Advance directives and living wills

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Summary

Under certain circumstances, living wills or advance directives may carry legal force in the UK. This paper traces the development of advance directives, clarifies their current legal position and discusses potential problems with their use. Case histories are used to illustrate some of the common dilemmas which doctors may face.

Keywords: advance directives; living wills

Case history 1

Mrs T is 82 years old, has had a severe stroke, and is not expected to recover any further independence. When she develops pneumonia the registrar starts her on intravenous antibiotics. Her daughter produces a Living Will, written on a pre-prepared form and witnessed by her general practitioner, which Mrs T drew up six months earlier after her brother had suffered a stroke. In it she states that she would not wish to be kept alive if she suffered a severe stroke which would leave her dependent on others for daily care.

Discussion

The Living Will seems valid but the doctor (preferably the consultant) should check that the patient's details are correct and should talk with the general practitioner who witnessed it and the daughter. If he is convinced that it is valid, he should stop the antibiotics and prescribe supportive/palliative care only. This should include 'basic care' (warmth, hygiene, analgesia) but artificial feeding (which is regarded as a medical treatment), antibiotics, etc, should be avoided. He should carefully document his decision and explain the management plan to the daughter and to junior medical, nursing and other staff.

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An Advance Directive is a statement made by a mentally competent adult stating how they wish to be treated should they, at some stage in the future, lose mental capacity.¹⁻³ Advance Directives are seen as a way of extending autonomy by allowing patients to be involved in decisions from which they would otherwise be excluded because of their incapacity.⁴⁻⁶ Consent for surgical procedures is a basic form of Advance Directive; patients give consent pre-operatively (when they are competent) for treatment which will be carried out when they are incompetent (under anaesthetic).

Advance Directives may take several forms and this has led to a variety of terms. The BMA Code of Practice⁴ uses the general term Advance Statements to cover all of these. Some authors prefer to distinguish between Advance Directives (which suggest that treatments are specifically requested) and Advance Refusals (refusing treatments). In the American literature a further distinction is made for the nomination of proxy decision makers (Enduring Power of Attorney for Health Care). The lay press tend to use the term Living Will.

For the purposes of this paper we will use the terms Living Will and Advance Directive interchangeably to refer to any statement made in advance by a competent person stating their wishes about treatment should they become incompetent. Case histories are used to illustrate some of the common dilemmas which doctors may face.

Competence (or capacity)

The terms competence and capacity can be used interchangeably and can be defined⁷⁻⁹ as the ability to:

- understand, in general terms, the nature of any proposed treatment, its consequences and side-effects
- understand the effect of not having the treatment
- reason consistently over time about this
- reach a decision based on this reasoning
- communicate this decision.

Competence is decision specific (patients can be competent to make some decisions and not others) and may also be variable over time. If there is doubt, the assumption is in favour of competence. If a patient is incompetent then, in the UK, their doctor has the obligation to make decisions about their treatment 'in their best interest'. Relatives do not have any legal right to be consulted or to make decisions on behalf of incompetent patients although it seems likely that doctors would want to consult them about the 'best interest' of incompetent patients.⁴⁻⁸ This contrasts with the situation in many parts of the US where patients can nominate a friend or relative to act as a surrogate decision maker¹⁰⁻¹¹; if they have not made such a nomination then there is sometimes a legal provision for relatives to make decisions for them.¹¹ In Scotland (but not in England, Wales or Northern Ireland) the powers of a tutor dative might allow the legal nomination of a healthcare proxy.⁴

Consent

Patients must consent to medical examination and treatment.⁹ For certain procedures explicit consent is sought, although for most it is implied. In order to be valid, consent must be obtained from a fully informed and mentally competent patient. Patients may withdraw consent at any time and doctors who ignore a valid withdrawal of consent may be liable to a charge of assault. Mentally incompetent patients cannot give valid consent and no-one else can consent on their behalf.⁹⁻¹²

Legal perspective and history of Advance Directives

The right of a competent adult to refuse medical treatment for reasons which are "rational, irrational or for no reason" was established in the Sidaway case in

Case history 2

Professor K is an 68-year-old retired university teacher who made a Living Will at the onset of his dementia three years ago. In it he stated that when his memory got so bad that he was unable to recognise friends or concentrate on reading his books then he should not have any life-saving or life-prolonging treatments. His general practitioner is called because he seems to have developed bowel obstruction. The Professor is confused and has been unable to recognise most of his friends for some time. Nonetheless, he seems to understand that an operation is being considered to relieve his pain and vomiting and he appears willing to have this. The general practitioner arranges admission.

