

How do you think we could improve the advance care directive in Western Australia?

- 1. By making advance health directives strongly advisory, but not ultimately binding, especially when implementing the directive would be contrary to good medical practice.**

There is a substantial body of research on advance care directives which raises serious doubts as to their effectiveness in ensuring that those who make such directives achieve the supposed goal of such advanced directives.

Fundamental problems with Advance Care Directives include prescribing forms of medical treatment without knowing the precise circumstances in which a directive may be used. This means that ACDs run the risk of being too specific, and not covering certain situations, or too general, bringing problems with how to interpret directives.ⁱ

These and other problems with advanced health directives are confirmed in the landmark paper examining the extensive experience with such directives in the United States, “*Enough: the failure of the living will*” by Angela Fagerlin and Carl E. Schneider.ⁱⁱ

[P]eople who sign living wills have generally not thought through its instructions in a way we should want for life-and-death decisions. Nor can we expect people to make thoughtful and stable decisions about so complex a question so far in the future ... [D]rafters of living wills have failed to offer people the means to articulate their preferences accurately. And the fault lies primarily not with the drafters; it lies with the inherent impossibility of living wills’ task. ... [L]iving wills seem not to increase the accuracy with which surrogates identify patients’ preferences. And the reasons we surveyed when we explained why living wills do not affect patients’ care suggest that these problems are insurmountable.ⁱⁱⁱ (Fagerlin and Schneider, page 38).

Consent to medical treatment is not held to be legally valid unless an appropriately qualified medical practitioner has explained to the patient the nature and purpose of the treatment, as well as any risks or side effects, and what alternatives are available. It is simply not possible to ensure that a person completing an advanced health directive is adequately informed before signing it.

It seems perverse to make uninformed decisions on future medical treatment binding.

Fagerlin and Schneider write:

Nor do people reliably know enough about illnesses and treatments to make prospective life-or-death decisions about them ... For such information, people must rely on doctors. But doctors convey that information wretchedly even to competent patients making contemporaneous decisions. Living wills can be executed without even consulting a doctor, and when doctors are consulted, the conversations are ordinarily short, vague, and tendentious. In the Tulskey study, for example, doctors only described either ‘dire scenarios . . . in which few people, terminally ill or otherwise, would want treatment’ or ‘situations in which patients could recover with proper treatment.’^{iv}

In July 2004 Western Australian Deputy State Coroner Evelyn Vicker warned carers in nursing homes of their legal duty to ignore "refusal of treatment" cards promoted by euthanasia societies. The Coroner was reporting on the death of Grace Kathleen Parsons, who died in a Busselton nursing home after choking on her lunch. The Coroner found that staff at the nursing home did not give Grace Parsons life saving medical treatment because they were aware of the refusal of treatment card. One doubts that Grace Parsons imagined when she signed this card that she would be left to choke to death on a piece of roast beef.^v

Section 103 of Queensland's *Powers of Attorney Act 1998* usefully provides that a health professional is protected from liability for departing from a direction given in an advance health directive:

(a) if a health provider has reasonable grounds to believe that a direction is uncertain;

(b) if a health provider has reasonable grounds to believe that a direction is inconsistent with good medical practice; or

(c) if a health provider has reasonable grounds to believe that circumstances, including advances in medical science, have changed to the extent that the terms of the direction are inappropriate.

These conditions provide protection for liability for doctors, and help ensure that advanced health directives, which can be a useful guide to a person's preferences for health care treatment, are not inappropriately applied in ways that could be contrary to the person's actual intentions or that violate good medical practice.

This approach effectively treats all advance care directives as non-binding. Health practitioners would still be obliged to "as far as is reasonably practicable, comply with" any provision of an advance care directive that relates to health care subject to giving effect to professional standards and current standards of health care.

2. By providing clear reference to goals of care and values in Advance Care Directives, including on the ACD form.

This practice is already standard in NSW and Victoria. The WA Advance Directive does not provide information about this on the form. The NSW system has an entire document dedicated to it. Having values and goals of care written down can help doctors make decisions that reflect patient's wishes. It helps to convey the general approach to a patient's care that the patient would like to receive without committing to a specific action in a given situation. In this way, medical professionals can receive information via an ACD about specific treatment in certain circumstances, as well as a more general approach when designated situations are not in view.

Compare the WA form:

http://healthywa.wa.gov.au/~media/Files/HealthyWA/Original/HP11536_advance_health_directive_form.pdf

With the form from Victoria:

3. By encouraging people to make ACDs in relationship with medical professionals, especially GPs and specialists.

This would address the problems outlined by Fagerlin and Schneider above, and enable the doctor to provide clear and detailed advice on what patients can expect in relation to their illness. They may then how the patient may wish to address these issues, or what possible choices or decisions the patient may end up having to make. This could mandate the need for a person to provide evidence of consultation with a GP or specialist in order to draw up any legally binding Advanced Care Directive.

4. By providing an effective way to store/access ACDs that makes it easy for doctors to find information on a patient's wishes and values

Direct and easy access to Advance Care Directives can often present a problem for doctors, as there is no centralized system of storage/access for ACDs. This is made worse by time pressures, and dealing with other medical records that patients have. Governments generally recommend that patients share advanced care planning documents with their healthcare providers by uploading them online to their MyHealth record, and lodging them with their treating doctor, GP and hospital. Having a system that directly integrates ACDs into the medical record systems is important, so that doctors and other medical professionals have direct and easy access to this information.

i Medical Treatment for the Dying: Discussion Paper, p.13 at:

<http://www.health.wa.gov.au/publications/documents/Medical%20Treatment%20for%20the%20Dying%20Discussion%20Paper%20May%202005.pdf>

ii Angela Fagerlin and Carl E.Schneider , "Enough : the failure of the living will", *Hasting Centre Report*, March-April 2004, p 30-42; http://www.thehastingscenter.org/Pdf/Publications/Hcr_Mar_Apr_2004_Enough.Pdf

iii Ibid, p. 38

iv Ibid., p. 33 citing J.A. Tulsky et al., "Opening the Black Box: How Do Physicians Communicate about Advance Directives?" *Annals of Internal Medicine* 129 (1998): 441, 444

v Personal communication from Dr E.D. Watt, who attended the coronial hearing.