

Advance directives: partnership and practicalities

INSTITUTE OF MEDICAL ETHICS WORKING PARTY
ON THE ETHICS OF PROLONGING LIFE AND
ASSISTING DEATH

SUMMARY: *When patients are no longer able to participate effectively in decision making, an advance directive or living will may assist clinicians faced with choices about whether or not to prolong their lives. But living wills are an imperfect substitute for active patient participation. The opinion of an informed proxy could help to interpret what a patient's wishes might have been in the light of his or her present condition and its possible treatment. Practical suggestions are made about informal arrangements whereby general practitioners might help to make such an opinion available when needed.*

Keywords: *living wills; treatment withdrawal; patient choice; euthanasia; medical ethics.*

Introduction

IN an earlier paper, we argued that doctors may be morally justified in assisting death — but only on rare occasions when a patient's moral claim for relief from intolerable suffering outweighs society's need to maintain a clear distinction between killing and allowing to die.¹ Our argument presupposed that there was no moral objection to allowing such patients to die. But reports of life-sustaining treatment being continued in such circumstances, sometimes against the wishes of patients and their families, are too common to ignore. It may be useful, therefore, to discuss some ethical principles and practicalities of not prolonging life. In this paper we shall do this with particular reference to patients who are no longer competent, that is have lost the capacity, to express their present wishes, and to the role of advance directives.

Ethical principles and practice

The general ethical principles which determine when it is appropriate to prolong life are seldom disputed, except by those who hold that life is an absolute good whatever the patient's circumstances (for example, sanctity of life, as held by orthodox jews and some christians). When a competent patient refuses treatment and/or when the burdens to a patient of treatment will clearly outweigh any benefits, it is generally agreed to be medically and morally appropriate to limit treatment to relieving suffering and promoting comfort, and not to prolong life.

Even when clinicians are certain that the benefits will out-

weigh the burdens, it is not ethical (or indeed legal) to use treatment which a well-informed patient steadfastly refuses to consent to. In practice this situation seldom arises. Sometimes it is less clear how to apply the principles. It may be difficult for clinicians to weigh the benefits against the burdens, for example, or for patients to translate technical medical options into consequences for their own lives. Difficulties also arise when the patient's competence is in doubt or is clearly lost.

Treatment of patients who are no longer competent

Patients no longer able to participate effectively in decisions raise difficulties because their present views on the prolongation of life cannot be known. But their views before they became incompetent also often cannot be determined. Were they still competent, moreover, their views might have changed as the prospect of death approached. That possibility understandably reinforces the clinician's normal presumption in favour of life; and this sometimes entails the risk of prolonging life inappropriately.

For example, a patient with alzheimers disease, said by her family to have formerly expressed a wish not to live on were she to become demented, may appear perfectly happy to the clinicians caring for her. If she develops an infection and is in respiratory distress which an antibiotic can probably relieve, or if she needs emergency surgery, her doctor may wish to proceed with these forms of treatment. Withholding them may prolong suffering in the short term, and the patient may live on despite analgesia or sedation. Her reported words of 10 or even 20 years earlier (when neither her dementia nor her current pain or distress were yet part of her lived experience) lack the moral force of a competent patient's considered refusal of life-prolonging treatment.

In these circumstances, a clinician often tries to justify antibiotics or surgery by the principle of double effect. This principle is applied when a good effect (the primary object) can be achieved only at the risk of an incidental but inevitable harmful effect. In this case, the primary object is not to prolong life but to relieve suffering. But the principle of double effect also requires that the means of achieving the primary object should not be disproportionate; and some clinicians would say that analgesics or sedation would be more proportionate means of relieving this patient's suffering than antibiotics or surgery. If they are correct, the principle of double effect does not necessarily resolve the question, since it would also justify treatment whose secondary effect may be the patient's death.

Clinicians, therefore, can be faced with a difficult moral conflict — between what the patient's family says about her former wishes, and what now, despite her mental impenetrability she seems to communicate non-verbally. There is no alternative to coming down on one side or the other. The ethical risk is that a clinician who does not reflect adequately on the situation will adopt a stereotyped response which does not treat the patient as an individual.

Advance directives: living wills

This risk would be reduced by greater public and professional recognition of the value of advance directives. If more people recorded, in advance, their wishes about life-prolonging treat-

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ment, clinicians would have a stronger obligation to enquire about and respect their wishes.

The best known form of advance directive is the living will, first given legal recognition in California in 1976.² The living will and its object have been defined by the Law Commission in England as:

'essentially a formal declaration by a competent adult expressing the wish that if he becomes so mentally or physically ill that there is no prospect of recovery, any procedures designed to prolong life should be withheld. The object is to rebut any presumption that the patient has consented to treatment which may be administered under the doctrine of necessity, and to give the patient power to direct in advance the treatment, or lack of treatment, that he wishes to receive at the end of his life should he lose the ability to do so at the time.'³

From the clinician's point of view, living wills can be useful. For example, a health team might conclude that life-prolonging treatment is futile for a patient who is no longer competent, and that most patients would regard such treatment as disproportionately burdensome to their carers, or unfair to other patients because of its resource implications. If a member of the patient's family, or another health carer, disputes this conclusion, urging that 'everything should be done' to save the patient, a clear statement of the patient's own wish not to have life prolonged in such circumstances will strengthen the health team's moral case.

