from the substitute decision-maker. The substitute decision-maker decisions that the person would make if they had the same information and advice.

In all situations, the overall guiding principle is to attempt to make the decision that the person themselves would make if they were able to do so (substituted judgement).

### Resources

- Advance Care Planning Australia Advisory Service: 1300 208 582 and website: advancecareplanning.org.au
- Advance Care Planning Australia Learning e-learning Module Three Advance care planning decision-making the legal implications: learning.advancecareplanning.org.au
- Office of the Public Advocate or equivalent in each state or territory:
  - ACT (Public Trustee and Guardian) (02) 6207 9800
  - NSW (Public Guardian) (02) 8688 6070
  - NT (Office of the Public Guardian) 1800 810 979
  - Queensland (Office of the Public Advocate) (07) 3224 7424
  - SA (Office of the Public Advocate) (08) 8342 8200; Country SA: 1800 066 969
  - Tasmania (Office of the Public Guardian) (03) 6165 3444
  - Victoria (Office of the Public Advocate) 1300 309 337
  - WA (Office of the Public Advocate) 1300 858 455
- State and territory government websites:
  - ACT: health.act.gov.au/public-information/consumers/advance-care-planning
  - **NSW:** health.nsw.gov.au/patients/acp/Pages/default.aspx
  - NT: nt.gov.au/law/rights/advance-personal-plan
  - **Queensland:** qld.gov.au/law/legal-mediation-and-justice-of-the-peace/power-of-attorneyand-making-decisions-for-others/advance-health-directive
  - **SA:** sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/ health+topics/health+conditions+prevention+and+treatment/end+of+life/ advance+care+directive
  - **Tasmania:** dhhs.tas.gov.au/palliativecare/advance\_care\_planning\_for\_healthy\_dying
  - Victoria: health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/ advance-care-planning
  - WA: healthywa.wa.gov.au/Articles/A\_E/Advance-care-planning

# Glossary

Term	Description
Advance Care Directive (ACD)	A type of written advance care plan recognised by common law or specific legislation that is completed and signed by a competent adult. It can record the person's preferences for future care, and appoint a substitute decision- maker to make decisions about health care and personal life management.
Advance Care Plan	A plan that states preferences about health and personal care, and preferred health outcomes. The plan may be made on the person's behalf, and should be prepared from the person's perspective to guide decisions about care.
Advance care planning (ACP)	The process of planning for future health and personal care, whereby the person's values, beliefs and preferences are made known so they can guide decision-making at a future time when that person cannot make or communicate their decisions.
Clinical care plans	A health professional-directed plan for care. These may or may not include specific reference to a person's preferences, and ideally will have been discussed with the person. These may be referred to as medical orders if completed by a doctor.
Health record/file	A comprehensive compilation of information traditionally placed in the medical record but also covering aspects of the person's physical, mental and social health that do not necessarily relate directly to the condition under treatment. The record(s) may be paper-based, electronic or both. Also referred to as records, files, case notes, electronic health records, medical records, patient file, client file and care plan.
Jurisdiction	A state or territory within Australia.
Medical orders	Documents completed by a doctor that outline the plan of care in relation to emergency treatment of severe clinical deterioration. They may include 'not for resuscitation' orders and other treatment limitations. They may also include decisions regarding transfer to hospital. In some jurisdictions, medical orders are part of a state-based approach.
Person	Consumers of services provided by hospitals, residential aged care facilities and general practice. Used interchangeably with resident, patients and clients.

Term	Description
Person-centred care	Care that is respectful of, and responsive to, individuals' preferences, needs and values. Person-centred care ensures the person's values and goals guide decisions regarding their care.
Substitute decision-maker	<ul> <li>The person called upon to make medical treatment decisions on behalf of a person whose decision-making capacity is impaired. A substitute decision-maker can be:</li> <li>someone chosen (and appointed) by the person</li> <li>someone assigned to the person by law (identified by a legislated hierarchy), or</li> <li>someone appointed on the person's behalf by a guardianship tribunal.</li> <li>For the purposes of advance care planning, only a person chosen and appointed by the person is relevant.</li> </ul>
Substituted judgement	Attempting to make the decision that the person themselves would make if they were able to do so.

