



Information about advance care planning for healthcare staff

What is advance care planning?

Advance care planning (ACP) involves a patient thinking about and communicating to others how they would like to be treated in the future if they have a condition where they can no longer speak for themselves. This may happen, for example, because of a stroke, progressive dementia, or becoming unconscious from some form of accident or illness.

ACP is relevant for everyone, but particularly for people with progressive, life-limiting conditions such as cancer or late stage chronic disease. Other triggers to undertake ACP include diagnosis of early cognitive impairment and admission to a residential aged care facility.

An advance care directive (ACD) is a document that describes a person's acceptance or refusal of certain treatments in anticipation of a time when the person is unable to express those preferences because of illness or injury. Completion of an ACD is one component of the broader advance care planning process. Sometimes the terms advance care plan and advance care directive are used interchangeably.

Why is it important?

Undertaking ACP means that future decisions about a person's care are more likely to reflect their wishes. It helps them raise sensitive issues about the future with those close to them that they might otherwise avoid. It will mean that other people will not have to make decisions on the person's behalf without knowing what that person's real feelings and wishes would be. It reduces the chance of confusion and conflict when others are making decisions about a person's care. It means that the patient and the people close to them can feel comfortable and reassured that there will be a common and calm approach to their care toward the end-of-life.

The policy context of ACP

The main Policy Directive from NSW Health relevant to ACP is to do with patient consent – Consent to Medical Treatment – Patient Information (PD2005_406).

Other guidelines published by NSW Health that are directly relevant to ACP include:

- Using Advance Care Directives – New South Wales (2004)
- Guidelines for end-of-life care and decision-making (2005)
- Decisions relating to No Cardiopulmonary Resuscitation (CPR) Orders (2008)

The legal basis of ACP/ACD

Advance care planning has its legal basis within the common law right to determine one's own medical treatment. Clear messages about the legal basis of ACP/ACDs are provided in the above documents:

"Health practitioners should not provide treatment or perform a procedure where there is an unequivocal written direction, such as an Advance Care Directive, by the patient that such treatment is not to be provided in the circumstances which now apply to the patient" (Consent to Medical Treatment – Patient Information Policy Directive PD2005_46, Page 8)



“An advance care directive that complies with the requirements set out in this document is legally binding in NSW, and functions as an extension of the common law right to determine one’s own medical treatment. A failure to comply with such an advance care directive refusing a particular treatment may result in the health professional incurring criminal or civil liability for providing that treatment.” (Using Advance Care Directives – NSW, Page 5)

The requirements referred to in the last quote are document standards that should be met before an ACD is considered to have sufficient authority to act on and are outlined below.

- **Specificity:** the ACD should be clear and specific enough to guide clinical care in the circumstances under consideration
- **Currency:** while an ACD prepared some time ago may not reflect the current intentions of the patient, it should still be accepted as valid. People should be encouraged to update their ACD periodically
- **Competence:** the person must have been competent to make their own health care decisions when the ACD was made
- **Witnessing:** while this is not essential, it is encouraged to allow follow-up if necessary and to allay fears of forgery or the ACD being written under pressure from another person.

What does ACP involve for healthcare staff?

- helping a person identify who their substitute decision maker would be and whether they need to formally appoint someone in this role as an Enduring Guardian
- supporting a person to discuss their current health problems and likely treatment choices into the future with their GP and Specialist doctors
- encouraging a person to explore and discuss their values and wishes about their end-of-life care with people who will be their substitute decision makers if the need arises
- organising documentation related to ACP discussions and ensuring this is maintained in a prominent way in the person’s medical records
- ensuring that ACP documentation is referred to and used in any care planning and treatment decisions for the person in the future.

Which healthcare staff are responsible for ACP?

ACP has not been developed as the role of one particular group of healthcare staff. There are several levels of responsibility.

All clinical staff with a direct caring role for patients, medical records staff and patient-related administrative staff such as ward clerks and receptionists should: understand what ACP is; be able to explain ACP to patients in general terms; be able to locate and provide information about ACP to patients; and be able to recognise and manage ACP forms within the medical records system.

Staff with a patient management role, such as doctors, registered nurses, social workers and other allied health staff in hospitals, community health settings and residential aged care facilities should be able to do all the above, as well as: initiate and facilitate discussions with a patient and/or their substitute decision makers; fully document outcomes of ACP discussions in the relevant format for their own organisation; take responsibility for knowing if a patient has an ACP; and ensuring any ACP is referred to and used in any subsequent care planning.

