

# Advance directives in the UK: legal, ethical, and practical considerations for doctors

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## SUMMARY

*In the United Kingdom (UK), advance directives have recently received considerable attention from professional and voluntary organizations as well as medical journals and the media. However, despite such exposure, many doctors remain uncertain of the importance or relevance of advance directives with regard to their own clinical practice. This paper addresses these uncertainties by first explaining what advance directives are and then describing the current legal status of such directives in the UK. Examination of the cases underpinning this status reveals several key elements: competence, information, anticipation, applicability, and freedom from duress. Each is discussed.*

*Although this paper focuses on legal issues, it is important that medical law does not dominate medical ethics. Accordingly, the paper also discusses some important philosophical and sociological considerations that have remained largely unexplored in the medical press. Finally, the paper deals with practical matters, including how the general practitioner might be involved.*

**Keywords:** *advance directives; autonomy; community; ethics; living wills; principles.*

## Introduction

IN 1990, the United States (US) Congress passed the Patient Self Determination Act, which became effective a year later. This Act obliges health care providers in each of the states to notify patients of that state's policy on advance directives and on the individual's right to make either instruction directives (living wills) or proxy directives (nominating a proxy with durable power of attorney for health care) relating to possible future medical treatment.<sup>1</sup> Having watched developments overseas, and in the light of some recent legal cases at home, the British Medical Association (BMA) clearly needed to provide some guidance as to the situation in Britain, and in 1995 published a report on advance statements about medical treatment.

The report is intended to reflect 'good clinical practice in encouraging dialogue about individuals' wishes concerning their future treatment', and speaks theoretically of six different types of advance statement:

- A requesting statement reflecting an individual's aspirations and preferences.
- A statement of general beliefs and aspects of life that the individual values.

- A statement naming a proxy.
- A directive giving clear instructions refusing some or all treatment(s).
- A statement specifying a degree of irreversible deterioration after which no life-sustaining treatment should be given.
- A combination of the above.<sup>2</sup>

This paper looks at the current legal basis for the BMA's report and aims to clarify in what kinds of situation a statement made in advance may be legally binding in Britain today; the term 'advance directive' will be used to cover written statements of this kind. As thinking about advance directives only in legal terms is unwisely limiting, this paper will go on to briefly discuss some important ethical considerations underpinning the directives, and will illustrate the sociological dimensions to their entering the domain of medical practice. The paper concludes with practical advice for doctors.

## The current legal situation in Britain

Unlike the USA, Britain has no statute regulating anticipatory decision making; instead, it is case law that provides authority. In the case of *Re T* (key case 1) (see end of this article), although the pregnant woman's refusal of a blood transfusion was deemed invalid, the court outlined the conditions for a legally valid, anticipated refusal as follows:

- The patient must be competent at the time of the declaration.
- The patient must be informed in broad terms about the nature and effect of the procedure.
- The patient must have anticipated and intended the refusal to apply to the circumstances that subsequently arise.
- The patient must be free from undue influence when issuing the declaration.

The legal import of valid anticipatory decisions was then supported by the House of Lords in the case of *Anthony Bland* (key case 2). The position was taken further in the case of *Re C* (key case 3), in which the court was prepared to endorse an anticipatory decision. To appreciate the situations in which an advance directive may have legal authority, it is therefore necessary to look at the legal background to the above criteria in greater detail.

## Competence

English law holds that a legally competent person, and nobody else, is empowered to make treatment choices. In 1992, Lord Donaldson stated that the competent patient's right of choice exists whether 'the reasons for making that choice are rational, irrational, unknown, or even non-existent'.<sup>3</sup> This liberty applies to the refusal of treatment. In the tragic case of *Anthony Bland*, a persistent vegetative state victim of the Hillsborough football disaster, Lord Keith stated that treatment choice may extend to the future, such as when a competent person has given clear instructions (which need not necessarily be written<sup>4</sup>) that 'on entering into a condition such as the persistent vegetative state ... he is not to be given medical care, including artificial feeding, designed to keep him alive'.<sup>5</sup> It should be noted here that an advance directive can only authorize acts (or refusals) that the patient, if competent, could authorize; there is no legal sub-

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**Key cases**

1. *Re T (adult: refusal of treatment)* [1992] 4 All ER 649.
2. *Airedale NHS Trust v Bland* [1993] 2 WLR 316.
3. *Re C (adult: refusal of treatment)* [1993] 1 WLR 290.

