Making an advance directive

George S Robertson

See p 250

The introduction in Britain of advance directives—which allow a person to state in advance of becoming incompetent that they wish to take part in treatment decisions when no longer mentally competent—has now been advocated by the medical and legal establishments. The practical application of directives relating to health care would be simplified by the adoption of a standard model document together with guidelines summarising the background clinical conditions and any subsequent acute events that may make it appropriate to trigger the use of a directive. As no specific legislation exists, good communication is needed at the various stages between the drafting and implementation of directives if the system of directives is to be successful.

It is now accepted that a patient who is adequately informed and mentally competent has the right to refuse any proposed medical treatment provided that the refusal does not create a hazard to the health of others. An advance directive for health care is a statement, usually in writing, in which a person seeks to extend this right into a future time when he or she may not be fully competent.

Legislation for advance directives (or "living wills") has existed in the United States since the California Natural Death Act was introduced in 1976, and 47 of the 50 states now have some form of law governing the limitation of treatment near the end of life, usually with specific provision for advance directives.

British position

In contrast, the introduction of advance directives in Britain has been slower and less legalistic. Concerns have been expressed about directives, in particular about their value in enhancing patients' autonomy at a time when "the incompetent person is ... quite literally a different person from the person who completed the directive."[1] Some would argue, however, that the risk of becoming a different person may in itself prompt individuals to make an advance directive as a means of preserving their original viewpoint. After fuller discussion of the benefits of advance directives, on the basis, in part, of experience in the United States (where, for example, studies of doctors' opinions found that over 80% of doctors became more positive towards directives once they knew more about them[2,3]), the medical and legal establishments in Britain have now endorsed their use.

The BMA declared its "strong support for the principle of an advance directive," and indicated that recent legal cases attest to the right of an informed and competent patient to make an advance decision which would at a future time be legally binding on doctors.[4] The House of Lords Select Committee on Medical Ethics commended the development of advance directives and concluded that legislation for their use is generally unnecessary.[5] The Crown Prosecution Service and the King's College London Centre of Medical Law and Ethics, in evidence to the select committee, expressed the view that suitably drafted advance directives are already legally valid in Britain,[6] an opinion reflected by the Law Commission.[7] The British government, in its response to the select committee, concurred on the value of such directives, and endorsed proposals for a code of practice.[8] A recent High Court ruling concluded that advance directives by mentally competent patients about future treatment are legally binding.[9] Since the legal validity of statements made at a time of competence is now beyond question doctors in Britain need to address the practical aspects of advance directives in ways that will accord with patients' perceived wishes as well as with current ethical and legal advice.

Drafting an advance directive

The BMA's advice is that people should draft advance directives "with the benefit of medical advice" and that "it is not necessary to adopt a particular form of words."[4] This could involve doctors (presumably, mainly general practitioners) in discussions that may be difficult and lengthy. In the early stages of developing advance directives in Britain many general practitioners will probably not be familiar with the subject and may be uncertain how best to advise their patients. Patients will also need advice on the best terminology to express wishes in a format that in practice may be interpreted by a different doctor and often outside primary care.

A detailed British report suggested that advance directives could be either general and brief or specific and more lengthy.[10] Experience in the United States suggests that detailed, treatment specific directives produce a more uniform interpretation by clinicians.[11-13] The BMA's view is that a general statement would be "unlikely to have the same force of law as a specific statement."[4]

Because of the complexity of drafting an advance directive a strong case exists for recommending a model document with some scope for expressing special personal wishes. This would provide a framework for patients and their doctors to reach a meaningful understanding.

The trigger for using an advance directive will usually be when an acute clinical event occurs in a patient with a longstanding or progressive condition that has already severely compromised the quality of life as judged and defined by the patient when still competent. Agreement on the future circumstances for invoking an advance directive may best be achieved by discussion between the individual, a friend or relative, and the family doctor. This could be informed by a range of background conditions and possible acute triggering events, which, while not being exhaustive or immutable, may be outlined in guidelines or a code of practice without being specified in detail in a model directive. The suggested text of a model directive is a modification of a document proposed by Age Concern and the Centre of Medical Law and Ethics[10] that was based on an earlier draft[14] (box).