Living wills may be less helpful to clinicians when the case for and against life-prolonging treatment is more finely balanced, as in our example of the patient with alzheimer's disease. In that example, even a living will (unless it expressed the patient's preference for active treatment in every eventuality) might appear to lack the moral force of a competent patient's considered refusal of treatment.

From the patient's point of view, living wills are essentially an attempt to counterbalance the technological imperative to prolong life, by securing respect for the patient's own wishes. Their main limitation (even if given legal recognition) is that they may not be the most practical or effective way of achieving this in certain circumstances. Even so, living wills can be reassuring to a person who is seriously ill, or who is aware of the possibility of a sudden crisis or accident.

Some reasons why living wills may fail to achieve the patient's intentions have been noted by the Law Commission.

'Very detailed living wills risk failing to foresee a particular turn of events, whereas those written in general terms may be ambiguous in their application to particular circumstances and require considerable interpretation by medical practitioners. Either may result in an outcome which the patient might not have wished. Doctors who are unhappy with the terms of a living will can circumvent its operation by refusing to confirm clinically that the triggering condition, normally terminal illness, has actually occurred. The force of paternalism should not be underestimated.'³

Because of these problems, other forms of advance directive are sometimes advocated, including enduring or 'springing' powers of attorney (the former take effect immediately, the latter only after a specific contingency). Their legal and legislative aspects have been examined by the Law Commission,³ and will not be discussed here. We wish, rather, to propose a complementary way of embodying some of the intentions behind advance directives.

Partnership and practicalities

Living wills and other advance directives appear unable to supply the missing factor which most clearly distinguishes patients who are no longer able to make their own decisions from those who are. What is missing, essentially, is not a statement of the patient's wishes, but the patient as a partner in the process of decision making. Clearly, there will never be any entirely satisfactory way of making good that loss. But one way of preparing for it is by securing the cooperation of clinicians as willing and informed advocates of their patients' wishes. To this end, we make the following practical proposals.

The government health departments should make generally available a card (similar to the organ donor card carried by many people) stating simply that if the bearer became 'so mentally or physically ill that there is no prospect of reasonable recovery, any procedures designed to prolong life should be withheld.' The card would carry the name and telephone number of the bearer's doctor, or of another person whom they wished to be consulted.

When making these cards available, the health departments, and bodies responsible for the education of clinicians, should undertake public and professional education. This would explain that the initiative was intended to protect communication with patients against the depersonalizing pressures of technology and bureaucracy, by strengthening the role of doctors and others (not only health professionals) as patients' advocates.

The specific purpose of the cards would be to tell clinicians treating a patient whose wishes could not be determined, of an informed proxy opinion on how to interpret the patient's wishes in the light of his or her condition and its possible treatment. This would be likely to prove most helpful when treatment choices had to be made for a patient whose condition had become stable, rather than when immediate action is required following emergency admission or in the casualty department.⁴ The most helpful proxy opinion would be one based on experience both of medical decision making and of the individual — ideally that of a doctor, or another health professional, in whom the patient had trusted sufficiently to confide his or her feelings. An interpretation of the patient's wishes by a layperson might be no less valid, but would rely on the medical implications being adequately explained by the clinicians treating the patient.

How far to draw these arrangements to patients' attention would be a matter for the judgement of individual doctors. Some doctors might prefer simply to respond to enquiries; others might sometimes initiate a discussion of the subject. Clearly the latter would be best done not at a time of crisis: an appropriate time might be when a patient registered with a general practitioner, when sensitive discussion of this subject could assist in establishing a long-term relationship, or in a consultation with a clinician responsible for a patient's long-term care.

If patients wished to discuss the subject, doctors would explain the reasons for the arrangements and, if the patients then wished to discuss their own feelings, doctors would offer to make a note of these in their record. Doctors would promise that if their advice were ever sought, they would try to represent the patient's wishes as faithfully as possible. They would ask patients to let them know if their views changed; and, if they changed doctors, to inform the new doctor of their views. If the patient wished some other person to be consulted, either additionally or alternatively, that person's name would be recorded in the notes or could appear on the card. It might be helpful for patients to confide details of this arrangement to another member of their family. The proxy should not be someone for whom being consulted presented a conflict of interest.

We recognize that these suggestions raise further ethical, legal and logistic questions. The statement on the proposed card, for example, allows too many different interpretations to be used as

a legal document. But that is not its purpose: the aim is not to specify what (legally or morally) should be done, but to provoke thought about the individual to whom it is done. These proposals, moreover, are intended to encourage cumulative rather than immediate change. Many people, both doctors and patients, are reluctant to talk about death, and the value of these proposals will depend on how far they encourage patients to raise their own questions, and doctors to respond sensitively to them. Current debate in the United Kingdom and other countries^{5,6} suggests that inappropriate prolongation of life is a major anxiety for many people. Putting these proposals into practice would be a significant test of public opinion on the subject, from which important lessons could be learned, both for future legislation and for professional education.

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