**Key points**

- Advance directives now have a legal basis in the UK.
- Awareness of the legal basis assists appreciation of the clinical relevance of advance directives.
- Doctors are likely to become increasingly involved with advance directives.
- Doctors should be prepared for the types of situation in which advance directives might be encountered.
- Medical ethics should not be reduced to medical law.
- Philosophical issues are as important as legal issues.

stance to an advance directive requesting an unlawful act such as assisted suicide.<sup>6</sup> The Law Lords' statements have two implications for doctors. First, as advance directives are made when a person is competent, assessment may be needed to determine if capacity has been lost. Ian Kennedy has argued that the test for competence should be a person's ability to understand treatment options and the consequences of his or her decision.<sup>7</sup> Recently, the Law Commission voiced the need for a 'functional' test of competence.<sup>8</sup> These opinions are in line with Lord Justice Thorpe's division of the decision-making capacity into three stages: comprehending and retaining information, using (believing) it, and 'weighing it in the balance to arrive at a choice.'<sup>9</sup>

The second relevant implication for doctors is that, as the making of an advance directive becomes more popular, they will undoubtedly be increasingly called upon by patients to advise and assist them. In such situations, doctors should be thinking clearly about the competence of the patient, including possibly recording an opinion. In the future one can envisage the courts calling on doctors' evidential opinions of competence when determining the validity of an advance directive.

**Being informed**

English law requires a competent patient to be informed in broad terms of the procedure that is intended,<sup>10</sup> and Lord Donaldson extended this to advance directives of consent or refusal. He added that there is a 'duty to inform about likely risks (including any special risks attaching to the treatment being administered by particular persons), but a failure to perform this duty sounds in negligence and does not, as such, vitiate a consent or refusal.'<sup>11</sup>

What this means is that a valid advance directive should be made by an informed patient, with the duty to inform resting with the doctor. If an incapacitated person can be shown to have made an advance directive without sufficient information, the directive may be deemed invalid. However, doctors cannot assume that insufficient information was given, and cannot presume that, if the patient had the necessary capacity (now), she would reverse her decision. An obvious problem exists in that advance statements are often couched in general terms, and Lord Donaldson has importantly pointed out that 'if there is any doubt, with regard to the intended scope of an anticipated refusal, it will be decided in favour of preserving life.'<sup>12</sup>

**Anticipation and applicability**

As mentioned above, for an advance directive to be legally binding, the patient must have anticipated and intended the refusal to apply to the circumstances that subsequently arise. This requirement somewhat overlaps with that for the provision of adequate information, and one can see the potential for problems.

A person may have what she believes to be a clear idea of a given situation without being aware of the clinical spectrum of possibilities. It is virtually impossible to foresee every circumstance that may arise, and consequently there will often be doubt as to whether the individual had truly anticipated the situation that occurs. As stated by Lord Justice Straughton in *Re T*, an apparent consent or refusal 'may not be a true consent or refusal if it was made without reference to the particular circumstances in which it turns out to be relevant.'<sup>13</sup> There are two helpful ways to avoid this. One is to make any advance directive as clear and specific as possible. If a general form is being used it can be augmented by voicing specific concerns about specific situations; along similar lines, and of increasing popularity in the USA, is to use a disease-specific form, which is more likely to cover the relevant situations that may arise.<sup>14</sup> The second way to avoid problems is to keep the directive contemporaneous, thereby showing repeated consideration.

Nonetheless, advance directives will often necessarily refer to general conditions or states, and the law encourages doctors to assess applicability and intent. Lord Donaldson recommended that physicians have to consider not only whether the patient had the capacity to decide, but also 'what was the true scope and basis of the decision.'<sup>15</sup> This recommendation may, however, be unfair to patients. It encourages subjective interpretation by physicians who may, knowingly or not, introduce personal interests or normative values into their assessment. A fairer alternative may be the use of a 'disinterested' judicial forum.

**Freedom from duress**

For an advance directive to be legally valid it must have been made without duress. The reasons for this are obvious, but deciding what constitutes duress may not be straightforward.

In essence, making an advance directive is making a choice about treatment and extending that to the future. As any self-determined choice should be adequately informed, advance directives are really an expression of informed consent or refusal to future treatment options.

So the consensus on informed consent can be considered to apply to advance directives, whereby a degree of persuasion may be anticipated but coercion is unacceptable.<sup>16,17</sup> A valid advance directive should therefore bear no evidence of coercion by relatives, friends, or health care workers.