Background clinical conditions

The range of background clinical conditions could comprise dementia, the persistent vegetative state and irreversible coma, and terminal malignancy (box).

Department of Anaesthesia, Aberdeen Royal Infirmary, Aberdeen AB9 2ZB
George S Robertson, *consultant*

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Advance directive for health care

Name:
Address:
Hospital unit number:

It is my express wish that if I should develop
(a) senile, severe degenerative brain disease (due to Alzheimer's disease, arterial disease, AIDS, or other agency or
(b) serious brain damage resulting from accidental or other injury or illness or
(c) advanced or terminal malignant disease or
(d) severely incapacitating and progressive degenerative disease of the nerves or muscles
and have become mentally incompetent to express my opinion about accepting or declining life sustaining treatment, and if two independent physicians conclude that, to the best of current medical knowledge, my condition is irreversible then the following points should be taken into consideration:

- In the event of a cardiac arrest, regardless of the cause, I should not be given cardiopulmonary resuscitation
- Any separate illness—for example, pneumonia or a heart or kidney condition—that may threaten my life should not be given active treatment unless it appears to be causing me undue physical suffering
- During such an advanced illness, if I should become unable to swallow food, fluid, or medication then these should not be given by any artificial means except to relieve obvious suffering
- During such an illness, if my condition deteriorates without reversible cause, and as a result my behaviour becomes violent, noisy, or in other ways degrading, or if I appear to be suffering severe pain, then any such symptoms should be controlled with suitable drug treatment, regardless of the consequences on my physical health and my survival, within the extent of the law.
- Other requests:

The object of this directive is to minimise distress or indignity which I may suffer or create during an incurable illness, and to spare my medical advisers or relatives, or both, the burden of making difficult decisions on my behalf.

Signed:
Date:

Witness 1:
Witness 2:
Statement by one witness: I ..... declare that in my opinion the above person ..... is of sound mind.

Signed:
Date:

DEMENTIA

Because elderly people are living longer the incidence of illnesses that cause dementia is increasing, and commentators have singled out dementia as being "the most common condition for which an advance directive would be appropriate."[4,15] The greatest demand for advance directives will probably come from elderly people who are still competent.[16]

In the past few years it has become evident that patients in the late stages of AIDS are also at risk of developing an illness that causes dementia. The Terrence Higgins Trust has produced a model advance directive for people with AIDS, but its format is not ideal for broader use.

PERSISTENT VEGETATIVE STATE AND IRREVERSIBLE COMA

Recent legal judgments in Britain have highlighted the persistent vegetative state as another condition for which prior wishes for limitations of treatment, including artificial nutrition and hydration, may be appropriate.[17] An American study found that 90% of a large group of nurses and doctors would refuse a range of specified treatments if they were in an irreversible coma.[18] Interest in advance directives relating to the persistent vegetative state will probably come from younger age groups at risk from the causal agencies.

TERMINAL MALIGNANCY

Although the public's perception of terminal cancer as being inevitably painful may be changing because of improvements in the management of pain, advance directives will probably provide reassurance in several ways. Firstly, the directives may be used to encourage doctors and nurses to give aggressive treatment for pain in malignancy in the knowledge that patients accept the possibility of death being hastened, even though the primary intention is the control of symptoms.[16] Secondly, an advance directive may be used to address concerns that terminally ill people are often kept alive too long with artificial nutrition and hydration, antibiotics, and other life sustaining treatments, which many see as pointless.[19] Thirdly, advance directives in terminal care may encourage and improve discussions on end of life decisions. Despite persuasive evidence that patients want to have such discussions doctors remain reluctant to become involved.[20]

Triggering conditions

Recent British studies have shown that a person's wishes not to receive aggressive treatment can be related to definable stages of illnesses that cause dementia. Thus 86% of elderly patients would not want artificial ventilation if they were too confused to be safely left alone,[21] and only 10% of over 300 outpatients questioned would definitely want cardiopulmonary resuscitation for a cardiac arrest if they were senile and no longer able to recognise family and friends.[22]

