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1. Position rationale

GPs develop ongoing and trusted relationships with their patients and are well positioned to initiate and promote advance care planning (ACP). ACP is the embodiment of person-centred healthcare and a response to the challenges that an ageing population and modern healthcare present. When a patient loses the ability to make decisions about their care (accounting for approximately one in four patients at the end of life), ACP ensures that a patient's expressed wishes remain the focus of decisions made about their care. ACP has also been shown to both improve end of life care and patient and family satisfactionⁱ.

2. Background

Awareness and acceptance of ACP has grown considerably over the last decade. Medicine has expanded from 'cure' to include the management of chronic and incurable conditions and frailty.

For many, this is in the context of fluctuating or failing cognition. Hence patients and their elected Substitute Decision Makers are often asked to make complex decisions about 'burden or harm' versus 'benefit' of various options for care. Decisions need to be patient-centred and not disease focused.

At its heart, ACP is the embodiment of person-centred healthcare. When a patient loses the ability to make decisions about their care, there are risks that the healthcare system will prolong their suffering by keeping them alive in a condition they would not wish to be in, and fail to attend to their wishes and concerns. ACP addresses these issues by ensuring that a patient's expressed wishes remain at the forefront of decisions in relation to their careⁱⁱⁱ, resulting in improved end of life care and patient and family satisfaction.^{iv}

It is in general practice where patients have ongoing and trusted relationships with their GP and where ACP is perhaps best initiated and promoted.^v Many GPs have already embraced ACP into their practice but many others do not know or do not feel confident that they know enough about it.^{vi vii} This position statement outlines what ACP is and the reasons why the College believes it should be incorporated into routine general practice.

3. What is advance care planning?

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.^{viii}

ACP promotes the expression of a person's values, beliefs and life goals. In the event that a person is unable to express their preferences due to anticipated deteriorating health, an accident or sudden illness, these articulated values, beliefs and life goals, help guide future care, including how decisions are made and by whom. Although often about end-of-life care (the last 12 months) or terminal care (the last days to weeks of life), ACP is a process that all patients, and especially those who are at risk of deterioration in health, can benefit from. A person may also wish to complete an advance care plan for other reasons (for example, there may be some treatment the patient would never wish to receive) or simply for peace of mind in case of unexpected illness or injury.

ACP will often lead to the completion of an Advance Care Directive (ACD). An Advance Care Directive is a written document, intended to apply to future periods of impaired decision-making capacity, which provides a legal means for a competent adult to instruct a Substitute Decision Maker and/or to record preferences for future health and personal care. ACDs are not clinical care or treatment plans, but clinical care or treatment plans can and should be informed by ACDs. Although a completed ACD is desirable for the purposes of ACP, the discussions that are central to ACP are valuable in their own right. It is important to note that verbally communicated instructions and values also hold weight.

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.

Although state and territory government laws vary on ACP and ACDs, Advance Health Directives in some form are legally binding documents in every state/territory of Australia. It is worth GPs familiarising themselves with some of the forms used in their state or territory. The RACGP website provides links to state-based resources: www.racgp.org.au/guidelines/advancecareplans.

4. The vital role of general practice

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

GPs should consider raising the topic with all older patients. For example, when they attend for their over 75 year health check, when dementia is suspected, those with life-threatening, complex and chronic illnesses and those patients with terminal illness. In doing so, the GP should be mindful of the competency and mood of the patient and ensure that the patient understands the purposes of ACP and an ACD and how it will be used in the future. Although encouraging their patients to engage in ACP, GPs should make it clear that documenting wishes in an ACD is not a requirement. The GP should however, also ensure that the patient understands that documented wishes, that are witnessed, have more legal certainty than those that are only made verbally.

Initiating a conversation about ACP which focuses on outcomes such as life goals, values and quality of life beliefs, rather than detailing types of treatment options a patient consents to or refuses, is likely to be more constructive. For example, encourage patients to talk about and record in their ACDs the situations they would like to avoid, personal circumstances and level of functioning considered acceptable or intolerable, interventions that they may consider to be overly intrusive or their preference for palliative care. ACDs that follow this structure are more likely to be useful as a guide to help clinicians apply patients’ wishes to future medical care. Some patients, however, may want to record specific detailed wishes of the care and treatment they wish to receive, or not receive, under certain circumstances, and if so, they should be supported to do this.

GPs should encourage patients to have conversations with their family, carers and other health professionals involved in their care, to make them aware of their wishes and the existence of an ACD, if there is one. This will help avoid future misunderstanding or family disagreements. A copy of an ACD should be included in medical files and be available to accompany patients across healthcare settings.

ACP will often involve ongoing conversations between a GP and a patient and their selected Substitute Decision Maker(s). It may be something a GP and their patient will return to and discuss and update regularly over many years, and may not end with the signing of a legally recognised document such as an Advance Care Directive. On occasion, GPs may be asked to witness an ACD they have not instigated. Whilst GPs are not under any obligation to do so, if the GP is confident the person is competent and understands their ACD, a GP’s signature can improve confidence in the document and ultimately help ensure a patient’s wishes are followed.

5. More information

The RACGP website, under the Clinical Resources tab, provides links to all state and territory specific information and resources: www.racgp.org.au/guidelines/advancecareplans. Links are also provided to training and development resources produced by other organisations, including the UK’s Gold Standard Framework Centre’s guidance for clinicians to support earlier recognition of patients nearing the end of life.

ⁱ Maria J. Silveira, Scott Y.H. Kim, and Kenneth M. Langa. Advance Directives and Outcomes of Surrogate Decision Making before Death. *N Engl J Med* 2010; 362:1211-1218 April

ⁱⁱ Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ*. 2010 Mar 23;340:c1345. doi: 10.1136/bmj.c1345

ⁱⁱⁱ Rhee J, Zwar N, Lynn A. Uptake and implementation of Advance Care Planning in Australia: findings of key informant interviews. *Australian Health Review*; 36(1) 98-104. Published: 9 February 2012

^{iv} Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ*. 2010 Mar 23;340:c1345. doi: 10.1136/bmj.c1345

^v Commonwealth of Australia. A Healthier Future For All Australians - Final Report of the National Health and Hospitals Reform Commission - June 2009

^{vi} Darvall L, McMahon M, Piterman L. Medico-legal knowledge of general practitioners: disjunctions, errors and uncertainties. *Journal of Law and Medicine*. 2001;9(2):167-84

^{vii} Commonwealth Parliament of Australia. Older people and the law. Report of the House of Representatives Standing Committee on Legal and Constitutional Affairs, Inquiry into Older People and the Law 2007

^{viii} The Clinical T, and Ethical Principal Committee, of the Australian Health Ministers’ Advisory Council (AHMAC). *A National Framework for Advance Care Directives. Consultation Companion Guide for the Draft Framework. Draft ed.* Canberra: AHMAC; 2010