Discussion

There is no doubt about the patient's considered wishes in his Advance Directive but there is now some doubt about his competence. If he is now competent then his contemporaneous decision overrules the terms of the Advance Directive. Competence is decision specific; he could be competent to make a decision about surgery but incompetent for other decisions. If there is doubt then doctors should assume competence. A second opinion might be helpful here. In any event it might reasonably be argued that surgery is being proposed for its palliative role (relieving his pain and suffering) rather than as a life-prolonging measure.

Case history 3

Jenny is 15 years old and well known to the A&E department. She suffers from a 'borderline personality disorder' and has been admitted for repeated overdoses. She is admitted after a paracetamol overdose and is carrying a note refusing all treatments including Parvolex.

Discussion

Since she is under 18 years old she would not be able to make a valid Advance Directive, although she would be entitled to have her opinions considered. However, even if she were old enough, it is unlikely that her refusal of treatment would be considered valid, as her competence at the time of writing the note could be questioned. Emergency treatment should be given while the issue is clarified; perhaps her psychiatrist might help the A&E staff in this.

1985.^{4 12 13} In 1992 the Court of Appeal upheld the right of an adult to refuse treatment,^{4 14 15} irrespective of the wisdom of that refusal and this was confirmed by three judges in the Bland case.¹⁶ In *Re C*¹⁷ the High Court issued an injunction supporting an advance refusal of treatment. Following publicity surrounding some of these court cases, a House of Lords Select Committee suggested that the medical profession should establish a Code of Practice for the use of Advance Directives²; the BMA subsequently produced such a Code in conjunction with the Medical and Nursing Royal Colleges.⁴ The Bland case was not the first to establish the legal status of Advance Directives but it is probably the most well known; although it did not involve a Living Will, three judges stated that, had such a statement been available, it would have been legally binding. So, even though there is no legislation governing their use in the UK, it is now clear that the British courts would find Living Wills refusing certain treatments valid under common law provided that certain basic principles were met. A report of the Law Commission⁸ has recently recommended that legislation is introduced to clarify the situation although no decision has yet been made on this.¹⁸

In the US, living wills were first proposed in 1967² and were initially closely associated with the 'right to die' and euthanasia movements. However, they became more accepted when it became clear that they were an instrument for exercising autonomy rather than simply the right to die. (The Voluntary Euthanasia Society in the UK produces a Living Will form but many organisations which support the use of Advance Directives are strongly opposed to euthanasia.^{1 4}) The use of Advance Directives has been enshrined in legislation in most states of the US since the first Natural Death Act in California in 1976. They came to particular prominence following the Cruzan case in 1990,^{19 20} which involved a decision about withdrawal of artificial feeding from a young woman in a persistent vegetative state. The difficulties which arose from the case led to Federal Legislation (the 1991 Patient Self Determination Act) which made it compulsory for hospitals and nursing homes to give patients the opportunity to make an Advance Directive at the time of admission.^{19 21} The use of Advance Directives is also governed by legislation in many Canadian provinces²² and in South Australia a Natural Death Act was passed in 1983.²³

The relevance of American experience in this area to British practice

Colin Currie, a British geriatrician and medical author, has observed that, in the US, the ready availability of high technology medicine, a fear of litigation by doctors, and a fee-for-service system for paying them, combine to encourage American physicians to perhaps over-investigate and over-treat.²⁴ The result, Currie claims is that "Elaborate and uncomfortable treatments of dubious advantage or none to the frail elderly are deployed [in the US] on a scale unimaginable in Britain and for reasons that those familiar with US medicine will understand. The technologies are available, respected and oversold".

