My Wishes

Information about advance care planning for General Practitioners

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.

The role of the GP

GPs often have a long-term relationship with their patients, including those with serious chronic disease and life-limiting illness such as Alzheimer’s disease and other forms of dementia. As a GP, you can play a vital role helping these patients to understand their medical condition and to plan for possible choices they may have to make about their future healthcare.

The Royal Australian College of General Practice (RACGP) believes that advance care planning should be incorporated into routine general practice and they have published a Position Statement on the issue.

“ACP is a process of reflection, discussion and communication that enables a person to plan for their future medical treatment and other care, for a time when they are not competent to make, or communicate, decisions for themselves. ACP is about person-centred care and is based on fundamental principles of self-determination, dignity and the avoidance of suffering.”

“Position Statement: Advance care planning should be incorporated into routine general practice”

What does advance care planning involve for GPs?

Advance care planning will often involve the following components:

• Discussions about prognosis and possible future scenarios and patient concerns
• Appointment of a substitute decision maker(s) and their involvement in initial and subsequent ongoing documented discussions
• Reaching consensus on current and possible future ‘goals of care’. These goals may be supported by a statement describing the reasoning underpinning the choices a patient has made
• Discussing choices around preferred place of care during their illness and in the ‘terminal phase’
• Documenting these discussions in an easily retrievable format, held by the patient, their substitute decision-maker, their family and GP.

All of the above components can be strengthened if the patient’s primary carers and family are involved in some way.
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 Ministry of Health policy 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. These 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.

The legal basis of advance care directives has been firmly established in a case before the NSW Supreme Court – Hunter New England Area Health Service v A [2009] NSWSC 761.

Working with the residential care staff and systems

Many residential aged care facilities have developed policies and procedures to adopt a more systematic approach to advance care planning. Typically this will be done with input from some of the GPs visiting the facility. These procedures might include ACP discussions in the early family case conferences or as part of the annual resident review. GPs are encouraged to find out what systems are in place in the facilities they visit and work collaboratively with staff to ensure these systems can provide the best quality of care for the residents.

There are several Medicare items that GPs can use when undertaking ACP discussions with residents and/or their person responsible. These include Over-75 Health Check, Comprehensive Medical Assessment, Contribution of GP to Care Plan and Contribution to Case Conference.

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

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

RACGP Position Statement
Advance care planning should be incorporated into routine general practice. September 2012. Available at: http://www.racgp.org.au/policy/clinical

RACGP website information about advance care planning

AMA Position Statement
The role of the medical practitioner in advance care planning - 2006

Advance Care Planning information from NSW Health
A website with frequently asked questions and links to other NSW resources. Available at: http://www.health.nsw.gov.au/patients/advance_care/pages/default.aspx

Planning what I want
An Australian Medicare Local 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

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

Using Advance Care Directives NSW

Guidelines for end-of-life care and decision making

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