# **Resources and supporting documents**

- Advance Care Planning advisory service: 1300 208 582, 9am–5pm, Mon–Fri (AEST)
- Advance Care Planning Australia website: advancecareplanning.org.au
- Advance Care Planning state documents relevant to each state/territory: advancecareplanning.org.au/resources/advance-care-planning-in-my-state
- Advance Care Planning Australia legal factsheets for providers and consumers: advancecareplanning.org.au/resources
- Advance Care Planning Australia webinar What is advance care planning?: advancecareplanning.org.au/education-and-training
- Advance Care Planning Australia webinar We're all different: advancecareplanning.org.au/ education-and-training
- Advance Care Planning Australia's website has resources that can be included in an introductory workshop for health and care workers: advancecareplanning.org.au/for-healthand-care-workers
- Advance Care Planning Australia provides written and audio bilingual resources in a range of languages. These include resources for the individual, the substitute decision-maker and care workers: advancecareplanning.org.au/resources – see other languages
- Advance Care Planning Australia Learning e-learning Module One Advance care planning introduction: learning.advancecareplanning.org.au
- Advance Care Planning Australia Learning e-learning Module Two Advance care planning conversations: learning.advancecareplanning.org.au
- Advance Care Planning Australia Learning e-learning Module Three Advance care planning decision-making the legal implications: learning.advancecareplanning.org.au
- Advance Care Planning Australia Learning e-learning Module Four Advance care planning implementation: learning.advancecareplanning.org.au
- Advance Care Planning Australia Learning e-learning Module Six Advance care planning and dementia: learning.advancecareplanning.org.au
- Advance Care Planning Australia Learning e-learning Module Eight engaging people from a culturally diverse background in advance care planning: learning.advancecareplanning.org.au
- Advance Care Planning Australia Learning e-learning Module Nine Advanced communication (due for release January 2018)
- Advance Care Planning Australia has developed a number of fact sheets explaining advance care planning: advancecareplanning.org.au/docs/default-source/acpa-resource-library/acpafact-sheets/acp\_fact\_sheets\_for\_patients\_and\_familys\_version-4\_july17.pdf?sfvrsn=6 or advancecareplanning.org.au/resources

- Advance Care Planning Australia Learning has an online e-learning module to help start conversations and involve people living with dementia: learning.advancecareplanning.org.au
- Linkages project resources include videos, case studies and a manual, available on Advance Care Planning Australia resource hub: advancecareplanning.org.au/resources
- Office of the Public Advocate or equivalent in each state or territory:
  - ACT (Public Trustee and Guardian): (02) 6207 9800
  - NSW (Public Guardian): (02) 8688 6070
  - NT (Office of the Public Guardian): 1800 810 979
  - Queensland (Office of the Public Advocate): (07) 3224 7424
  - SA (Office of the Public Advocate): (08) 8342 8200; Country SA: 1800 066 969
  - Tasmania (Office of the Public Guardian): (03) 6165 3444
  - Victoria (Office of the Public Advocate): 1300 309 337
  - WA (Office of the Public Advocate): 1300 858 455
- State or territory government websites:
  - ACT: health.act.gov.au/public-information/consumers/advance-care-planning
  - NSW: health.nsw.gov.au/patients/acp/Pages/default.aspx
  - NT: nt.gov.au/law/rights/advance-personal-plan
  - **Queensland:** qld.gov.au/law/legal-mediation-and-justice-of-the-peace/power-of-attorneyand-making-decisions-for-others/advance-health-directive
  - SA: sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/ health+topics/health+conditions+prevention+and+treatment/end+of+life/ advance+care+directive
  - Tasmania: dhhs.tas.gov.au/palliativecare/advance\_care\_planning\_for\_healthy\_dying
  - **Victoria:** health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/ advance-care-planning
  - WA: healthywa.wa.gov.au/Articles/A\_E/Advance-care-planning
- The Australian Commission of Quality and Safety in Health Care. The National Consensus Statement: Essential elements for safe and high-quality end-of-life care (cited 2017 [accessed Nov 2016]).
- Australian Aged Care Quality Agency Accreditation Standards Fact Sheet aacqa.gov.au/providers/residential-aged-care/resources/brocah0011accreditationstandardsfa ctsheetenglishv14.1.pdf
- Australian Aged Care Quality Agency Home Care Common Standards Fact Sheet: aacqa.gov.au/providers/home-care/processes-and-resources/resources-specifically-forhome-care/fact-sheets/homecarecommonstandardsv14\_0.pdf