Those who practice in the UK will be aware that the pressures are often in the opposite direction here, encouraging us to do less rather than more. So, while Advance Directives in the US have been largely used to discourage doctors from over treatment this might not be such a priority in the UK. In addition, in the US, some authors have seen the use of Advance Directives as a way of limiting healthcare costs. Most British advocates of Advance Directives would see them as a clinical tool rather than an administrative instrument to reduce costs.²⁵

Types of Advance Statement

The BMA code of practice has identified a number of types of Advance Statement⁴:

- a requesting statement; patients make requests for specific treatments
- nomination of a proxy or surrogate decision maker
- a refusing statement; patients refuse specific treatments
- refusals of all active treatment when a certain degree of irreversible deterioration has occurred.

In English Common Law, those types of Advance Statement refusing certain treatments may carry legal force.

The current legal position

Advance Directives carry legal force in common law if the following conditions are met^{4 14 15}:

At the time the Advance Directive was drafted the patient:

- was an adult (aged 18 or over)
- was competent

Case history 4

Mr DF is 46 years old and has had motor neurone disease for six years. He is chairman of the local patient support group and is confined to a wheelchair. He has had several hospital admissions with pneumonia and, after the most recent one, he writes a letter to the consultant, with a copy to the general practitioner and to his son, stating that for further infections he would be willing to accept antibiotics if indicated, but does not want intubation, ventilation or cardiopulmonary resuscitation. A few weeks later he is re-admitted with severe pneumonia. He is drowsy and delirious. The consultant is contacted but he tells his registrar that all possible treatment, including ventilation, should be given as clinically indicated. He says that he disapproves of Living Wills in principle and, anyway, they have no legal force and that the relatives are trying to interfere in clinical decisions.

Discussion

The Living Will is probably legally valid and, as such, should be complied with. It is likely that the patient was aware of the consequences of his statement when he made it and he almost certainly knew about the likely course of his disease. If the consultant has a conscientious objection to Living Wills then he should pass the patient's care over to a colleague, but this does not allow him to ignore a valid directive.

Case history 5

Mrs JE is 70 years old and has small cell carcinoma of the bronchus. She was told her diagnosis yesterday, and the consultant has agreed to meet with her and her son today to discuss treatment options. At this meeting the son produces a Living Will which his mother has just made refusing all treatment; he asks the consultant to witness it.

Discussion

The document is most unlikely to be valid. The patient has not had an opportunity to discuss and consider treatment options; her consent (or withdrawal of consent) is not fully informed and therefore is not valid. She may also be acting under pressure from her son. The consultant should explain that the document is unlikely to be valid and refuse to sign it; he should explain the diagnosis, prognosis and treatment options to them. He should then arrange to see them again after a few days or perhaps see Mrs JE alone. He needs to satisfy himself that she understands the treatment options and that she is making a free choice without undue pressure from her son.

- was aware of the nature and consequences of the statement
- could envisage the circumstance under which the Advance Directive would apply
- was not acting under duress

At the time the Advance Directive came into effect:

- the circumstance were as envisaged by the patient at the time of drafting
- the Advance Directive had not been revoked
- the patient was now incompetent

The Advance Directive itself:

- refuses certain treatments or specifies a degree of deterioration beyond which active treatment should not be given.

