

Medico-Legal Society Essay 2003

The legality of advanced directives

John Chal

“The bias against treatment in some advance directives is so strong as to limit the autonomy of the health care team and informal carers. For instance, some suggested directives dictate that in the event of Alzheimer’s disease all life-sustaining treatment should cease; this would forbid the giving of insulin to a diabetic patient with Alzheimer’s disease if the directive were legally binding. Withdrawal of insulin in these circumstances might well be morally objectionable to the whole health care team, and it is hard to see how the autonomy of health care professionals could be safeguarded if such directives were legally binding. Another example would be a legal document specifying no surgery, which could prevent the pinning of a fractured hip.”

**Lord Ralinson of Ewell, House of Lords,
Select Committee on Medical Ethics, House of Lords Vol. II, 13.7.93:208**

Introduction

Doctors have a responsibility to make the care of their patients their first concern. This is essential when considering any of the growing range of life-prolonging treatments and modern health care practices, which make it possible to extend the lives of patients who, through life-threatening conditions, might otherwise die.

The best known written code for medical practitioner is the Hippocratic oath¹. The central statement is: *“I will use my power to help the sick to the best of my ability and judgment; I will abstain from harming or wronging any person by it.”*

Therefore, the initial response to an advanced directive is to ignore it, and simply administer the antibiotics or treatment required to help a patient recover and, remain alive. However, dilemmas may arise concerning treatment and preserving life, and in these instances the question arises as to whether it is in the best interests of the patient to start or continue the treatment. Reaching a satisfactory answer may mean addressing a number of difficult ethical and legal issues.

The main questions that arise in terms of advanced directives are:

- Whether the ethical principle requiring doctors to show respect for human life would mean that doctors should offer all means at their disposal to treat, and prolong the life of a patient? Or would it allow for the possibility of withholding or withdrawing a life-prolonging treatment?
- Are there circumstances in which withholding or withdrawing life-prolonging treatment would be unlawful?
- What are the responsibilities in the decision-making process of the patient, doctor, healthcare team, family members and other people who are close to the patient? What weight should be given to their views?

These issues have caused considerable debate amongst the profession, public and in the courts, highlighting a number of concerns within the wider community. These include concerns about:

- the possibility of over/or under-treatment;
- concerns that some doctors may make decisions about treatment without access to up to date clinical advice; and
- concerns that doctors may make judgements about the appropriateness of treatment (or non-treatment) on a quality of life basis regarding patients, particularly the very young or very old, which patients or society as a whole may not support.

¹ Lloyd GEL, ed. *Hippocratic writings*. Harmondsworth: Penguin, 1978.

It is also clear that the profession requires more guidance on what is considered ethically and legally permissible in this area; that patients and their families should have greater involvement in making these decisions², with better arrangements to support them when facing these distressing situations.

There is guidance available to doctors based on long established ethical principles, which include doctors' obligations to show respect for human life; protect the health of their patients; and to make their patients' best interests their first concern (as outlined below). This takes account of those areas of broad consensus so far established within the medical profession and the public about what can be regarded as good practice in applying the principles to decisions health care treatment.

Thus, doctors have an obligation to work within the law. A summary of the current legal background against which decisions should be made about withholding or withdrawing treatment is provided below in the labelled section.

Advanced Directives

An advance directive informs doctors and health professionals what kind of care a person would like to have if they became unable to make medical decisions (for example, if one is in a coma). A good advance directive describes the kind of treatment a person would want depending on how sick they are. For example, the directives would describe what kind of care a person would want if they have an illness that they are unlikely to recover from, or if they were permanently unconscious. Advance directives usually tell doctors that a person does not want certain kinds of treatment.

An advanced directive is a document that provides a person the opportunity to give directions about future medical care. It can also serve as a legal document designating another individual to make decisions on behalf of another, if they are unable to make those decisions for them self. This document will speak on one's behalf if they become incapacitated.

Traditional living will states one's wishes about life-sustaining medical treatments if one is terminally ill. In a health care Power of Attorney, one may appoint someone else to make medical treatment decisions for them if they are unable to make them. However, unlike most living wills, an advance directive is not limited to cases of terminal illness. If one cannot make or communicate decisions because of a temporary or permanent illness or injury, an advance directive helps to keep control over health care decisions. In a health care advance directive, a person states their wishes about various aspects of their health care, including decisions about life-sustaining treatment.

