Advance care planning

Sara Bird

Background

Good Medical Practice: A Code of Conduct for Doctors in Australia[1] states that in caring for patients towards the end of their life, good medical practice involves facilitating advance care planning.

Objective

This article discusses the role of advance care planning in end-of-life care, with an emphasis on the ethical and legal framework for advance care directives.

Discussion

There has been an increased focus on advanced care planning and advance care directives in Australia, partly driven by the ageing population and technological advances, as well as the principle of patient-centred care. General practitioners have an important role in initiating and facilitating advance care planning.

Keywords

advance directives; palliative care; ethics; legislation and jurisprudence

CPD

Case

On 1 July 2009, Mr A presented to hospital suffering from septic shock. The following day, he was transferred to the intensive care unit, where he was intubated, ventilated and commenced on dialysis.

On 14 July 2009, the hospital became aware of an unsigned document that had been prepared by Mr A in 2008. The document was a proforma worksheet used by Jehovah's Witnesses to indicate their attitude to various forms of medical treatment. On the worksheet, Mr A had ticked 'I refuse' for dialysis and a number of other medical treatments.

Medico-legal issues

The hospital sought orders from the NSW Supreme Court that Mr A's document should be considered to be a valid advance care directive (ACD) and that the hospital would be justified in ceasing dialysis, in accordance with Mr A's wishes as expressed in the document.
On 15 July 2009, the Court made the declarations sought by the hospital.[2] The judgment outlined the following principles, which are applicable to ACDs:

- A person may make an ACD: a statement that the person does not wish to receive medical treatment, or medical treatment of specified kinds. If an ACD is made by a capable adult, and is clear and unambiguous, and extends to the situation at hand, it must be respected. It would be a battery to administer medical treatment to the person of a kind prohibited by the ACD (though there may be a qualification if the treatment is necessary to save the life of a viable unborn child).
- There is a presumption that an adult is capable of deciding whether to consent to or to refuse medical treatment. However, the presumption is rebuttable. In considering the question of capacity, it is necessary to take into account both the importance of the decision and the ability of the individual to receive, retain and process information given to him or her the bears on that decision.
- If there is genuine and reasonable doubt as to the validity of an ACD, or as to whether it applies in the situation at hand, a hospital or medical practitioner should apply promptly to the Court for its aid. The hospital or medical practitioner is justified in acting in accordance with the Court's determination as to the validity and operation of the ACD.

- Where there is genuine and reasonable doubt as to the validity or operation of an ACD, and the hospital or medical practitioner applies promptly to the Court for relief, the hospital or practitioner is justified, by the 'emergency principle' in administering the treatment in question until the Court gives its decision. The emergency principle means emergency medical treatment that is reasonably necessary in the particular case may be administered to a person without the person's consent if the person's condition is such that it is not possible to obtain his or her consent, and it is not practicable to obtain the consent of someone else authorised to give it, and if the person has not signified that he or she does not wish the treatment to be carried out. [
- It is not necessary, for there to be a valid ACD, that the person giving it should have been informed of the consequences of deciding, in advance, to refuse specified kinds of medical treatment. Nor does it matter that the person's decision is based on religious, social or moral grounds rather than upon (for example) some balancing of risk and benefit. Indeed, it does not matter if the decision seems to be unsupported by any discernable reason, as long as it was made voluntarily, and in the absence of any vitiating factor, such as misinterpretation, by a capable adult.[2]

Discussion

The importance of advance care planning, ACDs and quality care at the end of life has been a focus of government policy and professional groups over the past few years. In part, this focus has been driven by Australia's ageing population, medical and technological advances, which can prolong life, and an increase in demand for patient autonomy and patient-centred care.

What is advance care planning?

Advance care planning is a process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known so they can guide decision-making at a future time when that person cannot make or communicate his or her decisions.[3] Advance care planning is about person-centred care and is based on fundamental principles of self-determination, dignity and the avoidance of suffering.[4]

An advance care planning discussion will often result in an advance care plan. Advance care plans state preferences about health and personal care and preferred health outcomes. They may be made on the person's behalf and should be prepared from the person's perspective to guide decisions about care. There are many ways of recording an advance care plan including oral and written versions.

What is an advance care directive (ACD)?

