

ADVANCE DIRECTIVES

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This paper was originally presented at the 'Christian perspectives on the end of life' CASE Conference in March 2010. Dr Best has authored a number of papers on bioethical issues which can be found on the CASE website (www.case.edu.au). Her most recent paper, which discusses the arguments for and against euthanasia from a Christian perspective, appears in issue #25 of Case magazine (December 2010).

An observer of Western media might be confused by stories of families pleading for an expensive treatment to prolong the life of a loved one sitting alongside reports of lawsuits where other families are demanding that life-prolonging treatment be ceased or even that euthanasia be made legal. What are we to make of this? What is the appropriate response in the face of life-limiting illness?

For Christians, these are questions that do not have straightforward answers. This is because at the end of life there is a balance to be struck. On the one hand, we are not free to hasten death – it is God's to give and take away. Yet on the other hand, there is no imperative in the Bible that says we need (or even should) hold on to life at any expense - treatment should be proportional to the patient's situation. And it's okay to say it's time to go. Inside the poles of euthanasia on the one hand, and doing 'everything possible' on the other, I believe God has generously given us choices regarding what treatment we want to receive as our life comes to its end.

God created humans with free will. Since the Garden of Eden he has allowed us to make choices, even as important a choice as whether we will receive eternal salvation. Our freedom is an essential part of what it means to be human. A truly moral choice, therefore, will need to be one which is made freely.

The need for decisions to be made freely is a fundamental morality in modern medicine. Valid consent must be given by a mentally competent patient (the patient must be able to understand what doctors want to do and why), the decision must be made voluntarily (with no coercion or pressure from others), and it can only be made after all relevant information has been explained to and understood by the patient.

But what do we do when the patient is NOT mentally competent? When she is confused or unconscious and a decision needs to be made about treatment—what do we do then?

In this setting, an **advance directive** can be helpful in determining what the patient would have wanted had she been able to express her wishes. An advance directive explains a patient's preferences for treatment should they become unable to tell you themselves. Australian governments are showing increasing interest in these documents and it is helpful for us to understand what they are and how they can be used.

At the end of our lives, most of us will be very vulnerable. Christians are called to be salt and light in our community (Matthew 5): salt to preserve the good and light to illuminate God's truth. I believe this encompasses the need for Christians to be advocates for those

who are coming to the end of life, taking a role in public debate to ensure that justice is done and that at a time when our medical decisions have life or death significance, our choices are recognised.

In this paper I would like to briefly outline

1. the history of how advance directives developed
2. important features of advance directives
3. potential problems and how they can be avoided

Karen Ann Quinlan

On April 15, 1975, Karen Ann Quinlan was 21 years old and had just moved out of her parents' home in New Jersey, USA. It is thought that she probably stopped breathing after taking a cocktail of drugs and alcohol, which caused irreversible brain damage due to lack of oxygen (anoxic brain injury). She was resuscitated and initially put on a respirator, but remained in a coma, fed by a tube, for more than ten years before she died. Her case became famous when her parents went to court to get permission to let her die.

This story prompted much public concern regarding life-sustaining treatment. The vision of an invasive feeding tube and respirator symbolised oppressive medical technology which was unnaturally prolonging dying, keeping people alive as so-called 'living vegetables'. Members of the public expressed the need to protect themselves from being kept alive 'like Karen Ann Quinlan', and so the legal options of substitute decision - making were devised.

1. Living wills or Advance Care Directives are documents which permit people to express their wishes in advance and thereby leave clear evidence as to what treatment they would or would not want in the event that they become mentally incompetent. However, it soon became obvious that it was impossible to anticipate all possible medical scenarios - there are so many different things that **COULD** happen, you can't possibly cover them all. So this led to a second form of advance directive (AD) becoming popular, the

2. Enduring guardianship or durable power of attorney for health care (DPA).

This legal arrangement allows the patient to decide in advance **who** could make treatment decisions for them if they become incapacitated, the idea being that they would choose someone who shares their values and knows their wishes in detail, this person not always being the official next of kin. In many cases the one who knows the patient best may not be the next of kin. It is not uncommon for an elderly patient to have as next of kin a child who lives a fair way away, and it is the next door neighbour who cares for them who is best placed to know what treatment they would want.

In view of the context in which living wills arose and the development of prototypes by pro-euthanasia groups, some Christians are concerned that ADs represent a surreptitious method for legalising euthanasia. This fact should not lead us to reject ADs out of hand, but rather to examine them carefully. Obviously, under-treatment needs to be avoided as much as over-treatment, especially in the current political climate. But the greater use of advance directives could have advantages.

We know that for patients at the end of life, inappropriate prolongation of dying, loss of control and being a burden are things they want to avoid.¹ There are several ways we can help patients achieve this.

