

# Legislating for Advance Refusals of Treatment: What is at Issue?

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## 1. Introduction

Back in 1995 the Law Commission published comprehensive proposals for legislation to govern decision-making for the mentally incapacitated. The previous Government was somewhat chary of bringing these proposals before Parliament, but the present Labour Administration has embarked on a process of consultation precisely with that end in view. The first phase of that process (consultation on the proposals in the Green Paper *Who Decides?*) was completed in March.

Together with Dr John Keown, I wrote a lengthy Response to *Who Decides?* which was submitted to the Lord Chancellor's Department in March. We criticised a number of the proposals in the Green Paper which are seriously at variance with the respect owing to mentally incapacitated persons. This short article is confined to consideration of one of the proposals in the Law Commission's Draft Mental Incapacity Bill: the proposal to make advance refusals of treatment binding in statute law. Section 9(3) of the Bill makes it clear that doctors and other carers would be obliged to comply with advance refusals of treatment (including refusals of tube-feeding) which were suicidally motivated (i.e. in which it is made clear that the reason for refusal is to have an end put to one's life).

## 2. What are advance refusals of treatment?

An advance refusal of treatment is one kind of advance directive. An advance

directive (sometimes known as a 'living will') stipulates in advance the way one would wish to be treated in certain specified circumstances should one be incapable of making one's wishes clear at the time one needs treatment. An advance refusal of treatment makes clear what one would not wish to have done to one in circumstances in which one requires medical care. Since doctors cannot be obliged to give treatment which is contrary to their clinical judgment, advance refusals of treatment are the most significant type of advance directive.

Some patients are attracted by the idea of committing advance refusals of treatment to paper because they think they can thereby ensure that they do not receive unacceptable treatment. The scenario some have in mind is that of doctors employing all the apparatus of the intensive care unit to keep them alive when it would be more appropriate to leave them to die unencumbered by this technology.

## 3. Advance refusals of treatment and euthanasia.

There are those who choose to play on the fear of this kind of scenario to advocate legislation to make advance refusals of treatment binding. And among them are advocates of euthanasia who see the advancement of their cause by this legislative route.

How would such advancement be secured? By making it legal for a doctor to aim to end a patient's life by depriving the patient of treatment and

tube-feeding. There may be circumstances (see Section 7 below) in which it is reasonable to withhold or withdraw certain forms of treatment. But if the reason for doing so is an advance refusal of treatment in which a patient has made it clear that life-preserving treatment or tube-feeding would be unacceptable in certain circumstances *because he judges his life would not be worth living in those circumstances*, then it is evident that the reason for withholding or withdrawing is to put an end to the patient's life. *The patient's objective is made the doctor's objective by the advance directive.*

Once it is clearly seen that killing by omission has become the legal obligation of doctors (because of the binding force of advance directives), proponents of euthanasia will urge that it is unreasonable - because manifestly inconsistent - to continue to prohibit active euthanasia.

A number of questions are raised by what has been said here about advance refusals of treatment which are aimed at ending the patient's life:

Are not such advance refusals already binding in common law and, if so, what difference would legislation make?

One assumption behind what has been said is that both suicide and the intentional termination of a person's life by a doctor are moral evils which should be treated as unlawful. Does not this assumption need to be defended?

Another assumption behind what has been said is that doctors should not have to comply with advance refusals of treatment which are suicidally motivated (i.e. which aim at bringing about the death of the person who

makes them). But how can one reconcile this assumption with the fact that doctors are generally required to respect refusals of treatment made by competent patients? What is the morally significant difference between two refusals of treatment, each made when the patient in question was competent, but one in regard to treatment to be given when the patient is still competent, the other in regard to treatment to be given when the patient has become incompetent? If one refusal is to be respected, why not the other?

We can take each of these questions in turn.

#### **4. Are advance refusals of treatment already binding in common law?**

A number of judges in recent years have expressed the view that they are, a view shared by a number of practising lawyers and reputable academic lawyers. There are other lawyers who disagree, noting the fact that there has yet to be a case in which the contention that advance refusals are binding can be said to have been tested. There is therefore some element of uncertainty about the binding force of advance refusals of treatment. This is one reason why there is a drive to have statute law which makes unambiguous their binding force.

#### **5. Is it not necessary to defend the assumption that both suicide and the intentional termination of a patient's life by a doctor are moral evils which should be treated as unlawful?**

In many contexts it is of course necessary to defend this assumption. And different approaches to the defence will be required depending upon the beliefs one shares with whomever it is requires the defence.

For the purposes of the present article I shall offer no defence, in the belief that one is not required by my readers. If they are Catholics then I presume they share with me knowledge of the truth that for each of us our life is a fundamental good and a gift of God. We should cherish it as such and not neglect to care for it because of cowardice or laziness or intemperance. Since the life of each of us is a fundamental good and a gift of God, it is never open to us to judge it without worth (or not worthwhile) and for that reason to be deliberately ended. A life can be deliberately ended not only by a positive act (such as the injection of a lethal substance) but also by the deliberate omission of treatment or care decided upon precisely in order to end life.

