

Response to *Making Decisions*

(Leaflets Published by the Lord Chancellor's Department)

1

The Linacre Centre*

1. Introduction

The Linacre Centre for Healthcare Ethics is a research institute whose Trustees are the Catholic Archbishops of England and Wales. We produce academic and other material on a range of issues in healthcare, including euthanasia and the withholding and withdrawing of treatment or care. We also provide advice to individual health practitioners on ethical aspects of their work, in these and other areas.

We welcome the opportunity to respond to the consultation on *Making Decisions*, the leaflets produced by the Lord Chancellor's Department. In making this response, we wish to stress that nothing we say relies on the authority of the Church to which we belong. Our comments relate to concerns for human rights and human welfare which are quite widely shared.

We do not intend to criticize everything in the leaflets: on the contrary, they contain some helpful advice on managing (for example) the financial affairs of those who have difficulty, or anticipate difficulty in the future, in making decisions for themselves. However, the leaflets also contain, in our opinion, some morally unjustified advice on making decisions for mentally disabled people, both in regard to treatment and care and in regard to sterilization and abortion.

2. Refusal of treatment

Competent patients are morally and legally entitled to refuse medical treatment, though how far in advance such refusals can be made and exactly what they can encompass is a matter

for debate. As a general principle, competent patients have first responsibility for their own health, and should be permitted to make decisions about their health, even if these decisions are unwise.¹ Doctors and nurses should encourage the patient to accept medical treatment which they believe is warranted, but should not force treatment on a patient who refuses to accept it.

However, the situation changes if the patient's refusal is suicidally motivated - that is, motivated by the intention to avoid life itself, rather than some particular treatment. A person who refuses treatment with this motivation is suicidal, no less than a person who actively intervenes to end his / her own life. (For example, if someone takes an overdose, both the overdose and the person's subsequent refusal to have his / her stomach pumped out are suicidal.)

Like other suicidal people, those who are physically ill and suicidal need protection and support. There is no recognition in the *Making Decisions* leaflets of the possibility of suicidally-motivated refusals of treatment - for example, in the form of an advance directive. On the contrary, it is said repeatedly that advance refusals 'must be complied with' (Leaflet 2, p.8) - at least 'so long as the advance refusal of

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¹ See Luke Gormally (Ed), *Euthanasia, Clinical Practice and the Law*, London: The Linacre Centre, 1994, pp.135-137; Helen Watt, *Life and Death in Healthcare Ethics*, London: Routledge, 2000, pp.32-35.

treatment is clear and is applicable in the particular circumstances' (p.7). Does this mean that doctors could be prosecuted for saving the life of someone who took an overdose, if that person had signed an advance directive when he or she was competent?

Of course, it is impossible to prevent all suicide, by whatever means it is performed. Doctors typically have many patients to care for, and many demands on their time and attention. It would, however, be extraordinary if doctors were no longer permitted by law to prevent suicide in those cases where they can. It should be remembered that suicide has been decriminalized, but is still unlawful, as is shown by the fact that assistance in suicide is a serious crime.

The likelihood of a suicidal motivation being expressed in an advance directive is far from remote, in view of the widespread belief that life in some conditions - for example, permanent unconsciousness, or advanced Alzheimer's - is 'not worth living'. The Voluntary Euthanasia Society (VES) has produced a model advance directive, to which those who wish to plan in advance for incapacity are explicitly referred in Leaflet 6 (p.8). The VES is a well-known supporter of euthanasia and assisted suicide. The fact that the Lord Chancellor's Department is willing to refer individuals to the VES (which is also thanked in the Introduction) is extremely disturbing.

3. Withholding of treatment or care

Just as suicide can be committed by omission, the same is true of homicide. In the case of Tony Bland, three out of five Law Lords stated - the others not dissenting - that the aim of withdrawing tube-feeding was to end Tony Bland's life. Subsequent court

rulings have been similarly frank about the motivation behind the withdrawal of of tube-feeding from PVS or near-PVS patients.

Human life has value, even in the most deprived conditions, and euthanasia, whether by act or by omission, is a form of wrongful homicide. This position is shared by many people of different faiths, and of no faith. Human life has an objective, intrinsic value, however much or how little it is valued by the person whose life it is. Life is not the only aspect of a person's welfare, and need not be promoted by every possible means. However, it is one 'human good' among others, and should be recognized as such. Certainly, it is unacceptable to end life deliberately - by act or omission - on the grounds that it is not worth living.

While it is necessary to weigh the benefits and burdens of any intervention on behalf of the sick, treatment or care should never be withheld with the purpose of shortening life. Leaving aside the questionable portrayal of pouring food down a tube as 'medical treatment'², if tube-feeding or other interventions are withdrawn *with the purpose of shortening life*, this is euthanasia by omission.