As an important review of a recent paper from Canada states "The authors conclude that: an advance directive prepared by a healthy person is not a valid indicator of the preferences of a similar person when sick."³ This is not necessarily an argument

² The House of Lords (1994) *Report of the Select Committee on Medical Ethics* recommended that additional safeguards are needed to protect the interests of the vulnerable, and to ensure that doctors only take these decisions after appropriate consultation.

³ Comment in *Bulletin of medical Ethics review*, March 1993, p.17, on: Tierney, M C et al.

against advance directives, but it is an argument against them having the force of law. It is generally accepted that people change their minds when they become unwell, but an earlier advance directive might still be in force.

In a memorandum by the Association for Palliative Medicine (Ethics Group) in Britain, they stated that: “A comprehensive review on the subject of advance directives is given in the statement of November 1992 by the British Medical Association (BMA). The BMA is not in favour of legal enforcement of such documents, a view with which we entirely agree.”⁴ The BMA particularly highlighted the following points against allowing advance directives to be enforceable by law.

Ambiguity and the Scope for Misinterpretation

Whatever care is put into the wordings of advance directives the precise meaning of terms such as terminal illness, active treatment and competence will always be open to doubt.

Pressure on Vulnerable Groups

The likelihood of particularly the elderly and chronic sick who feel themselves to be a burden being pressurised into signing advance directives will increase if such documents become legally binding.

Bias

Bias against active treatment inherent in some published advance directives may limit rather than enhance an individuals’ autonomy.

Implications for Euthanasia

Deploring moves to make advance directives legally binding as part of a gradualist policy to legalise euthanasia.

Thus, they concluded that the interests of patients would be best served by resisting attempts to make advance directives enforceable by law⁵.

Hence, in light of the legal status and enforceability of an advanced directive, it appears that a patient’s wish to “be allowed to die if and when the opportunity were to present itself” should be adhered to and respected (for relevant case law and precedents, see the relevant section below.)

Respect for human life and best interests

Doctors have an ethical obligation to show respect for human life; protect the health of their patients; and to make their patients’ best interests their first concern. This means offering those treatments where the possible benefits outweigh any burdens or risks associated with the treatment, and avoiding those treatments where there is no net benefit to the patient.

“How reliable are advance Directives for Health care? A study of attitudes of the healthy and unwell to treatment of the terminally ill.” *Annals of the Royal College of Physicians and Surgeons of Canada*, 1992, 25, 267-70.

⁴ House of Lords (HL) *Select Committee on Medical Ethics*, Vol. II, 13.6.93: 183

⁵ *Ibid.*,

Benefits and burdens for the patient are not always limited to purely medical considerations, and doctors should be careful, particularly when dealing with patients who cannot make decisions for themselves, to take account of all the other factors relevant to the circumstances of the particular patient. It may be very difficult to arrive at a view about the preferences of patients who cannot decide for themselves, and doctors must not simply substitute their own values or those of the people consulted.

Adult patients who can decide for themselves

Adult competent⁶ patients have the right to decide how much weight to attach to the benefits, burdens, risks, and the overall acceptability of any treatment. They have the right to refuse⁷ treatment even where refusal may result in harm to themselves or in their own death, and doctors are legally bound to respect their decision⁸. Adult patients who have the capacity to make their own decision can express their wishes about future treatment in an advance statement.

Adult patients who cannot decide for themselves

Any valid advance refusal of treatment - one made when the patient was competent and on the basis of adequate information about the implications of his/her choice - is legally binding and must be respected where it is clearly applicable to the patient's present circumstances and where there is no reason to believe that the patient had changed his/her mind.

Where adult patients lack capacity to decide for themselves, an assessment of the benefits, burdens and risks, and the acceptability of proposed treatment must be made on their behalf by the doctor, taking account of their wishes, where they are known. Where a patient's wishes are not known it is the doctor's responsibility to decide what is in the patient's best interests.

Applying these principles may result in different decisions in each case, since patients' assessments of the likely benefits and burdens or risks, and what weight or priority to give to these, will differ according to patients' different values, beliefs and priorities. Doctors must take account of patients' preferences when providing treatment. However, where a patient wishes to have a treatment that - in the doctor's considered view - is not clinically indicated, there is no ethical or legal obligation on the doctor to provide it. Where requested, patients' right to a second opinion should be respected.

