

# Advance care planning and end of life decision making



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**BACKGROUND** Aging populations with greater rates of cognitive decline demand increased attention to the issues of end of life decision making and advance care planning (ACP). Legislatures have passed statutes that recognise the necessity for both substitute decision making and the declaration in advance of wishes relating to health care.

**OBJECTIVE** This article discusses ACP and the role of the general practitioner.

**DISCUSSION** Advance care planning provides patients, relatives and doctors with greater confidence about the future. There is good evidence that patients desire to discuss end of life care, and GPs are in a good position to engage their patients in considering the issues. They have a responsibility to confirm the decision making capacity of patients who write advance health directive documents, to inform and educate their patients about future health care, and to keep the ACP conversation going.

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

Health care expenditure per person is highest at older ages, being greatest for residential aged care facilities and acute hospital services.<sup>1</sup> 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 who do not wish to die in high technology hospitals must also be considered. A potential response to both concerns is advance care planning (ACP). Advance care planning 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 to make such decisions.

Australian data on ACP is limited,<sup>2,3</sup> although research conducted in Queensland<sup>4</sup> and the Northern Territory<sup>5</sup> demonstrated strong support from doctors, nurses and the general community for such actions. Nevertheless, a New South Wales study found very low levels of formal planning in the charts of residents in RACF.<sup>6</sup> This suggests that it is 'time for action'.<sup>7</sup> The commonwealth's Respecting Patient Choices program, recently piloted at the Austin and Repatriation Medical Centre in Victoria with plans for dissemination nationally, should enhance understanding of ACP in hospitals, and potentially, the wider community.<sup>8</sup> Such projects should assist health institutions and general practitioners to implement the

**Table 1. Summary of legislation affecting end of life issues**

State	Advance directive /refusal of treatment	Proxy/ agent*	Comments
VIC	Yes	Yes	Patient can write a 'refusal of treatment' certificate, but only for a current illness which does not have to be terminal. Medical Treatment (Enduring Power of Attorney) Act (1990) allows appointment of proxy
SA	Yes	Yes	Consent to Medical Treatment and Palliative Care Act 1995 confirms that a person over 18 years of age can write an AHD anytime (ie. anticipatory) but only for terminal illness
NT	Yes	No	Northern Territory Natural Death Act allows a person 18 years of age and over to make an AHD to refuse extraordinary treatment in the event of terminal illness
ACT	Yes	Yes	Refusal of treatment (as for Victoria). Protects health professionals who withhold/withdraw treatment at a patient's request
QLD	Yes	Yes	Powers of Attorney Act 1998 allows AHD and EPAs (proxy) for health/personal matters. Guardianship and Administration Act 2000 (and amendments 2001) increased scope. Proxy can now consent to withdrawing/withholding life sustaining treatment
NSW	Yes	Yes	Advance health directives that comply with the requirements of the NSW health document using advance care directives (2004) are legally binding. Individuals may also appoint their own guardians
TAS	No	No	No current legislation. Medical Treatment and Natural Death Bill (1990) not passed by Parliament. Tasmanian health department has 'dying with dignity' guidelines which recommend respecting AHD
WA	No	No	No current legislation. Private Members Bill for refusal of treatment by terminally ill people (Medical Care of the Dying Bill 1995) passed by Lower House November 1995, lapsed when election was called. This bill recommended patients be allowed to refuse palliative care

\* All states/territories have guardianship legislation

The USA, Canada and the Netherlands all have provision for AHD and proxy decision making. The UK does not have specific legislation for either, but a 1993 High Court decision (Re: C-Adult: Refusal of Medical Treatment) said AHD are legally binding and a House of Lords decision to withdraw tube feeding from a patient in a persistent vegetative state (Re: Bland) set an important precedent. In March 1995, a UK Law Commission report proposed a statute law for AHD. The issue is currently being debated again.

legislative recognition of ACP which has already been achieved.

## Legislation

A number of Australian states and territories now have specific legislation providing patients with a greater say in end of life decisions (*Table 1*). However, as each state and territory is responsible for its own health laws, there is no consistent legislation or policies on ACP in this country. Some states and territories have legislative provisions for patients to provide written instructions relating to their health care at a time of future incapacity (called variously 'advance health directives' [AHD] or 'living wills') and/or the appointment of surrogate decision makers or proxies (usually through an Enduring Power of Attorney) for personal/health matters. Other states have neither of these options in statute law, but have policies or guidelines advising health care providers to respect patients' wishes where possible. All states and territories have guardianship legislation, but in most cases a guardian will only be appointed where less formal mechanisms are inadequate.

## Enduring power of attorney for finances

Enduring power of attorney (EPA) legislation is not a new concept, but until the past decade or so in most states and territories it has only given the appointed proxy authority to make decisions relating to finances and/or property on behalf of the appointee. This has caused considerable confusion for health care providers, many of whom believed that a person holding an EPA also had the right to make health care decisions. There has been recent concern about poor financial decisions being made by appointed attorneys and in some cases, attorneys using the EPA to fraudulently access money or property belonging to the person who appointed them. However, it is well to remember that the only cases that come to the attention of the media and/or courts are those where the EPA is not working well. In the majority of cases, family members and others with EPAs do a very good job of protecting the rights and interests of their more vulnerable family members.

## Capacity

An important aspect of ACP is the issue of decision making capacity.<sup>9</sup> 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 that decision in some way. It does not mean that the patient has to make a decision that the doctor agrees with. For example, a competent patient has the right under common law – and

under statute law in some states and territories – to refuse any treatment, even life saving treatment such as a blood transfusion, dialysis or artificial nutrition and/or hydration; and this may be difficult for a health care provider to accept. However, proceeding to treat a competent and adequately informed patient who has refused treatment may render the health care provider liable to a charge of assault.