If any reader is looking for a secular defence of the assumption which relies on a rather minimal number of moral beliefs then they can find it sketched elsewhere.<sup>1</sup> Though it is not argued for here, it remains that the fundamental point to bear in mind in relation to the issues dealt with in this article is that morality forbids lethal choices in the sense of choices to end the lives of innocent human beings (by murder or by suicide). And the centuries-long tradition of common law has followed morality in this regard, with the lamentable exceptions of abortion since 1967 (in the UK) and the *Bland* judgments in 1992-93.

**6. If doctors are not to be obliged to override suicidal refusals of treatment made for the present by competent patients why should they override suicidal refusals of treatment made for a future**

<sup>1</sup> A fuller account can be found in Luke Gormally (ed) *Euthanasia, Clinical Practice and the Law* (London: The Linacre Centre, 1994), pp 118-133.

**situation in which the patient has become incompetent?**

We need to understand precisely why doctors are not obliged to override competent patients' suicidal refusals of treatment. It is not because such patients have either a moral or a legal right to suicide. That they do not have a moral right we have noted by implication in taking note of the moral wrongness of suicide (Section 5 above). Furthermore, suicide, though decriminalised, remains unlawful behaviour. And this is clearly shown by the fact that assistance in suicide is a crime which carries a substantial penalty.<sup>2</sup> Given both the wrongness and the unlawfulness of suicide, a doctor is obliged not to assist a patient in committing suicide. This obligation might be satisfied by discharging from his care a competent patient who persistently and suicidally refused the care needed to stay alive. Since competent patients will often be well-placed to make it difficult if not impossible to override their suicidal refusals of treatment or care it would not be reasonable to impose on doctors an additional obligation to override such refusal. Failure to do so should, therefore, not be construed as *respect* for the patient's choice (as the objection I stated in Section 3 represented it as being).

The situation is otherwise with the incompetent patient. Since it is not in

<sup>2</sup> Suicide was decriminalised in the *Suicide Act 1961* not out of respect for self-determination (in other words, to facilitate suicide) but out of a desire to help rather than punish the suicidal (in other words, to help prevent suicide). This should be abundantly clear to anyone who reads the Parliamentary Debates at the time of the passage of the Act. Despite the evidence, propagandists for euthanasia regularly speak of a legal right to suicide. More alarmingly, Lord Justice Hoffmann in the Court of Appeal in the *Bland* case seemed to share their view.

the interests of the incompetent patient to respect his suicidal advance refusal of treatment made while competent, the doctor should override it where he is in a position to do so. And at present he generally is. But proposed legislation may change the situation. And though he may not himself be legally obliged, for example, to supervise the starvation of a patient, he would be obliged to transfer the patient to the 'care' of a doctor willing to do precisely that.

There are those who say that to override the antecedent suicidal will of the now incompetent patient is to fail to respect the dignity of that patient. But the claim mistakenly demands respect for a past statement of choice rather than the actual living human being. Human worth and dignity belong fundamentally to us as living human beings, no matter how defective or debilitated we may be. And the most fundamental requirement of respect for another's dignity is respect for that person's life.

There is much loose talk<sup>3</sup> - in medical and legal circles - about 'respect for autonomy'. But autonomy as a capacity

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<sup>3</sup> One wonders how seriously people reflect on the logic of what they say about the import of 'respect for autonomy'. Some of the more extreme talk suggests opposition to any politically organised community and any law at all. The legal rhetoric sometimes used to uphold refusals of life-sustaining treatment - of "rights" to be "let alone" and to "control fundamental decisions involving one's body" - cannot be taken seriously because of its implications: it would nullify, for example, prohibitions against drug abuse, and would make consent a complete defence to homicide and assault. Autonomy, in the sense of liberty to do what one wants when what one wants *affects only oneself*, is arguably an empty notion. We are none of us monads, and what we do 'solely to ourselves' affects our relationships with others either directly (as in suicide) or indirectly through its effects on our character.

is to be valued precisely in so far as its exercise makes for the well-being and flourishing of the human beings who possess it. It is plain, however, that many exercises of that capacity, that is, many self-determining choices, are destructive of human well-being - both in the life of the chooser and in the lives of others affected by his or her choices. The mere fact that someone has elected to act or to be treated in a certain way establishes no title to moral respect for what has been chosen. The character of the choice must satisfy certain criteria in order to warrant our respect. The most basic criterion is that a choice should be consistent with respect for the fundamental dignity both of the chooser and of others.

### **7. Granted that suicidal refusals of treatment could never be morally permissible, what refusals of treatment or care may be morally acceptable?**

We need to begin by distinguishing between

- **ordinary care:** the provision of the nutrition, shelter, hygiene and comfort ordinarily necessary to sustain a life, and
- **medical treatment:** measures designed to restore or maintain bodily well-functioning in face of specific threats to health, or to achieve some approximation to well-functioning, or to mitigate symptoms (as in palliative care) which, uncontrolled, prevent one enjoying some of the other 'goods' of human living.