An ACD is one way of formally recording an advance care plan. An ACD is a type of written advance care plan, recognised by common law or authorised by legislation, which is signed by a competent adult. An ACD can record a person's preferences for future care and appoint a substitute decision-maker to make decisions about healthcare and personal life management.[3]

Code of ethical practice for ACDs[3]

1. ACDs are founded on respect for a person's autonomy and are focused on the person.
2. Competent adults are autonomous individuals and are entitled to make their own decisions about personal and health matters.
3. Autonomy can be exercised in different ways according to the person's culture, background, history or spiritual and religious beliefs.
4. Adults are presumed competent.
5. Directions in ACDs may reflect a broad concept of health.
6. Directions in ACDs can relate to any future time.
7. The person decides what constitutes quality of life.
8. The substitute decision-maker (SDM) has the same authority as the person when competent.
9. The SDM must honour residual decision-making capacity.
10. The primary decision-making standard for SDMs is substituted judgement.
11. A SDM should only base his or her decision on 'best interests' when there is no evidence of the person's preferences on which to base substituted judgement.
12. An ACD can be relied upon if it appears valid.
13. A refusal of a health-related intervention in a valid ACD must be followed, if intended by the person to apply to the situation.
14. A person, or their legally recognised SDM, can consent to treatment offered, refuse treatment offered, but cannot demand treatment.
15. A valid ACD that expresses preferences or refusals relevant and specific to the situation at hand must be followed.

Problems and challenges with ACDs

To date ACDs have not proved to be a popular planning tool. This is despite the fact that individuals are encouraged to discuss with their families how they would like their healthcare to be managed if they are no longer able to make their own decisions, and for general practitioners to incorporate advance care planning as part of routine healthcare, including raising the topic with all older patients. However, ACDs cannot solve all the challenges of substitute decision-making; they cannot resolve all conflicts in families, nor can they guarantee a smooth decision-making pathway for the health and aged-care sectors.[3]

Some of the concerns that have been raised in relation to the use of ACDs are:

- validity and reliability – the person making the ACD may lack the information required to make an informed choice, especially where the ACD is made prior to the onset of an illness for which a treatment decision must be made, and the way in which the ACD is written may be influenced by the manner in which questions are posed
- durability – an individual's treatment choices can change over time such that an ACD made at a particular time may not accurately reflect the person's wishes at a later date, and may not reflect advances in medical practice
- efficacy – the person's wishes may not be able to be accurately ascertained from an ACD with sufficient clarity to guide clinical management

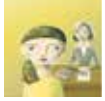

Table 1. State and territory restrictions on ACDs

State/Territory	Name of ACD	Restrictions
ACT	Health Direction	
NT	Direction	Effective only when a person has a terminal illness
Queensland	Advance Health Directive	For directions to withhold/withdraw life-sustaining measures: 1. direction cannot operate unless there is no chance of the patient regaining capacity and any of the following: • terminal illness/incurable condition and expected to die in 1 year • permanent coma/post-coma unresponsiveness • illness/injury so severe that no reasonable prospect of recovery without life-sustaining measures 2. for directions regarding artificial nutrition/hydration (ANH), commencing or continuing ANH would be inconsistent with good medical practice
SA	Anticipatory Direction	Effective only when a person is in the terminal phase of a terminal illness, or in a persistent vegetative state (still legally effective after 1 July 2014)
SA	Advance Care Directive	Effective from 1 July 2014
Victoria	Refusal of Treatment Certificate	Does not cover procedures that would be considered palliative
WA	Advance Health Directive	A treatment decision will not operate if circumstances exist that the person would not have reasonably anticipated at the time of making the directive and would have caused a reasonable person to change their mind about the treatment decision
Legislation in this area is evolving and a more detailed summary of the legislation in each state and territory can be accessed at Advance Care Planning Australia's website at http://advancecareplanning.org.au/advance-care-planning/for-professionals/the-law-of-advance-care-planning		

- accessibility – an ACD may not be able to be located when needed
- portability – each state and territory has a different legislative framework for ACDs.

As a result of these factors, medical practitioners may be concerned about following an ACD, especially where they do not believe it represents 'good' medical decision-making, or that the ACD may not represent the true wishes of the patient. Medical practitioners may also be concerned about potential liability, especially where there is conflict with the wishes of the patient's family.

Legislative Framework for ACDs

Legislation governing ACDs has been enacted in every Australian state and territory, except NSW and Tasmania where the common law applies with regard to ACDs. However, the legislation is complex and there is considerable variation in the scope of the legislation.

The legislative name of ACDs varies between jurisdictions, and there are differing restrictions that affect their operation, as outlined in *Table 1*.

Key points

- General practitioners should aim to incorporate advance care planning as part of the routine health care of older patients.
- A valid ACD that is clear, unambiguous and extends to the situation at hand must be followed.
- There is considerable variation in legislation across the states and GPs should be aware of the legislative requirements for ACDs in their own jurisdiction.

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