Where a patient lacks capacity to decide, the doctor, health care team or those close to the patient involved in making the decision, may reach different conclusions about the patient's preferences and what course of action might be in the patient's best interests. In these cases it is important to take time to try to reach a consensus about treatment

⁶ A patient will be competent if he or she can: comprehend information, it having been presented to them in a clear way; believe it; and retain it long enough to weigh it up and make a decision. From *Re C (Adult: Refusal of Medical Treatment)* [1994] All ER 819.

⁷ Note the provisions of the *Mental Health Act 1983*, England, permit compulsory treatment of detained patients for their mental disorder in certain circumstances.

⁸ *Re: A (Children) (Conjoined twins: surgical separation)* [2000] 4 All ER 961.

and it may be appropriate to seek a second opinion, or other independent or informal review.

In the rare circumstances where any significant disagreement about best interests cannot be resolved, legal advice should be sought on whether it is necessary to apply to the court for a ruling. Doctors practicing in Scotland have to take account of the statutory procedures for resolving disagreements, if an agreement as to treatment cannot be made.

Where patients lack capacity to make decisions about treatment, and there is a reasonable degree of uncertainty about the appropriateness of providing a particular treatment, treatment which may be of some benefit to the patient should be started until a clearer assessment can be made. It must be explained clearly to all those involved in caring for the patient that the treatment will be reviewed, and may be withdrawn at a later stage, if it is proving to be ineffective or too burdensome for the patient.

Choosing between options: patients who cannot decide for themselves

In cases where the dying process itself affects capacity, the correct course of action for the patient may have been decided previously, following the guidance above. Where no such advance care plan has been agreed, or the plan has not been reviewed recently or is not relevant to the patient's current condition, doctors and health professionals should follow the advice below.

Where patients have difficulty retaining information, communicating their views or are only intermittently competent, doctors should provide any assistance a patient might need to enable them to reach and communicate a decision. Failure to communicate may not be due to incapacity. The fact that the patient's choice appears irrational or does not accord with the doctor's or others' views of what is in the patient's best interests is not evidence in itself that a patient lacks capacity.

Where there are doubts about a patient's capacity to make a decision, medical practitioners should carry out a thorough assessment consulting relevant professional guidelines⁹, and taking into account any legal tests of capacity¹⁰. Where appropriate, a second opinion should be sought. Where these steps have been taken and a patient's capacity to decide remains in doubt, legal advice, as in the current situation must be sought, which may include asking a court to determine capacity.

Meeting the responsibility for assessing the patient's best interests

Where a patient lacks capacity to decide, reasonable steps should be taken to ascertain whether they have previously expressed their wishes in an advance statement. Doctors must respect any valid and clinically relevant advance refusal of treatment where they have no reason to believe that the patient has changed his/her mind. In making this assessment, it is necessary to consider whether the patient had foreseen the particular circumstances which have subsequently materialised, or would have

⁹ For example *Assessment of Mental Capacity: Guidance for Doctors and Lawyers*. The Law Society/BMA, 1995.

¹⁰ See *Re C (Adult: Refusal of Medical Treatment)* [1994] 1 All ER 819. Also in the UK, the *Adults with Incapacity (Scotland) Act 2000* establishes a statutory test of capacity.

been aware of and weighed up any advances in treatment options since their decision was made.

Where a patient's wishes are not known and a doctor is unaware of an advance refusal, they - as the senior clinician responsible for the patient's care - have responsibility to make a decision about what course of action would be in the patient's best interests. However, doctors should consult the healthcare team and those close to the patient for any information that may be relevant to the decision, including their views about what the patient's wishes might have been. They should pay due regard to any previous wishes of the patient about not disclosing information to particular individuals.

The legal background

This is not intended as a definitive statement of the law in this area. It is a summary of the main points.

Case law

Doctors have a duty to protect the life and further the health of patients. A number of legal judgements on withholding and withdrawing treatment have shown that the courts do not consider that protecting life (the 'sanctity of life' principle) always takes precedence over other considerations. The case law identifies some circumstances where withholding or withdrawing a life-prolonging treatment would be lawful, and establishes the following principles:

- An act where the doctor's primary intention¹¹ is to bring about a patient's death would be unlawful¹².
- Withholding or withdrawing treatment is regarded in law as an 'omission' not an 'act'.
- A competent adult patient may decide to refuse treatment even where refusal may result in harm to themselves or in their own death¹³. This right applies equally to pregnant women as to other patients, and includes the right to refuse treatment where the treatment is intended to benefit the unborn child¹⁴.
- Doctors are bound to respect a competent refusal of treatment and, where they have an objection to the decision, they have a duty to find another doctor who will carry out the patient's wishes¹⁵.
- There is no obligation to give treatment that is futile and burdensome¹⁶.