### Organ donation

End of life decisions that can cause great trauma for family members are those relating to organ donation. On the one hand, giving consent for a patient's organs to be used for others means accepting the death of the person they love; but on the other hand, the person's respiration and circulation must be continued until the organs can be removed, making it very difficult for family members to accept the person is really dead.

This issue received prominence earlier this year, when the Australian cricketer David Hookes died after an alleged altercation outside a Melbourne hotel and his family agreed that his organs could be used to give 'the gift of life to others'.<sup>10</sup> The family's decision was possibly made a little easier because they knew they were fulfilling his wishes. This is another potential benefit of ACP, not only in relation to organ donation but to withdrawing or withholding other life sustaining treatment. If a person has made their wishes clear, either in discussions with their appointed proxy or in a written AHD, it can make the doctor's decision easier and may also prevent family disagreements and recriminations at a time of great stress and trauma.

### ACP and the role of the GP

General practitioners 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.<sup>11</sup> Although a person of any age may be rendered incompetent because of an accident or illness, ACP is especially important for older people given the increasing rates of dementia and potential proximity to end of life. In addition to providing guidance and certainty for health care providers and family members about the care and treatment that 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, thereby allowing them to live the remainder of their life 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', ie. 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.

There is evidence to suggest that patients are receptive to discussing ACP. A study conducted in a general practice in Queensland in 2000,<sup>12</sup> found that while only a few patients knew about AHD, 70% wanted to know more about them, and 83% wanted family members to be substitute decision makers for health matters if they were too ill to make their own decisions. Many also wanted their GPs to be involved in such decisions.

General practitioners are adopting a more proactive approach to the care of their patients: a surgery visit by a child would usually prompt a check of immunisation status, while women of appropriate age should be prompted to keep Pap tests up-to-date. General practitioners are urged to provide information on ACP to all patients over 60 years of age, perhaps by initially giving the patient a brochure about options available in the relevant state or territory (available from most government departments of justice). General practitioners will be increasingly involved in facilitating the execution of advance care documents. In some states, these documents mandate patient education as well as a role in capacity assessment for doctors, and in most cases it will be GPs who will be approached for advice.

### Informed consent and ACP

The general principles governing informed decision making for medical treatment, or for its refusal, also apply to ACP. While the civil liability acts that a number of states have recently implemented following the recommendations of the Ipp Review of the Law of Negligence<sup>13</sup> have arguably somewhat weakened doctors' obligations in relation to disclosure, it remains the case that they must provide information about risks and consequences which are of significance to the particular patient, not just those which the doctor, or even a hypothetical reasonable person, would consider important.

### Conclusion

As we move into the 21<sup>st</sup> century, we will be confronted by more of the dimly foreseen consequences of medical progress. While some commentators are critical of an overemphasis 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.

### Summary of important points

- Advance care planning is a legally supported component of medical care.
- Advance care planning provides patients, families and doctors with confidence about future health care, assuming correct procedures are followed.
- GPs have a crucial role in initiating and facilitating discussions with their patients about the opportunities for advance care planning.
- The principles of informed decision making apply to advance decisions no differently from their application to current ones.

Conflict of interest: none declared.

### References

1. Australian Institute of Health and Welfare. Older Australians at a glance. Canberra: AIHW, 1999. Available at: [www.aihw.gov.au/publications/index.cfm/title/31.7](http://www.aihw.gov.au/publications/index.cfm/title/31.7)
2. Taylor D, Cameron P. Advance care planning in Australia: overdue for improvement. *Int Med J* 2002;32:475-480.
3. Taylor D McD, Tan S-L. Advanced directive knowledge and research appears lacking in Australia. *Emerg Med* 2000;12:255-256.
4. Steinberg MA, Cartwright CM, Najman JM, MacDonald SM, Williams GM. Healthy aging, healthy dying: community and health professional perspectives on end of life decision making. Report to the Research and Development Grants Advisory Committee (RADGAC) of the Commonwealth Department of Human Services and Health, 1996.
5. Cartwright CM, Robinson GW, Steinberg MA, et al. End of life decision making: perspectives of Northern Territory doctors, nurses and community members. The University of Queensland and Northern Territory University, 1998.
6. Nair B, McPhee J, Kerridge I, Saul P, Dobson A. Advance care planning in residential care. *Aust NZ J Med* 2000;30:339-343.
7. Vinen J. Advance care planning and advance directives: time for action. *Int Med J* 2002;32:435-436.
8. ARCHI Net NewsOct 2003. Australian Resource Centre for Healthcare Innovations (ARCHI). Available at: [www.archi.net.au/content/index.phtml/itemId/120954](http://www.archi.net.au/content/index.phtml/itemId/120954).
9. Biegler P, Stewart C. Assessing competence to refuse medical treatment. *Med J Aust* 2001;174:522-525.
10. Davies J-A. Dilemma of the off switch: a life and death decision. *The Bulletin*, February 3, 2004;26-33.
11. Commonwealth Department of Health and Family Services. *General Practice in Australia*, 1996.
12. Hawkins H, Cartwright C. Advance health care planning and the GP. Is it time to move forward? *Aust Fam Physician* 2000;29:704-707.
13. Review of the Law of Negligence Report. October 2002. Available at: [revofneg.treasury.gov.au/content/review2.asp](http://revofneg.treasury.gov.au/content/review2.asp). Accessed June 2004.

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