- Australian Aged Care Quality Agency Quality review guidelines: aacqa.gov.au/publications/ publications-providers-and-surveyors/QualityReviewguidelines.pdf
- Advance care planning: have the conversation. A strategy for Victorian health services 2014–2018 provides example phrases that can be used during the conversation: health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/advance-careplanning/acp-strategy
- ACPtalk conversational starter questions for advance care planning and discussion scripts: acptalk.com.au/tmp/acp-discussion-scripts.pdf
- ACPtalk provides information and discussion starters for having advance care planning conversations with people from various religious faiths and cultures: acptalk.com.au
- Contact the ACP Advisory Service for information about having advance care planning conversations with people living with an intellectual disability: 1300 208 582, Monday to Friday, 9am to 5pm (AEST).
- The Cognitive Decline Partnership Centre has resources for implementing advance care planning in community and home care settings: sydney.edu.au/medicine/cdpc/resources/ advance-planning.php
- Dementia Australia has a large range of resources including the Start2Talk website: dementia.org.au/planning-ahead
- Dying to Talk has a discussion starter resource that helps people think about what is important to them; it is useful in having an advance care planning conversation: dyingtotalk.org.au
- Videos displaying examples of successful and unsuccessful advance care planning conversations are available on the Victorian Department of Health website: health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/advance-careplanning/acp-resources
- Start2Talk provides general information about planning ahead, and includes information for multicultural and Aboriginal health workers: dementia.org.au/planning-ahead
- My Aged Care resource LGBTI advance care planning: agedcare.health.gov.au/sites/g/files/ net1426/f/documents/06\_2017/lgbti\_-\_advance\_care\_plan\_factsheet\_-\_print\_version.pdf
- Taking control of your health journey is an introduction to advance care planning for Aboriginal and Torres Strait Islander people: advancecareplanning.org.au/docs/default-source/ acpa-resource-library/acpa-publications/taking-control-of-your-health-journey.pdf?sfvrsn=12
- Palliative Care Australia: palliativecare.org.au
- Palliative Care Australia has a discussion starter kit to help people work out what's right for them: dyingtotalk.org.au/discussion-starter
- Palliative Care Australia has a discussion starter for Aboriginal and Torres Strait Islanders: dyingtotalk.org.au/download/6994
- palliAGED (Palliative Care Aged Care Evidence): palliaged.com.au

- My Values website: myvalues.org.au
- My Health Record: myhealthrecord.gov.au
- The advance care planning conversation: A 5-step general practice guide although targeted at general practice, the guide is also helpful for aged care staff: advancecareplanning.org. au/docs/default-source/DA-Resource-Library/linkages-project/5-5-step-general-planningconversation.pdf
- NSW health have a two part resource that will help support people with mental illness, their families and carers, and health professionals with the complex issues which might arise around Advance Care Planning for End of Life. The Introductory Guide will help support people with mental illness, their families and carers. This is also available in eleven community languages. The Comprehensive Guide will help support health professionals: health.nsw.gov.au/patients/acp/Pages/comprehensive-guide.aspx