The Advance Directive does not necessarily have to be written in a specific format or, indeed, written at all.⁴ Although it is often recommended that directives are witnessed by doctors and lawyers this is not a requirement. Children up to the age of 18 cannot make valid Advance Directives, although they are entitled to have their views taken into account.⁴ Patients cannot request treatment which are illegal (eg, euthanasia) or not clinically indicated, and there are difficulties if they exercise their own right to autonomy but infringe the rights of others. They cannot legally nominate a proxy or surrogate decision maker, except perhaps in Scotland.^{4, 8} If a woman is pregnant when her Advance Directive comes into force doctors are obliged to consider the needs of the foetus before complying with the directive; they may have to give emergency treatment while applying to the courts for further advice. Likewise, if a patient who had previously made an Advance Directive is now in a persistent vegetative state then the case must be referred to the courts. Patients detained under the Mental Health Act may make valid Advance Directives but only about aspects of their treatment not covered by the terms of their detention.^{4, 8}

Potential problems with Advance Directives**COMPETENCE**

The patient's competence at the time of drafting the Advance Directive may be questioned at a later date. Lord Donaldson stated¹⁵ that "doctors faced with a refusal of consent have to give very careful consideration to the patient's capacity [competence] to decide at the time when the decision was made..... The more serious the decision the greater the capacity required." Because competence varies and is not absolute⁷ this decision may be difficult. If the Advance Directive is witnessed by a doctor then the assumption is that they are satisfied that the patient is competent.⁴

CHANGE OF MIND

Some patients change their minds after they have made their directive,²⁶ but Emmanuel²⁷ argues that this may happen no more often than people change their minds about other major life decisions (such as making an estate will). In the one of the few relevant British studies, Bruce-Jones and colleagues²⁸ found that 10% of the elderly patients whom they questioned changed their minds about their preferences for resuscitation between admission to and discharge from hospital. Potter and colleagues had similar findings.²⁹ Lutrell and Summerville³⁰ argue against the suggestion that Advance Directives can be overruled on the basis that the patient may not feel the same in the future as when they draft the directive.³¹ Since, in the absence of a valid Advance Directive, decision making falls to doctors, they argue that, even if patient's values change, their previous values may be a more accurate reflection of their current ones than those of their doctor. The best way to avoid this may be to ensure frequent reviews of the Advance Directive while the patient remains competent.²⁷

ADVANCES IN TECHNOLOGY

Medical technology may develop between the time the Advance Directive is drafted and its implementation. For an Advance Directive to be valid, the patient must have been able to foresee the circumstance which would arise when it was called upon, and those circumstances must then actually arise. If a new drug or procedure becomes available, which was not foreseen at the time the directive was drafted, this may invalidate it. Doctors should remind patients that this is a potential problem area.

REFUSAL OF 'BASIC CARE'

Some patients may draft directives which refuse nutrition, hygiene measures and pain relief. Although this has not been tested in law, the BMA Code of Practice⁴ argues that patients should not have a right to refuse such 'basic care'. It suggests that they are putting healthcare professionals under unacceptable pressure by

Case history 6

Ben is 36 years old and has had AIDS for three years; he has had several admissions with pneumonia and is now in hospital with meningitis. John has been his partner for six years. John shows the consultant a Living Will in which Ben nominates him as surrogate decision maker. This was witnessed by their lawyer and a friend. John tells you that he thinks that Ben should not have any active treatment but Ben's parents, who are not on good terms with John, say that they are the official next-of-kin and they want him to have all active treatment, including ventilation if necessary.

Discussion

There is no legal provision for nomination of proxy decision makers. Both the parents and the partner seem to feel that they are entitled to make decisions 'in the best interest' of Ben, but this is not the case. In the current circumstances Ben's consultant is obliged to decide what is in his 'best interest'. However, to determine what is Ben's 'best interest' he will almost certainly have to consult with his parents and his partner; in particular he will want to try and discover what they think Ben himself would have wanted in these circumstances (rather than what they want for him). The fact that he has nominated his partner as a proxy suggests that John would certainly be in a strong position to give useful information about this. The consultant should document his decision-making process carefully.

Case history 7

Mr R is 92 years old and is admitted to hospital with septicaemia secondary to pneumonia; he is hypotensive, anuric, and has poor cardiac function. He has been almost bed-bound since a stroke four years before and has been cared for at home by his attentive family. His wife, a retired nurse, shows the consultant a Living Will which he drafted before his stroke stating that he wanted to be kept alive by all means possible, since their religion taught that all life was sacred; she wants him transferred to the intensive care unit and ventilated and asks specifically that he is given cardiopulmonary resuscitation (CPR) if necessary.

