

Advance care planning: rights and responsibilities

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Introduction

In the past few decades, factors such as an ageing population, increasing levels of dementia and rising healthcare costs, and the shift from medical paternalism to increased patient autonomy, have focused attention on end-of-life decision-making in Australia and internationally.

While resource issues are of concern to health policy makers, the rights and wishes of older people who fear aggressive end-of-life treatment, and do not want to die in high technology hospitals, must also be considered. A potential response to both concerns is Advance Care Planning (ACP). ACP allows competent patients to record their wishes for treatment they would or would not want if, at some future time, they are no longer competent.

Every competent adult has the legal right, under common law and also under statute law in some states and territories, to accept or refuse any recommended health care. This is relatively easy when people are well and can speak for themselves. Unfortunately, during severe illness people are often unconscious or otherwise unable to communicate their wishes—at the very time when many critical decisions need to be made. Options to address this problem include appointing someone to make decisions for you if you are unable to do that for yourself (by way of Enduring Power of Attorney for Health or Enduring Guardianship), and, or to put your wishes in writing in an Advance Directive (AD)—previously called a Living Will—and for the written document to be legally binding on healthcare providers. All Australian states and territories have legislation addressing some form of ACP (see Table 1).

The purpose of an AD is:

- to extend the right which a competent patient now has to a time when the patient may no longer be competent

- to ensure that the patient's wishes are known, and to assist healthcare providers to make decisions in line with the wishes of the patient
- to give patients/community confidence that their wishes regarding healthcare will be carried out if they cannot speak for themselves.

An important aspect of ACP is the issue of decision-making capacity. A person is said to have capacity if he or she is able to understand *the nature and the effect* of the decision to be made, and to communicate their decision in some way. It does not mean that the patient has to understand all the technical aspects of the potential treatment, nor make a decision that the doctor agrees with. While this may be difficult for a healthcare provider to accept, proceeding to treat a competent and adequately informed patient who has refused treatment may render the healthcare provider liable to a charge of assault. However, a request for euthanasia would not be followed as this would be in breach of the law.

It is imperative that we resist a return to the paternalism of the past and support what the community (including many health and legal professionals) has clearly indicated is required—respect for patient autonomy as part of a doctor-patient partnership.

General practitioners (GPs) are in an ideal position to introduce the idea of ACP to their older patients, as the majority of older people visit a GP at least once a year, and most do so more frequently. Many GPs now incorporate ACP into their routine practice, especially with their older patients or any patients with a chronic or life-threatening illness. Although a person of any age may be rendered incompetent because of an accident or illness, ACP is especially important for older people, given increasing rates of dementia and potential proximity to end-of-life. As well as providing guidance and certainty for healthcare providers and family members about the care and treatment that the person would or would not want at a time of incompetence, the very act of completing the document can give an older person a great deal of comfort and reassurance, allowing them to live their lives now without worrying about receiving unwanted treatment if they ever lose the capacity to speak for themselves. In this sense it serves as an insurance policy, i.e. the person may hope that it never needs to be used, but has the comfort of knowing that if such an occasion should arise their wishes will be known and respected.

In addition, it is advisable (and legally required in some states and territories) to have the AD signed by a doctor, who can explain any medical terms or other words that the patient is unclear about and can also make a statement about the mental capacity of the person who is making the document. Such documents should also be witnessed by an independent witness such as a Justice of the Peace, a Clerk of the Courts or a lawyer.

An argument that is sometimes made against ADs is that some medical practitioners may use them instead of good communication. While this may be so, it is unlikely that such a medical practitioner would have communicated adequately with or without the document. The ability to adequately discuss such issues with patients is a recognised deficit in many medical practitioners and this is now being addressed in Australian medical schools.

There is evidence to suggest that patients are receptive to discussing ACP. A study conducted in a general practice in Mackay, Queensland, in 2000¹ found that, while only a few patients knew about ADs, 70% wanted to know more about them and 83% wanted family members to be substitute decision-makers for health matters if the patient was too ill to make their own decisions. Many also wanted their GPs to be involved in such decisions.

Wishes as stated in an AD are not final while the patient remains competent. You can change them or totally revoke the AD at any time while you remain mentally capable of doing so. It is wise to review the AD every two years or if your health changes significantly.

It is important to keep the document in a safe place, and a copy should be given to your own doctor, to your Enduring Guardian if you have appointed one,

to a family member or friend and, if you wish, to your solicitor. If you are admitted to hospital or to a residential aged care facility (RACF)—previously called a hostel or a nursing home—make sure the hospital or RACF staff know that you have an AD and either give them a copy of it or tell them where a copy can be obtained. You may also wish to carry a card in your purse or wallet stating that you have made an AD, and where it can be found.

As we move into the twenty-first century, we will be confronted by more of the dimly foreseen consequences of medical progress. While some commentators are critical of an over-emphasis on control at the end of life, it is clear that citizens are seeking at least a measure of predictability and self-determination in relation to death and dying. Doctors, and particularly GPs, will be increasingly involved in working with their patients to establish reasonable, reviewable plans for times ahead when it is increasingly likely that our bodies will survive the minds which vouchsafe us meaning and the reason to live.

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References

1. Hawkins H, Cartwright C. Advance health care planning and the GP. Is it time to move forward? *Australian Family Physician*, 2000, 29: 704-707.

Table 1: Summary of Legislation Affecting End-of-Life Issues

State or Territory	Advance Directive/ Refusal of Treatment	Proxy/Agent*	Comments
New South Wales	Yes	Yes	Advance Health Directives (ADs) which comply with the requirements of the NSW Health document <i>Using Advance Care Directives</i> (2004), are legally binding. Individuals may also appoint their own guardians
Victoria	Yes	Yes	Patient can write a 'refusal of treatment' certificate, but only for a current illness which does not have to be terminal. <i>Medical Treatment (Enduring Power of Attorney) Act 1990</i> allows appointment of proxy
Queensland	Yes	Yes	<i>Powers of Attorney Act 1998</i> allows ADs and Enduring Power of Attorney (proxy) for health/ personal matters. <i>Guardianship and Administration Act 2000</i> (and amendments 2001) increased scope. Proxy can now consent to withdrawing/withholding life-sustaining treatment
Western Australia	No	No	No current legislation. Investigation into this issue is continuing
South Australia	Yes	Yes	<i>Consent to Medical Treatment and Palliative Care Act 1995</i> confirms that a person over 18 years can write an AD anytime, (i.e. anticipatory) but only for terminal illness
Tasmania	No	No	No current legislation. Tasmanian Health Department has 'Dying with Dignity' guidelines which recommend respecting ADs
Australian Capital Territory	Yes	Yes	Refusal of treatment (as for Victoria). Protects health professionals who withhold/ withdraw treatment at patient's request
Northern Territory	Yes	No	<i>Natural Death Act 1998</i> allows person 18 years and over to make an AD to refuse extraordinary treatment in the event of a terminal illness

* All states/territories have guardianship legislation