Civil Litigation & Procedure

Advance refusals of medical treatment

by Suzanne Woollard

In 1995 the Law Commission reported on Mental Incapacity (Law Com No 231), producing draft legislation and making wide-ranging recommendations for all types of decision-making in relation to mentally incapacitated adults under a new Court of Protection. One of the most notable provisions in the Mental Incapacity Bill ('the Bill') related to advance refusals of medical treatment. Despite the fact that the 1995 recommendations were widely welcomed no further action was taken to enact the Bill. In December 1997 the Government published a Green Paper entitled Who Decides? (Cm 3803). This has raised many questions in relation to the Law Commission's proposals and it is clear that further consultation is envisaged before any new steps will be taken towards legislation. The clause in the report dealing with advance refusals of treatment caused the greatest amount of public concern.

An advance refusal of treatment is defined in the Bill as:

'... a refusal by a person who has attained the age of eighteen and has the necessary capacity of any medical, surgical or dental treatment or other procedure, being a refusal intended to have effect at any subsequent time when he might be without capacity to give or refuse his consent'.

Advance statements perform a variety of functions. They may reflect an individual's aspirations, preferences for treatment, general beliefs and values and/or refuse medical procedures or specify a degree of irreversible deterioration (e.g. diagnosis of persistent vegetative state), after which no lifesustaining treatment should be given. An advance refusal is, however, limited to specifying treatment which a patient would not consider acceptable. Correspondence received by the Law Commission indicated misconceptions in the minds of consultees. First, that the proposals would entail the legalisation of euthanasia. This, the Government argues, is not the case; euthanasia is an active intervention with the express aim of ending life and remains a crime.

Second, it was thought that advance statements had no basis in existing law and that they would be legalised by the Bill.

THE COMMON LAW

A competent adult may refuse to consent to medical treatment, even if this may pose a risk of permanent injury to health or even lead to premature death. The right to refuse treatment also extends to a refusal of future treatment (confirmed in Airedale NHS Trust v Bland [1993] AC 789). Re T (Adult: refusal of medical treatment) [1992] 4 All ER 649 concerned the advance refusal of a blood transfusion by a patient who had been brought up as a Jehovah's Witness. The Court of Appeal stated that an advance refusal must be made by a person with capacity; it must be intended to apply to the circumstances which later arise; it must demonstrate a settled intention to persist in that refusal, even if it is injurious to health; and it should not be the result of undue influence from a third party.

The legal test for capacity was explored in Re C (Adult: Refusal of Treatment) [1994] 1 WLR 290. There is a presumption in favour of capacity, but this may be rebutted. C was a paranoid schizophrenic who refused to consent to the removal of a gangrenous foot. Thorpe I stated that the test of capacity was whether the nature, purpose and effect of the proposed treatment is sufficiently understood by the person. His Lordship used a three-stage analysis of decisionmaking. First, the treatment information should be comprehended and retained. Second, it should be believed. Third, it should be weighed and a choice made by the patient. In the recent case of Re MB [1997] 2 FLR 426, Butler-Sloss LJ confirmed the principles set out in Re T and Re C, but went on to refer to the test of capacity set out in the Bill. This states that a person is without capacity if unable, by reason of mental disability, to make a decision on the matter in question, either because the relevant information cannot be understood or retained, or because a decision cannot be made based upon that information.

There have been other developments in

relation to advance statements. In 1994, the House of Lords' Select Committee on Medical Ethics stated that it doubted the need for legislation in this area, but recommended the development of a Code of Practice. The following year the British Medical Association published a Code entitled Advance Statements About Medical Treatment. This aims to give guidance to health care professionals and other interested parties about the drafting and implementation of advance statements.

THE 1995 PROPOSALS

The Bill makes provision for a person with capacity over eighteen years to make an advance refusal of medical treatment. There is a presumption, in the absence of any indications to the contrary, that the advance refusal will not apply where it endangers the life of the maker or, if the maker is a pregnant woman, the life of the foetus. An advance refusal may not preclude the provision of 'basic care' (which includes maintenance of bodily cleanliness, the alleviation of severe pain and the provision of direct oral nutrition and hydration), or the taking of any action necessary to prevent the person's death or serious deterioration in his/her condition, pending a decision of the court on the validity or applicability of the advance refusal. No request may be made for futile or illegal treatment, thus confirming that 'mercy killing' remains a criminal offence. Clause 4 of the Bill provides a general authority to act reasonably in providing care to a mentally incapacitated adult, but this cannot override an applicable advance refusal. A person vested with a continuing power of attorney under cl. 12 can only override an advance refusal where the power expressly authorises it. The Law Commission recommended that an advance refusal should be made in writing, signed by the maker and witnessed, in order to reduce the potential evidentiary problems which may arise. The proposals, however, seek to maximise personal choice in relation to all decision-making and therefore an oral directive will have the same legal effect as a written one.