Many patients are empowered by the knowledge that they have the right to refuse treatment, even if it is a life-shortening decision.² The provision of Palliative Care³ reduces and can reverse requests for euthanasia.⁴ But encouraging patients to consider ADs is also a logical way to meet this need for control. Systematic implementation of a programme to increase use of ADs in Canadian nursing homes enabled patients to elect to be treated where they lived, instead of being sent to emergency every time they got sick. This was generally felt to be a great improvement.⁵ But if we want to avoid abuse, the way the document is written is important. It is worthwhile for us to spend time thinking about this, because an advance directive is probably coming soon to a health area service near you!

In order for ADs to fulfil their legal function it would be reasonable to expect that they would have certain features. They would need to be completed voluntarily by a person of sound mind aged over 18 years. It would be preferable to have precise language to avoid

¹ P. Singer *et al*, 'Quality end-of-life care'. *JAMA*, Vol. 281(2), 1999, pp163-168.

² Such a choice would not be euthanasia, as it would not involve killing the patient, but stopping treatment so that the underlying disease runs its course, and causes the ending of life naturally.

³ Palliative Care Australia defines Palliative Care as 'specialised care for dying people aiming to maximise quality of life, and to assist families and carers during and after the death'.

⁴ P.A. Glare, 'The euthanasia controversy. Decision-making in extreme cases', *The Medical Journal of Australia*, Vol.163, 1995, p558.

⁵ D.W. Molloy, 'Systematic implementation of an advance directive program in nursing homes', *JAMA*, Vol.283 (11), 2000, pp1437-1444.

confusion (what does *I never want a tube in my gullet* mean?) Use of a standardised form would ensure that all necessary information is provided. Treating physicians should be protected from being sued where they act on them in good faith. (If, for example, the family disagrees with what the patient wanted at the end and suggests that the doctor was negligent in her care).

We know that patient preferences for life-sustaining treatments can change over time.⁶ Compare the attitude towards illness of your average 20 year old to that of a 50 year old, for instance. This would suggest that there is an argument for requiring patients to review their ADs on a regular basis so that views expressed remain current, for example, every year, or after a change in health status. The option for the patient to revoke the AD at any time should also be available. Many people find the imagined hardship of illness is in fact not so bad once it happens to them. You might change your mind about the treatment you want. Witnesses would offer some protection against forgery and coercion.

Before considering the content of ADs in detail, it is helpful to compare the usefulness of the written document to that of DPA. Even though having things in black and white is reassuring, the advantage of DPA is that the patient would be able to discuss his preferences, values and goals so that decisions can be made in the **spirit** of the patient's choices, not just according to documentation. Any advance directive is best written in the context of discussions about advance health care planning, in fact it is the conversation

⁶ M. Danis *et al*, 'Stability of choices about life-sustaining treatments', *Annals of Internal Medicine*, Vol. 120 (7), 1994, pp567-573.
C.J. Ryan, 'Betting your life: an argument against certain advance directives', *Journal of Medical Ethics*, Vol.22, 1996, pp95-99.

around the writing of the AD, the advanced planning process, which can be the most helpful.

Consider the following scenario: an elderly man is admitted to hospital following a stroke which leaves him unconscious and unable to swallow. He is a widower and his next of kin is an adult daughter. In the Emergency department, the doctors insert a nasogastric tube (a plastic tube inserted through the nose and ending in the stomach) to allow safe feeding as the patient cannot swallow. The daughter arrives and produces her father's living will which states that he does not want to be kept alive through artificial feeding. The doctors explain that the tube is a temporary measure to allow feeding until they know whether and how much the patient will recover. The daughter is unsure of what to do, as she knows her father envisaged a permanent rather than temporary coma when writing the will. He'd had a friend in a nursing home who'd had one for six months before he died which caused him much suffering. Even though she now realises he hadn't been informed about the short-term option, the daughter is reluctant to go against her father's written request.

As is often the case, this happens on a Friday afternoon and the decision is postponed until Monday morning. By then the patient wakes up, starts swallowing, and has the tube removed. To his daughter's relief, he appreciates the medical care and eventually goes back to his nursing home.⁷

⁷ This is a true story.

Had this patient put a DPA in place rather than opt for a living will, less confusion and stress would have arisen. A variation on the DPA is to make available a personal letter indicating preferences, which is not a legal document, so it can be a guideline to help the doctors and surrogate decision-maker without being too specific. This is similar to the way things are done in the UK.

Regulation of decision-making at the end of life is decided in Australia on a state basis. Legislation providing for ADs exists in every state and territory except Tasmania and NSW, where common law applies. The legislation varies from state to state.

It is the responsibility of the doctor to ensure that the AD is valid before making treatment decisions, and if uncertain, she should treat according to the patient's best interests while seeking legal advice. If a valid AD is ignored, the physician is compromising patient autonomy and this may constitute battery, however withholding treatment in line with an invalid AD risks harm to the patient and may constitute breach of duty of care and negligence.⁸

New South Wales has always avoided the legislative pathway and regularly updates relevant Health Department documents such as *Guidelines for end-of-life care and decision making* (most recently in 2005) and *Using Advance Care Directives*⁹. According to the latter, written ADs complying with set requirements are legally binding and function as an extension of the common law right to determine one's own medical

⁸ P. Biegler *et al*, 'Determining the validity of advance directives', *Medical Journal of Australia*, Vol.172, 2000, pp 545-548.