Discussion

Patients cannot request treatments which are not clinically indicated in a Living Will (just as they cannot request them in a contemporaneous statement). He would almost certainly not survive a period of ventilation in intensive care so it would not be indicated; likewise, CPR would almost always be futile in cases such as this. The consultant should refuse to institute treatment which he felt was not clinically indicated and try and explain this sensitively to the family. It may help if he asks a respected colleague to confirm his opinion and perhaps involves the hospital chaplain in the discussion with the family; he should document his decision carefully.

insisting that they ignore their instincts to provide basic comforts and pain relief. In addition, refusal of hygiene measures may adversely affect others by, perhaps, leading to the spread of infection.

DOCTORS' OBJECTIONS

Doctors may object in principle to the patient's right to refuse life prolonging treatment. If a doctor is asked to help draft an Advance Directive, but disagrees with the patient's right to refuse treatment, then he should let the patient know this as soon as the subject is raised and the patient's care should be passed to a colleague.⁴ Such a doctor, if faced with a directive limiting treatment for an incompetent patient, should also pass care over to a colleague. However, if no other health professional is available and an emergency arises, then doctors are obliged to comply with patients' wishes in valid Advance Directives.

Surrogate or proxy decision making

There is no legal provision for surrogate decision making in the UK,⁴ (with the possible exception of an untested provision in Scotland) although British studies of elderly patients' views on resuscitation have found that 25–33% would not want their families involved in making decisions for them.³² In the US, many states have Surrogacy Acts²⁶ enabling relatives of incompetent patients who have not made Advance Directives to be asked to decide for them. Elderly Americans usually want family members (rather than friends, doctors or lawyers) to make decisions for them,¹⁰ although authors are divided upon whether patients actually discuss their health with their nominated proxies.^{10 27} Emmanuel found that proxy decision making was relatively inaccurate in relation to the previously expressed wishes of the patient.^{27 33} Bedell and colleagues found that doctors would rather discuss resuscitation with relatives than with patients themselves³⁴ and often appeared to wait until patients were incompetent before considering decisions. Legislation does not necessarily help; in a recent study the majority of patients entering New York nursing homes³³ were approached about making directives (in compliance with Federal Law) but this was usually done by social workers rather than doctors and the emphasis seemed to be on nomination of a proxy rather than a clear determination of the patient's wishes. This is in keeping with the letter, but not the spirit, of the law and erodes rather than enhances autonomy.

Decisions by proxies can either follow the 'Substituted Judgement' model (deciding what the patient themselves would have wanted) or the 'Best Interest' one (deciding what is best for the patient). In the US proxies are asked to use substituted judgement¹⁰ but proposals for proxy decision making in the UK⁸ advocate that the best interest principle be followed.

Helping patients to make Advance Directives

Directives are best made with adequate time for reflection and with advice from trusted medical attendants; patients should avoid making directives at the time of hospital admission or shortly after the diagnosis of a serious illness.⁴ If there is doubt about competence to make decisions then doctors can test this by explaining details to patients about their condition, its treatment and prognosis. They can explore their patient's understanding of this by asking them to envisage what might happen and what they might decide in various alternative situations. If doubt remains, then the opinion of a colleague or a specialist psychiatrist may be helpful.