THE 1997 GREEN PAPER

Five main areas of concern are highlighted by the Government.

Definition of an advance refusal

The Commission drew a distinction between 'expressions of views and preference' and 'advance decisions', but the draft legislation refers only to advance refusals, since this is the main problem area. There is, however, bound to be an overlap between the two, especially where the advance statement is made orally. At what point does an expressed wish or preference as to future treatment become an advance refusal? The effectiveness of an orally expressed directive will depend on a close dialogue between the patient and treatment providers and detailed notetaking by care staff for future reference. Other problems of definition concern the age-limit imposed upon the statutory advance directive. This confirms the present law in relation to refusals of treatment by mature minors (see Re W [1993] Fam 64), but it remains unsatisfactory that a person may, for example, legally marry but cannot refuse medical treatment in advance. The Bill makes no mention of confining the use of advance refusals to people with terminal conditions, as this would be inconsistent with the common law, which the Green Paper does not question.

Medical developments

This concern was voiced in 1994 by the House of Lords' Select Committee on Medical Ethics who feared that patients may be deprived of new treatments and procedures available since the directive was made. The Bill, however, seeks to remedy this problem by falling back on the best interests criteria. Clause 3 provides that anything done for and any decision made on behalf of a mentally incapacitated adult shall be done or made in his best interests. The Bill directs treatment providers to take into account the past and present wishes and feelings of the person concerned and the factors the person would take into account if able to do so. This would include considering whether the new treatment is something the person would have taken into account had he or she known about it. The outstanding issue, therefore, is whether the best interests criteria is sufficient to safeguard against the unintentional use of medical procedures developed since the drafting of the advance statement. The Green Paper confirms that the general statutory authority to act on behalf of a mentally

incapacitated adult cannot override an advance refusal of treatment, but notes that the Government wishes to ensure that a treatment decision could nevertheless be made based upon more recent medical developments if, having regard to the previously expressed wishes of the person, it would appear to be in their best interests to do so.

The patient's state of mind

How much information must a person understand in order for an advance directive to subsequently take effect? The Government raises the issue of patients who do not wish to be informed of the extent of their illness or the possible outcome of a failure to take treatment. How, in such cases, could a doctor be sure that the implications of the advance refusal are fully understood? The Green Paper suggests that there should be a that 'relevant requirement the information' be given, so that an informed choice can be made. The statutory requirement is that a person shall be regarded as able to understand the information, if able to understand an explanation of that information in broad terms and simple language, for the very reason that the test should be as wide as possible and not require the patient to understand all the detail. There is also a concern about advance refusals which are made by those who have not consulted a health-care professional beforehand, as they may be made based upon erroneous ideas and information. In a case such as this, however, the advance refusal may not be deemed to apply to the treatment proposed for the patient.

Life sustaining treatment and basic care

The Government questions whether an advance refusal should only apply when the life of the patient is in danger, if the refusal has specifically acknowledged the risk of death. This safeguard would mean that, if in doubt, a doctor may preserve the life of the patient if that is in his best interests. Similar concerns are voiced in relation to pregnant women. The Green Paper questions whether there should be a requirement that if an advance directive is to apply during pregnancy there should be a specific reference to this fact. In relation to advance refusals concerning treatment in childbirth, there is an issue concerning whether, if the life of the patient is in danger, they should only apply if the refusal has referred to the risk of death.

The Law Commission proposed that 'basic care' could not be excluded by an

advance refusal, on the ground of public policy, in order to preserve the health and cleanliness of the patient and others in close proximity. The Green Paper casts doubt upon this by questioning whether a person has a right to exclude basic care. The Government also identifies the possibility of forced oral feeding of patients, where a person has lost competence and steps are necessary to avert a risk of serious harm to the person concerned. Clearly this would not be desirable and the Government wishes to avoid this situation.

The liability of health care professionals

It is recommended that where health care professionals either withhold care in accordance with the patient's wishes, or proceed with treatment only to find that, unknown to them, it is against the wishes of the patient (for example where there is no knowledge or suspicion that an advance refusal exists), they should not incur liability. The Green Paper questions whether this provides an appropriate balance between protecting health care providers and protecting patients. This provides a sensible compromise as health carers may not always know of the existence of an advance statement and cannot be expected to delay treatment unduly in order to search for one.

CONCLUSIONS

The Green Paper correctly identifies that there is great strength of feeling on the subject of advance refusals of health which arises from inveterate personal, moral, religious and ethical views. It also observes that confusion exists in relation to the legality of advance refusals, and the fear that the proposed legislation would legalise euthanasia. It is therefore not surprising that there is a reticence on the part of the Government to proceed immediately with legislation. Instead, there is a recognition that this is an evolving area of law and that there is merit in postponing further policy development until there has been more of an opportunity to consider the impact of case law and the operation of the BMA's Code of Practice. This may be wise, although it does mean that the present uncertainties amongst lawyers and healthcare professionals will remain.

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