¹¹ *R v Cox* (1992) 12 BMLR 38.

¹² For a very rare exception in the case of conjoined twins see *Re: A (Children) (Conjoined twins: surgical separation)* [2000] 4 All ER 961.

¹³ *Airedale NHS Trust v Bland* [1993] 1 All ER 821 at page 860 per Lord Keith and page 866 per Lord Goff and *Re AK (Medical Treatment: Consent)* [2001] 1 FLR 129.

¹⁴ *St George's Healthcare Trust v S (No 2). R v Louise Collins & Others, Ex Parte S (No 2)* [1993] 3 WLR 936.

¹⁵ *Re Ms B v a NHS Hospital Trust* [2002] EWHC 429 (Fam).

¹⁶ *Re J (A Minor) (Wardship: Medical Treatment)* [1990] 3 All ER 930.

- *Where an adult patient has become incompetent, a refusal of treatment made when the patient was competent must be respected, provided it is clearly applicable to the present circumstances and there is no reason to believe that the patient had changed his/her mind*¹⁷.
- For children or adults who lack capacity to decide, in reaching a view on whether a particular treatment would be more burdensome than beneficial, assessments of the likely quality of life for the patient with or without the particular treatment may be one of the appropriate considerations¹⁸.

The Courts' approach to decision making

Case law also suggests that: Where a patient's capacity to consent to or refuse a treatment remains in doubt after appropriate steps have been taken to assess their capacity, or where differences of opinion about a patient's best interests cannot be resolved satisfactorily, legal advice should be sought about applying to the courts for a ruling.

When the Court is asked to reach a view on whether it is in an incompetent patient's best interests to withhold or withdraw a treatment, it will have regard to whether what is proposed is in accordance with a responsible body of medical opinion. However, the Court will determine for itself whether treatment or non-treatment is in the patient's best interests¹⁹.

Legal developments

It is also important to note that the English *Human Rights Act, 1998* may have implications for this area of medical decision making by incorporating into English law the *European Convention on Human Rights*. Notably under that Convention, Article 2 requires that *a person's right to life be protected by law*; Article 3 *prohibits inhuman and degrading treatment*; and Article 8 *requires respect for private and family life*. As relevant case law emerges, the exact scope of these rights and how they may be balanced against one another will become clearer. At present the case law confirms that the existing common law principles are consistent with the *European Convention on Human Rights*²⁰. It is also clear that doctors' decisions are likely to be subject to greater scrutiny and the decision making process will need to be open, transparent and justifiable.

Personal view

I believe that if a patient's advance directive was too restrictive to allow a simple or basic procedure that would stop a patient from gaining substantial benefits from the doctor's perspective, the doctor should give their own ethical principals priority. While this over-rides individual autonomy, doctors and practitioners hold much more

¹⁷ *Airedale NHS Trust v Bland* [1993] 1 All ER 821 at page 860 per Lord Keith and page 866 per Lord Goff.

¹⁸ *Re B* [1981] 1 WLR 421; *Re C (A Minor)* [1989] All ER 782; *Re J (A Minor)* (Wardship: Medical Treatment) [1990] 3 All ER 930; *Re R (Adult: Medical Treatment)* [1996] 2 FLR 99.

¹⁹ *Re A (Male Sterilisation)* [2000] FCR 193.

²⁰ *A National Health Trust v D* (2000) 55 BMLR 19; *NHS Trust A v M and NHS Trust B v H* (2000) 58 BMLR 87.

experience and skill in such medical matters, and hence are more qualified than a layperson as to benefits, which may be gained from simple/basic procedures.

On the other hand, the reverse may also be true, if an advance directive requesting treatment be provided, doctors may judge that treatment would be of little benefit to the patient in the given circumstances and unilaterally decide to withhold or withdraw treatment.

However, I would agree with the law's answer, and while it may not be morally correct - as it goes against the Hippocratic Oath, and various other codes of practice which all doctors and practitioners should adhere to – patients ultimately must be respected, and have a personal right to choose and be autonomous.