Doctors helping patients draft Advance Directives should ensure:

- that the patient is competent
 - that they are aware of the legal standing of the directive
 - that they understand the implications of it
 - that they can accurately foresee circumstances when it might apply
 - that they are informed of the medical diagnosis, prognosis and potential for treatment
 - that they are aware that some patients may change their minds after making directives or that medical technology may develop
 - that they have plans to regularly review the directive
 - that they are not acting under pressure.
- Patients may use a pre-prepared form or may wish to draft their own statement. If they do this they should be advised to include on it the following items⁴:
- the patient's name, address and date of birth
 - the name and address of their general practitioner and/or hospital consultant
 - whether advice was sought from health professionals

Useful sources of further information in the UK

BMA Ethics Division, BMA House,
Tavistock Square, London WC1H 9JR

The Centre for Medical Law and Ethics,
King's College London, Strand, London
WC2R 2LS

The Exchange on Ageing, Law and
Ethics (Eagle), Age Concern, Astral
House, 1268 London Road, Norbury,
London SW16 4ER

*Sample Advance Directives are available
from:*

Voluntary Euthanasia Society, 13 Prince
of Wales Terrace, London W8 5PG

Terrence Higgins Trust, 52–54 Grays
Inn Road, London WC1X

- the patient's signature, the date, and a date for review
- the signature of a witness
- a clear statement of the patient's wishes
- the name and address of a nominated person.

Patients should be aware that it is their responsibility to ensure that the Advance Directive is available to any doctors who may be treating them.

The Institute of Medical Ethics Working Party³⁵ has proposed that this is best done through the use of a card (similar to an organ donation card) which patients could carry with them stating their wishes. The Working Party also suggests that regular, documented discussions between general practitioners (acting as informed proxies) and patients would help ensure that patients' decisions were properly informed, would clarify the circumstances under which Advance Directives might come into effect, would encourage patients to keep their directive updated and would help ensure that the directive was known about at the relevant time.

What to do when presented with an Advance Directive

Doctors should check that the patient whom they are treating is the one referred to in the directive, examine the patient to determine competence and satisfy themselves that the patient is currently incompetent. They should ensure that the patient was over 18 when the directive was drafted. If possible they should contact any witnesses. If a doctor was a witness then they should question them to ensure that the patient was competent at the time of drafting and was not acting under duress. If a proxy is nominated they may be able to give further information about the patient's wishes; they should be made aware that their proxy status is not legally recognised. Doctors should check that the current circumstances are identical to those envisaged by the patient and, if it is clear that the directive is valid, comply with any requests to withhold treatment. If it is clear that the directive is invalid then they should treat the patient in what they consider to be their 'best interest'.

In cases of uncertainty or disputes, refusal of basic care, or possible pregnancy, then they should give emergency treatment while seeking further advice; initially this might be a second opinion from a respected colleague but in extreme cases it may mean resorting to the courts. If the existence of a directive is suspected but it is not immediately to hand, then doctors should also give emergency treatment while the uncertainty is resolved. Decisions should be carefully documented.

Proposals for future development of Advance Directives

The Law Commission recently made proposals for changes in the law covering Advance Directives.⁸ The new government apparently regards these proposals favourably and has published a consultation document to encourage further discussion of them.³⁶ The Commission proposes legislation to recognise advance refusals of treatment and proxy decision making. The proxy would be asked to act in the patient's 'best interest' and could be overruled by the courts if this were in doubt.

Disease-specific Advance Directives have been proposed by Singer³⁷ as a more accurate means of giving patients information and determining their wishes; these are pre-prepared forms listing interventions which may be considered in some illnesses which patients can refuse treatments individually rather than refusing all treatment.

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Medical Anniversary

Sir THOMAS BRUNTON, 14 March 1844

Sir Thomas Lauder Brunton (1844–1916) was born at Hiltonshill, Roxburghshire, UK. He graduated MB at Edinburgh (1866) and published a notable MD thesis on digitalis when still a house physician at the Edinburgh Royal Infirmary. In the *Lancet* of 27 July 1867, he reported his successful use of amyl nitrite in the relief of angina pectoris. This was his greatest single contribution to medicine. He became lecturer in clinical pharmacology at the Middlesex Hospital (1870), and after a year assumed the same appointment at St Bartholomew's.

He became an FRS at the age of 30, and delivered many named lectures at the Royal College of Physicians, including the Harveian Oration (1894). He delivered the Lettsomian Lectures to the Medical Society of London (1886), was knighted in 1900 and received a baronetcy (1909). He died in London on 16 September 1916. — *DG James*