It is important to emphasise that ACP needs to be approached in a systematic way across the organisation – rather than being seen as the responsibility of one or more groups of staff. This means there should be a clear commitment to ACP from senior management; ACP roles built into routine



patient management systems; readily available information, forms and other resources; and comprehensive education for all stakeholder groups.

Using ACP documents in end-of-life decision-making

Medical decision-making at the end-of-life can be a complicated and difficult process. It is not always clear how treatable or reversible a certain condition is. If an ACP/ACD does exist, it may not be specific or clear enough to guide decisions about care. It may be difficult to access substitute decision-makers or they may be unsure about what treatments they want their loved one to have. The process of decision-making is also influenced by the experience and seniority of the treating medical officer and other staff, and whether there are clear policies and protocols in place.

In the context of these difficulties, it would be naive to suggest that an ACP/ACD will always be automatically followed by a medical officer having to make end-of-life medical decisions, especially in an emergency situation.

However, medical officers and other staff involved in end-of-life medical decisions must:

- make every effort to ascertain if there are any ACP/ACD documents in existence by checking the medical records and asking the patient or their family
- make every effort to clarify the reversibility of the current problems and the patient's prognosis as accurately as possible
- carefully consider the currency, specificity and relevance of any ACP/ACD documents in terms of the current clinical situation
- refer to any ACP/ACD documents in discussions with substitute decision-makers about treatment decisions
- make medical decisions and recommendations that reflect the wishes of the patient as stated in an ACP/ACD that they consider to be current, specific and relevant to the current situation
- seek guidance from more senior staff if they are unclear about how to incorporate ACP into their end-of-life decision making
- document these considerations and the decision-making process fully in the patient's medical record, including reasons why an ACP/ACD may not have been followed.

What if the patient already lacks capacity?

If the patient is already at a stage where they cannot nominate a substitute decision-maker and they cannot write an ACP/ACD (such as in moderate-severe dementia), there are still benefits from the 'person responsible' undertaking advance care planning on behalf of the patient. In this case, the 'person responsible' can consider and document the values and wishes they believe the person would have expressed themselves if they were able to. Having these considered and documented will make it easier to make important decisions about the person's care at the end-of-life.

The My Wishes Advance Care Planning Program

While it is important that patients and their 'persons responsible' are free to choose any format of ACP, the My Wishes program has been developed by the local health service as part of the medical records system and to be used across different care settings.

The program consists of the following processes and associated documents:

- *Statement of Values and Wishes*
- *Record of Advance Care Planning Discussions*



The forms that are part of the program can be completed by the patient themselves or by their 'person responsible' if the patient has already lost capacity. The program also includes a series of information sheets, practice guidelines for staff and educational resources, which can be found on the website listed below.

FURTHER INFORMATION

The South Western Sydney Local Health District My Wishes Advance Care Planning Program

Further information about this program and copies of the ACP forms can be obtained from www.mywishes.org.au

Planning Ahead Tools website from NSW Government

A comprehensive site with practical information about a range of topics including Wills, Power of Attorney, Enduring Guardianship, advance care planning and elder abuse. It has a program that allows you to build your own plan. Available at: <http://www.planningaheadtools.com.au>

start2talk

A practical website for people in all parts of Australia who want to plan ahead for themselves or help somebody else plan ahead. The website has a number of worksheets that can be completed and stored online or else printed out and completed by hand. Available at: www.start2talk.org.au

'My Health, My Future, My Choice' and 'A Plan of Care'

Two booklets that help people either plan for themselves or plan for someone who has lost capacity. While some of the information is specific to New South Wales, much of it is relevant in any setting. Published by the Advance Care Directive Association. Available at: <http://www.advancedirectives.org.au>

Planning what I want

An Australian website that has information for the general public as well as healthcare professionals. It includes general information on a range of ACP-related topics, examples of forms and several video clips from experienced practitioners. Available at: <http://www.planningwhatiwant.com.au>

Respecting patient choices

A comprehensive Australian website with a range of information related to ACP. Available at: <http://www.respectingpatientchoices.org.au>

Using Advance Care Directives NSW

A 13 page booklet published by NSW Health to provide advice to health professionals on the best practice use of advance care directives within an advance care planning process. Available from the web at: www.health.nsw.gov.au/policies/gl/2005/pdf/GL2005_056.pdf

Guidelines for end-of-life care and decision making

A 17 page booklet published by NSW Health that focuses on a process for making end-of-life decisions about care. Available from the web at: http://www.health.nsw.gov.au/policies/gl/2005/pdf/GL2005_057.pdf

For further information go to:
www.mywishes.org.au