Patients should be as fully involved as possible in the planning and implementation of their own health care. Patients have the moral right to determine what will be done with their own person, and also be given correct information, and all the information required for making informed judgments as well as the options to accept, refuse, or terminate treatment without bias.

Thus, in conclusion, where an adult patient has become incompetent, an advanced directive indicating refusal of treatment, made when the patient was competent must be respected, provided it is clearly applicable to the present circumstances and there is no reason to believe that the patient had changed his/her mind. As per *Airedale NHS Trust v Bland* [1993] 1 All ER 821 at page 860 per Lord Keith and page 866 per Lord Goff. Hence, it appears that my advice to doctors in such situations, would be that they respect the legally binding advanced directive of their patient. This follows on from decisions in the United Kingdom and the United States (however, there seems to be a lack of similar cases in New Zealand).

References

Web Sites:

The British Medical Journal Search Page

<http://bmj.com/all.shtml>

ANZSPM Ethical Guidelines, Ethical Guideline #1,
Guide to Ethical Principles of Informed Consent

<http://www.anzspm.org.au/guidelines/consent.html>

The New Zealand Medical Association Guide to Practice

<http://www.nzma.org.nz/guide/>

The New Zealand Palliative Care Strategy, page 13, Appendix 1: New Zealand Work
on Palliative Care, Ministry of Health

<http://www.moh.govt.nz/moh.nsf/c7ad5e032528c34c4c2566690076db9b/73da3876f5471cabcc256b71007a2232?OpenDocument>

Books and Journals:

'*Assessment of Mental Capacity: Guidance for Doctors and Lawyers*'. The Law
Society/BMA, 1995.

'*Ethical Decision-Making in Palliative Care*', Ethics Working Party, August 1997,
National Council for Hospices and Specialist Palliative Care Services.

Faden, R.R., and T.L. Beauchamp. 1986. *A History and Theory of Informed Consent*.
New York: Oxford University Press.

Harris, John "Consent and end of life decisions" J Med Ethics Feb 01, 2003 29: 10-
15.

Lloyd, GEL, ed. *Hippocratic writings*. Harmondsworth: Penguin, 1978.

Medical Research Council of the United Kingdom (MRC-UK). 1999. *Interim
Guidelines for Research Involving Human Participants in Developing Societies:
Ethical Guidelines for MRC-Sponsored Studies*. London: MRC.

O'Neill, O "Some limits of informed consent" J Med Ethics Feb 01, 2003 29: 4-7.

Sayers G M , S Perera "Withholding life prolonging treatment, and self deception" J
Med Ethics Dec 01, 2002 28: 347-352.

Tierney, M C et al. Comment in Bulletin of medical Ethics review, March 1993, p.17,
"How reliable are advance Directives for Health care? A study of attitudes of the
healthy and unwell to treatment of the terminally ill." Annals of the Royal College of
Physicians and Surgeons of Canada, 1992, 25, 267-70.

United Nations, General Assembly. 1996. *International Covenant on Civil and Political Rights*. Res 2200A(XXI) at 52, UN Doc A/6316, 999 U.N.T.S. 171. New York: United Nations.

Cases and Statutes:

Airedale NHS Trust v Bland [1993] 1 All ER 821

A National Health Trust v D (2000) 55 BMLR 19

NHS Trust A v M and NHS Trust B v H (2000) 58 BMLR 87.

Re: A (Children) (Conjoined twins: surgical separation) [2000] 4 All ER 961.

Re A (Male Sterilisation) [2000] FCR 193.

Re B [1981] 1 WLR 421; *Re C (A Minor)* [1989] All ER 782

Re AK (Medical Treatment: Consent) [2001] 1 FLR 129.

Re C (Adult: Refusal of Medical Treatment) [1994] All ER 819.

R v Cox (1992) 12 BMLR 38.

Re J (A Minor) (Wardship: Medical Treatment) [1990] 3 All ER 930.

R v Louise Collins & Others, Ex Parte S (No 2) [1993] 3 WLR 936.

Re Ms B v a NHS Hospital Trust [2002] EWHC 429 (Fam).

Re R (Adult: Medical Treatment) [1996] 2 FLR 99.

St George's Healthcare Trust v S (No 2).

Adults with Incapacity (Scotland) Act 2000

Mental Health Act 1983, England,