**Ordinary care** is almost always owing to patients; to deny it to someone when it is possible to provide it is contrary to the basic respect owing to any human life. Nor in most circumstances should

one refuse ordinary care for oneself. A directive of that kind should be given only if it is clear that the provision of ordinary care for one would impose great burdens on the providers or would effectively deprive others of that care when they have at least as good a claim to it as oneself. Such motives for refusal are clearly altruistic rather than suicidal.

There may be good reasons for declining particular **medical treatments**. The duty to care for one's life does not override *all* other considerations and does not require one to take every possible measure to prolong it. Specifically, one has no duty to accept treatment which is

- either **futile**: because it cannot achieve its therapeutic purpose. Thus, treatment which is designed to be life-prolonging is reasonably refused as futile if one is irreversibly in the terminal phase of dying.
- or excessively **burdensome in its consequences** : the burdens may be physical (e.g. pain), psychological (e.g. stress), social (e.g. disruption of life-style or relationships), or economic (e.g. in draining one's own or others' financial resources). A judgment that treatment is excessively burdensome in its consequences may be made without any reference to the anticipated benefits of treatment (i.e. one simply finds the burdensome consequences unbearable) or may be made precisely by reference to the anticipated benefits of treatment (i.e. one thinks them too small or too unlikely to warrant bearing the burdensome consequences).

Clearly, refusals of treatment because it is either futile or burdensome focus on the value or 'bearability' of *the treatment*. As such, they are to be

distinguished from refusals of treatment which view one's own life, either now, or in some anticipated future, as 'futile' or 'unbearable'. Refusals of treatment of the latter kind which are intended to put an end to one's life are the suicidal kind we have been discussing.

Judgments of burdensomeness are inevitably highly individual, not only because of the particular nature of a patient's condition and the conditions attending his treatment, but also because certain of the burdens consequent on treatment depend on the individual sensibility, sensitivity, and circumstances of the patient.

#### **8. Is there a case for committing morally acceptable refusals of treatment to writing in the form of an advance directive?**

For reasons that will be explained in the next section, it is difficult to think of a good case for setting down a categorical refusal of specific therapies which one intends to bind a doctor at some unspecified time in the future.<sup>4</sup>

There may well be a case for setting down, in the form of a declaration which one intends to be advisory in character, a statement of the kinds of things one anticipates one may find burdensome to oneself or a statement of one's desire not to have treatment which one anticipates will be excessively burdensome to others. The case for doing so may be strong if one anticipates that those who have to act for one will be largely ignorant of one's sensitivities and outlook, or if one thinks that relatives may need written testimony of one's desires in order to

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<sup>4</sup> Of course I have in mind genuine therapies here. If the word 'treatment' comes to cover euthanasia, for example, there will be a case for an advance categorical refusal of it.

relieve them of potential embarrassments in saying what one had desired.

**9. Granted also that suicidal advance refusals of treatment should be unenforceable and should be overridden, is there any case for any sort of advance directives being made legally enforceable?**

The case against seems rather strong. First, as a matter of practical politics, if we have enforceable advance directives in any form we will almost certainly get enforceable suicidal advance refusals of treatment.

Secondly, it is difficult to anticipate in one's specification of future conditions the precise combination of acute and chronic symptoms one is likely to display and the extent of one's capacity for recovery if given adequate treatment. Furthermore, the 'incompetence' which may make an advance directive operative may be only transitory but may, in depriving one of appropriate treatment, have the effect of leaving one permanently impaired in ways one finds much harder to bear precisely in so far as one recovers competence. In general, in depriving people of appropriate medical care advance refusals of treatment are likely to leave many patients alive but in a worse condition than they might otherwise be (e.g. bedridden instead of mobile).

Thirdly, an advance refusal may have the effect of excluding new methods of treatment which one did not envisage at the time of making the declaration. Fourthly, legally enforceable advance directives are all too likely to impose profoundly demoralizing limits on doctors and nurses: they may be obliged to act in ways which they know to be clearly contrary to the best

interests of patients. The State itself has an interest in maintaining conditions supportive of the proper practice of the professions of medicine and nursing. Furthermore, the litigation which is likely to be caused in consequence of making advance refusals of treatment binding by statute may well intensify the already unfortunate tendency to 'defensive' medical practice, since proposed legislation will create new areas of liability and hence of litigation.

Fifthly, the litigation referred to will arise from the fact that advance directives deal with hypothetical future scenarios, not present specific situations. In consequence, many will raise questions about their applicability which can only be resolved by applications to the courts. The legal costs of this are likely to bear heavily on an already overburdened health service budget.

## 10. Conclusion

Advocacy of legally enforceable advance refusals of treatment seems to have two main sources:

- its perceived strategic importance in achieving legalization of active euthanasia. For that reason alone it is an advocacy to be resisted.
- the breakdown of trust between patients and doctors, and the consequent desire of patients to have tools to control the behaviour of doctors. The causes of this breakdown are complex: the absence of shared understandings of life, death and health; the loss of a common morality; changes in the pattern of provision of medical and nursing care, so that for so much of the time one seems to be in the hands of strangers and moral aliens; and so on. I would suggest that

having legally enforceable advance refusals of treatment will do nothing to restore trust between patients and doctors. The consequent litigation and defensive behaviour can surely only make matters worse.

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