Accordingly, in an advance directive a person should probably include a specific refusal of cardiopulmonary resuscitation and intensive treatment if any of a range of clinical conditions develops. Decisions to withhold cardiopulmonary resuscitation are influenced mainly by futility and by evidence of a prior informed refusal, which is best conveyed with a written advance directive.[23] If one of the stipulated background conditions is present an advance directive could be invoked for serious acute illnesses, such as pneumonia, a major myocardial infarction, a ruptured aortic aneurysm, a fractured hip, a cerebrovascular accident, acute renal failure, and similar acute conditions, with the understanding that nursing care and treatment for symptoms will always be continued (box). Decisions to withhold active treatment, including cardiopulmonary resuscitation, should be reached after discussion with medical

Background clinical conditions

Dementia
Alzheimer's disease
Multi-infarct (vascular) brain failure
AIDS

Persistent vegetative state or irreversible coma
Post-traumatic condition
Vascular disorder
Hypoxic or anoxic injury
Poisoning
Drug overdose or toxicity

Terminal disease
Malignant disease
Neurological or muscular disorder:
  Multiple sclerosis
  Motor neurone disease

Possible conditions that trigger use of an advance directive

Cardiorespiratory arrest
Primary respiratory failure:
  Chronic obstructive airways disease
  Emphysema
Pneumonia
Cardiac failure secondary to acute myocardial infarction
Acute renal failure
Ruptured aortic aneurysm
Major gastrointestinal haemorrhage
Hemiplegia or other major stroke:
  Cerebral thrombosis
  Cerebral haemorrhage
Peritonitis
Major accidental trauma:
  Fractured femur
  Spinal injury
  Head injury

and nursing colleagues and with relatives or friends if appropriate. Decisions and the reasons for making them should be clearly documented.[23]

Other practical considerations

A person is generally presumed to be mentally competent to make and sign an advance directive unless convincing evidence exists to the contrary. Competence is best confirmed by having a person's signature witnessed by two people, one of whom should be a doctor who can attest to the person's soundness of mind.[10]

Most medical and legal experts consider that the content of an advance directive should be reviewed periodically, although it would be impractical to do this more often than about every five years and undesirable if the person's competence had become questionable. The procedure for modification or revocation should be simple and could be effected orally or in writing or by the signatory designating an appropriate other to act on his or her behalf. Specific modifications to the text of an existing directive should be in writing or as an authorised transcript of an oral instruction. All relevant documents should be clearly amended.

People who make an advance directive should inform chosen relatives or friends, their family doctor, and their legal adviser. The original document should be retained in the signatory's personal papers, and ideally copies should be placed in hospital case records, general practitioners' records, and with their legal adviser. Case records should be clearly identified as containing a directive, and the BMA suggests that people who have drafted an advance directive should carry a card indicating that fact.[4] To be effective a card system would need central coordination and sponsorship in terms of the production and issuing of cards, and this might best be done by the BMA in collaboration with the royal colleges and the Department of Health.

Similarly, the issuing of model directives should be under central guidance, with documents available, for example, in general practice surgeries, hospitals, and legal offices. Simple guidelines could be provided for those interested in making a directive. In the future it may be appropriate for individual hospitals to maintain a computer record of those who have made an advance directive, and this could be accessible to general practitioners and other hospitals.

If a British system of advance directives is to be effective it should be subject to occasional review and updating, with information on the number of people making directives, the clinical application of these, and any recurring difficulties in their interpretation. This would be facilitated by the adoption of model documents and standard procedures for recording their use.

Interim position

The BMA's view that "it would be helpful for patients facing loss of capacity to nominate a person they trust to express their views later,"[4] is a reasonable interim position. Many widely differing views exist, however, on proxies, and the function and credibility of nominees may remain uncertain even if specific legislation is introduced.[10] This subject will require further debate and may demand separate professional guidelines.

Conclusion

Decisions to limit treatment are an increasingly common feature in the clinical management of patients towards the end of life, and not necessarily only in hospitals with high technology facilities. Advance directives allow patients to influence these decisions by expressing a personal view of the balance between the quality and duration of life. British doctors can now give advice on directives in the knowledge that these documents reflect not only patients' wishes but the carefully considered perspective of current medicine and the law.

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