There is no recognition in the *Making Decisions* leaflets of the possibility of euthanasia by omission, or of any other objection to court-authorized cessations of tube-feeding. On the contrary, it is made clear that anyone

² While the insertion of a gastrostomy tube into the patient's stomach is a simple form of medical treatment, pouring food down the tube once inserted is arguably better described as nursing care, like feeding with a spoon or straw. If a nasogastric tube is inserted through the nose into the stomach, even the insertion of the tube could reasonably be described as nursing care.

with a 'legitimate interest' can apply to the court for a ruling on the withdrawal of tube-feeding from someone in a 'persistent vegetative state' (e.g. Leaflet 2, p.10). It is also said that people can refuse in advance to be 'kept alive by artificial means' (Leaflet 6, p.8), and that those close to the patient may be able to say if the patient had 'strong views about particular health conditions or treatments' (Leaflet 1, p.9; Leaflet 3, p.12).

Of course, there is nothing wrong with those close to the patient giving information on which forms of treatment the patient would find particularly burdensome. However, the danger is that those who see the patient's *life* as a burden ('She would not have wanted to live like this') may be able to obtain withdrawal of treatment or care from the patient *intending that she die*. Whether the relatives (for example) are sincerely trying to benefit the patient in ending her life, or whether they are thinking of their own interest in securing an inheritance (or avoiding future care), it is inappropriate for such homicidal motivations to affect decisions for that patient.

4. Best interests

The leaflets state at various points that decisions for non-competent patients must be made 'in their best interests'. However, the account of 'best interests' given in the leaflets is overwhelmingly subjective. Only in one leaflet - leaflet 2, intended for health professionals - is there any mention of the patient's *clinical* best interests. In none of the leaflets is there any mention of the patient's interest in not being killed intentionally - for example, by having treatment withdrawn on the grounds that his / her life is not worthwhile. Nor is there any attempt to *list* the objective interests of patients: for

example, their interest in respectful and efficient nursing care. The interests of patients often seem to be collapsed into 'what they wanted' or 'what is important to them' (or, in practice, into the views of other people on 'what they wanted' or 'what is important to them'). While there is no objection to those close to the patient giving information to be used in establishing the patient's objective interests (for example, in avoiding unduly burdensome treatment), it is these objective interests which should be the focus of attention.

As we have seen, the patient may have wanted to die: should this perceived interest be satisfied - even, perhaps, if it was orally and informally expressed? The leaflets suggest that even oral and informal statements be given weight, and do not recognize the possibility of a patient being suicidal at the time of making such a statement. If even a passing expression of unhappiness at some existing or possible health problem could result in an untimely death for the patient, is this really in the patient's interests?

5. Advance directives

The treatment of advance directives in the *Making Decisions* leaflets is cursory, leaving much unsaid. It is repeatedly stressed that advance refusals of treatment must be complied with, with no reservation mentioned with regard to suicidally-motivated refusals (or indeed, refusals of pain relief or nursing care, including the provision of food and fluids). Nor is there any warning of other possible problems with the implementation of advance directives, which have been outlined not only by Christian medical organizations (the Guild of Catholic

Doctors;³ the Christian Medical Fellowship⁴), but to some extent by secular medical organizations, such as the British Geriatrics Society,⁵ the BMA⁶ and the GMC.⁷

Doctors are aware of the dangers of advance refusals, in terms of new discoveries, uncertain diagnoses and lack of information on the part of those who sign them. While normally, when a competent patient refuses medical treatment, the doctor will have had an opportunity to explain the treatment beforehand, this is often not the case with advance refusals of treatment. It will be very hard to ensure that normal standards for 'informed consent' (or, in this case, refusal) have been met, when the advance refusal may have been made with no medical consultation at all. In the case of *Re: AK* dealing with an advance refusal of treatment, it was explicitly said by Mr Justice Hughes that 'Care must be taken to investigate how long ago the expression of wishes was made. Care must be taken to investigate with what knowledge the expression of wishes was made'.⁸

It is striking that Leaflet 6 mentions the possibility of consulting a lawyer on making an advance directive (p.4) but does not mention - let alone recommend - consultation with a doctor. The sole reference to a doctor

lies in the suggestion on p.8 that a copy of the advance directive be *lodged with* a doctor or lawyer. Nor are lawyers given any warning in Leaflet 4 of the medical complexity of advance refusals, or advised to suggest that their client discuss an advance refusal with (for example) his or her G.P.

Given the gravity of an advance refusal of potentially life-saving treatment, would it not be wise to consult a doctor before signing such a refusal - or perhaps to think again about the wisdom of signing it at all? The vague reference to keeping people alive 'by artificial means' (Leaflet 6, p.8) is a case in point: the patient may deprive him or herself of valuable treatment which will alleviate pain or disability, simply on the grounds of its 'artificiality'. As the British Geriatrics Society has pointed out, advance refusals which are obeyed during a period of temporary incapacity may have the effect of the patient surviving in a much more disabled state than would otherwise have been the case.⁹

Many patients fear that if they do not sign an advance directive, they will be burdened with inappropriate treatment at the end of their lives. However, doctors are themselves aware of the need to weigh the burdens of treatment against any benefits it may bring. A culture of absolutely binding advance directives could have the effect of reducing trust in doctors to give appropriate care. It could encourage doctors to rely on advance directives as an easy and legally safe option, rather than making an effort to communicate with patients, and to promote their interests where communication is not possible. Advance directives, in that they can be motivated by the view that

³ Guild of Catholic Doctors, *Advance Directives or Living Wills*, 1998.