⁹ Both documents are available at <http://www.health.nsw.gov.au/>

treatment. Non-compliance with such a directive may technically result in the physician incurring legal liability, but it is recommended in the *Directives* that it be used as an aid to decision making only. The resulting ambiguity is seen as a problem by many health professionals. Despite this, in my opinion no legislation and relying on a clinician's judgement for each case is better than bad legislation.

Appointment of a substitute decision-maker is possible under guardianship legislation in all Australian states and territories.

As mentioned previously, ADs have traditionally contained instructions to avoid over-treatment. It is also possible to express a wish to avoid under-treatment. An AD cannot instruct the treating doctor to perform an illegal act (such as euthanasia), or to prescribe treatment which is not clinically appropriate. You can't have something through an AD that you can't have any other time. However, it is possible to indicate that the patient is keen for all appropriate life-prolonging measures to be used. And for all situations, whatever the patient requests, the comfort of the patient is vital. I believe that it should never be possible for the patient to refuse basic supportive nursing care and palliative care, a point which is not made clear in all current legislation. (Palliative care is aimed at providing symptom relief and aims to neither hasten nor defer death.) I believe that it is not good for our health professionals or our society to allow this to happen. No-one should be abandoned in their dying.

Consideration of the likely events surrounding the need for an AD makes it obvious that it would be sensible to encourage patients to write an AD with their general practitioner, who is aware of their medical history and who also could let the relevant people know that an AD exists should the need arise. The most common reason an AD is ignored is because no-one knew it existed. Remember that by the time you need it, you won't be able to tell anyone yourself – so make sure you hand out copies to the people who will use them!

The doctor is also in a position to assess the patient's mental competence at the time, so that the document is not considered invalid. Possible situations for patients to consider when writing an AD are limitless, but should include issues such as resuscitation (when the heart stops beating), mechanical ventilation (when breathing stops), tube feeding (through the nose or the stomach) and dialysis (replacing lost kidney function). Patients can make better decisions when better informed about what the intervention entails, when it might be considered, benefits compared to burdens, and consequences of it not being used.^{10,11}

Watchers of prime time medical dramas on TV may be interested to learn that although there the success rate of cardiopulmonary resuscitation (CPR) is such that 67% patients get to go home by the end of the episode, in real life things are different. Up to 22% patients will get to go home if someone actually notices them collapse, but it can be as

¹⁰ B. Lo & R. Steinbrook, 'Resuscitating Advance Directives', *Archives of Internal Medicine*, Vol. 164 (14), 2004, pp1501-1506.

¹¹ E.K. Prenskey, 'Knowledge and perceptions in advance care planning', *Journal of Aging and Health*, Vol.20 (1), 2008, pp89-106.

little as 1% if they don't. TV gives us unrealistic expectations of successful outcome.

When educated on actual survival rates, patient requests for CPR in the event of cardiac arrest is halved.

We have a healthcare system that puts great emphasis on informed consent. You might think that acting on an AD that was completed without medical input is the equivalent to treating without *informed* consent. Yet current legislation in South Australia, the Australian Capital Territory, the Northern Territory and Western Australia does not require the input of a medical practitioner to make the AD legally valid. In fact, the following features are not mandatory in all current Australian legislation for ADs: use of a standardised form, mandatory palliative care, insistence on precise language, regular review and easy revoking.

In the event of an emergency there may not be time to ascertain whether an AD exists, whether it is legal, and exactly what it includes. In such a situation it is preferable for a doctor to act in accordance to what is perceived to be in the patient's best interests without fear of liability, while legal advice is sought as a matter of urgency so that the patient's views, if available, can be taken into account as quickly as possible.

Institutionalised patients should keep a copy of written ADs in their notes.

Now, some general practitioners reading this may be thinking, 'How much time is something like this going to take?' It doesn't have to be a complicated process, but something that can happen over time as part of ongoing care. *Respecting patient*

*choices*¹² is a programme which originated in Victoria and which is now being piloted across the country by the Federal Government. It puts ADs firmly in the context of advance care planning and offers training to medical personnel to assist them in the process. It is an encouraging initiative.

In summary, in the current environment where patients desire more control in their terminal illness, advance care planning allows patients to make informed choices about their future care. As a part of this process, development of a precise format for ADs with clear legal ramifications would do much to empower patients, reduce unnecessary suffering, and neutralise the push for euthanasia. But safeguards need to be in place within such legislation to avoid misunderstanding and abuse. These precautions are not present in all current AD legislation in Australia. While we should not automatically oppose the introduction of ADs, we need to be alert to the need to do all we can to make sure they are well constructed.

¹² <http://www.respectingpatientchoices.org.au/>