**Ethical and sociological considerations**

Unfortunately, the scope of this paper leaves many philosophical, ethical, and sociological considerations untouched; however, a few need to be mentioned. The first is that it is unfortunate how the subject of advance directives seems to have ended in the domain of medical law. Although an emerging theme in medical ethics, most of the recent articles on advance directives in the medical press have covered legal or practical matters.<sup>18-20</sup> While these are obviously important — indeed this paper attempts to clarify certain issues — it is not in the interests of doctors or patients to reduce medical ethics to medical law.

An opportunity may have been lost, for instance, for practitioners to engage in the complex but relevant debate on the concept of personhood.<sup>21,22</sup> Am I the same 'person' now as I was 10 years ago? While physical continuity remains most important legally, comments made during the Anthony Bland case suggest that the law is contemplating a concept of personhood that entails consideration of psychological capacity. This has serious implications not only for advance directives but also for issues such as persistent vegetative state, euthanasia, and the diagnosis of death. It is also very pertinent to the way practitioners think about and

interact with the people they treat, especially those with psychological morbidity.

The next point worth consideration has both ethical and sociological dimensions, and addresses the reasons underlying the emergence of advance directives. What has created public interest sufficiently strong to result in legal recognition of advance directives? One of the main factors has surely been a growing emphasis over the past three decades on the individual's right to autonomy; in a sense, advance directives are a self-binding projection into the future of this right. During these past 30 years there have been dramatic developments in Western medical ethics. Bioethics has emerged as a demarcated academic discipline, one that has provided a new set of jobs for philosophers and clinicians. The dominant form of bioethics to develop has been 'principlism', an approach originally advocated by the American philosophers Beauchamp and Childress, but now widely adhered to, and holding considerable popularity, in the UK.<sup>23</sup>

Principlism argues that any medico-ethical dilemma can be analysed by the application and balancing of four principles: respect for autonomy (self-determination), non-maleficence (not inflicting harm), beneficence (doing good), and justice (some concept of fairness).<sup>24</sup> The first of these principles, respect for autonomy, is generally the most powerful principle. This is not surprising given that principlism has emerged from the USA in what could be called the era of the individual, a time in which public concerns about medicine have focused on human rights and decisions relating to technological advances. But despite its useful framework, principlism has come in for some strong criticism: insubstantial basis for selecting these principles, lack of rules for ordering them, and insufficient attention to social context.<sup>25-27</sup> There is also an argument that the effect of putting autonomy on a pedestal has been damaging. The world may well be a more harmonious place if individuals were thinking less about themselves and fostering an atmosphere of communitarianism instead.<sup>28</sup> In addition, there is legitimate concern that the corollary of individualism and technological advancement is diminishing communication with doctors, which may result in patients being literally 'abandoned to their own autonomy.'<sup>1</sup> Advance directives, with their emphasis on refusal of treatment and lack of faith in doctors, may be a reflection of such developments.

It remains to be seen how popular or practicable advance directives will prove to be. Their emergence should be welcomed, albeit with caution,<sup>29-31</sup> an approach reflected in the Lord Chancellor's refusal last year to consider legislation allowing nomination of a proxy (with continuing power of attorney for health care decisions) before a full public debate on the subject. Finally, it is worth reminding ourselves that if patients had less fear about their medical futures, advance directives might become redundant.<sup>32</sup> The best way to alleviate such concerns remains through good communication between doctors and patients and through promoting an environment of trust.<sup>33,34</sup>

### Concluding practicalities

A general practitioner is likely to be involved with advance directives in one of two roles:

- To advise patients on the circumstances in which an advance directive might be appropriate and valid, and on the phrasing of the directive.
- As a repository of the advance directive, which would be forwarded to the appropriate department on request. It may be helpful to adopt a tagging system for the notes, alerting practice staff that the patient has an advance directive.

With advance directives becoming increasingly popular, doctors should be aware of the present situation and, if necessary, relay this concluding message to patients: an advance directive is currently not seen to be legally binding on a doctor although it should be persuasive, i.e. should be followed by a doctor in clinical practice. Although advance directive forms can be designed by the individual, formatted versions are now available from The Terence Higgins Trust (Tel: 0171 831 0330) and The Voluntary Euthanasia Society (Tel: 0171 937 7770); there are important differences between the forms produced by these organizations. Alternatively, the form in Robertson's article in the *British Medical Journal* could be used as a framework.<sup>20</sup>

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