⁴ Christian Medical Fellowship, Submission from the Christian Medical Fellowship to the Select Committee of the House of Lords on Medical Ethics, 1993.

⁵ British Geriatrics Society, *Legally Binding Living Wills or Advance Directives*.

⁶ BMA, *End of Life Decisions: Views of the BMA*, June 2000; BMA, *Advance Statements About Medical Treatment - Code of Practice*, April 1995.

⁷ GMC, 'Withholding and Withdrawing Life-Prolonging Treatments: Good Practice in Decision-making', May 2002 (draft).

⁸ [2001] 1 FLR 134E-G.

⁹ British Geriatrics Society, *Legally Binding Living Wills or Advance Directives*.

life in some conditions is worse than death, can also promote the spread of negative views of disability.¹⁰

6. Contraception, sterilization and abortion

In addition to their advice on treatment and care of the mentally disabled, the leaflets also contain some disturbing advice on contraception, sterilization and abortion. There is some recognition of the fact that not all mentally disabled people are capable of consenting to a sexual relationship. However, Leaflet 1 suggests that for those who *are* capable of a sexual relationship 'this should be made possible' by carers with 'contraception and other safeguards' (p.8) - which would presumably include abortion. Several leaflets refer to a situation where a court can be asked to authorize sterilization or abortion for a mentally disabled person (e.g. Leaflet 2, p.10).

Mentally disabled people have a right to marry, like other people, if they are capable of doing so. In the case of a mentally disabled person who is capable of consenting to marriage, there is certainly an argument for carers 'making this possible' by means of new accommodation arrangements. Whether carers are obliged to make similar arrangements for unmarried people is, however, a very different question.

As far as contraception is concerned, it should be remembered that many contraceptives are, in fact, abortifacient in effect, in those cases where conception has already taken place. Even those who do not - like the Catholic Church - oppose the use of contraceptives in principle can

appreciate the objection to abortion, whether chemical or surgical in form. Pregnancy is not a disease, and abortion does not cure, but rather harms, the woman on whom it is performed. For a court to authorize abortion on a mentally disabled woman is for the court to agree that her child may be deliberately destroyed. This is not in her interest (let alone the child's interest) and at least some mentally disabled women who are judged incompetent may be capable of seeing this for themselves. Will courts and doctors be prepared to force abortions on mentally disabled women who realize they are pregnant, and want to keep their babies?

Sterilization for contraceptive reasons, while a less serious harm than abortion, is nonetheless an act of permanent mutilation, not a health-promoting act. If a woman is not capable of consenting to sterilization, she is not capable of consenting to sexual intercourse. Rather than being sterilized, a mentally disabled woman who is not in a position to marry and have children should be protected from sexual abuse. Sterilization of the mentally disabled will remove, in the eyes of their carers, one important reason for giving them appropriate protection. It will also reassure potential abusers that the likelihood of their being detected has been substantially reduced.

7. Conclusion

The *Making Decisions* leaflets contain some good advice on making decisions for mentally disabled people in some areas of their lives. However, in the area of healthcare we believe the leaflets need extensive revision, both in regard to what they include and to what they omit. Autonomy is overstressed: in particular, the statement that 'every adult has the right to make

¹⁰ Christian Medical Fellowship, Submission from the Christian Medical Fellowship to the Select Committee of the House of Lords on Medical Ethics, 1993.

their own decisions' needs to be heavily qualified. There are many cases where the law trumps autonomy, even with regard to competent adults - from assisted suicide to the wearing of seatbelts to the use of recreational drugs.

The role of the doctor in protecting patients' interests is neglected in the leaflets: it is often unclear that the 'best interests' of the incompetent person are his or her *objective* best interests, including clinical best interests. On the contrary, 'best interests' often seem to be collapsed into what the patient wanted, or would have wanted, or (in practice) what other people think (or say) the patient wanted, or would have wanted. There is also no recognition of the medical complexity of advance refusals of treatment, nor of the fact that advance refusals - like contemporaneous refusals - can have a suicidal motivation.

The leaflets are uncritical of existing law permitting abortion and sterilization of mentally disabled women, and deliberate killing by omission of patients in a 'persistent vegetative state' or similar condition. Case law in this area constitutes a serious injustice to disabled people, and these leaflets (and the draft legislation they follow¹¹) will do nothing to restore the law to a more humane state. Despite many good features of the leaflets in the *Making Decisions* consultation, they fail to protect the very people whose interests they are designed to serve.

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¹¹ The Linacre Centre produced a critique of the proposals in *Who Decides*.