

Human Dignity, Autonomy, and Mentally Incapacitated Persons

(A Response to *Who Decides?*)

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Submitted by the Linacre Centre for Healthcare Ethics at the request of the Roman Catholic Bishops of England, Wales, Scotland and Ireland

Preface

The following Response to *Who Decides?* concentrates on proposals in the Green Paper relating to decision-making for mentally incapacitated persons in respect of their healthcare. The reason for this concentration is twofold: first, that the expertise of The Linacre Centre is in the field of healthcare ethics, and, secondly, that, as it happens, the most questionable proposals advanced by the Law Commission concern decision-making in regard to the medical care of mentally incapacitated persons.

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Bishops of Ireland (President: Archbishop Sean Brady).

Our comments on *Who Decides?* are intended as a contribution to public policy debate on what are in fact fundamental issues of justice for our society. Nothing we say relies on the doctrinal authority of the Church to which we belong. We aim to commend the positions for which we argue to those who do not share our religious beliefs but who are concerned for the basic rights of all human beings, however underdeveloped or incapacitated.

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1. Introduction: A threat to the vulnerable?

Who Decides? is in large part an exercise in commending the Law Commission's legislative proposals as drafted in the Bill published with their Report on *Mental Incapacity*. The Government, we are told, is "in a number of areas ... minded to accept the principles underlying the Law Commission's recommendations". (1.4) The three principal contentions in our critique of both documents are:

they exhibit a serious failure to uphold a true valuation of the lives of those who are not

capable of making decisions for themselves. This failure is most glaring in the scope the legislative proposals provide for assistance in suicide and euthanasia by planned omission.

they attach an unwarranted value to autonomy (exercises of self-determination) in ways which are seriously damaging to the "best interests" of those lacking capacity to make decisions for themselves.

in their proposals to legalise non-therapeutic experimentation and the using of the mentally incapacitated as sources of organs and tissue a crudely utilitarian attitude to those patients is exhibited: they are regarded as exploitable without regard for even the tenuous criteria of their 'best interests' advanced elsewhere in the proposed legislation.

If the proposed legislation becomes law in its present form the regulatory machinery it establishes will not unambiguously protect those vulnerable patients who are mentally incapacitated; what it will in part regulate is their exploitation.

We would emphasise that this Submission is based on ethical and legal considerations which make no assumptions based on religious belief or derived from religious authority. It is based on considerations the cogency of which should be recognisable by anyone who sees that if there is to be justice in society certain basic truths about human beings have to be acknowledged.

We welcome the opportunity to comment on the Consultation Paper *Who Decides?*¹ issued by the Lord Chancellor's Department. We acknowledge the need to clarify the legal position of those undertaking the care of mentally incapacitated adults who are not detained under the Mental Health Act 1983. And there is evidently merit in having a common framework of law to regulate decision-making for the mentally incapacitated which embraces their health and welfare broadly understood as well as their financial interests. In what follows we will be mainly concerned with decision-making in respect of health care for the mentally incapacitated.

The task of producing such a comprehensive framework of law to regulate decision-making for the mentally incapacitated is extremely delicate. There are influential ideological tendencies in our society which depreciate the value of the lives of the mentally incapacitated and there are grounds for thinking that these tendencies have to some degree found expression in the legislative proposals advanced by the Law Commission.²

It may seem implausible to suggest that a tendency to depreciate the value of the lives of mentally incapacitated

¹ *Who Decides? Making Decisions on behalf of Mentally Incapacitated Adults*. A Consultation Paper issued by The Lord Chancellor's Department, December 1997. Numbers in the main text refer to paragraphs in *Who Decides?*

² The Law Commission (Law Com No 231) *Mental Incapacity*, London: HMSO, 1995. References to the Report internal to the main text take the form LawCom231, followed by the number of the paragraph of the Report. References to the Bill drafted by the Law Commission take the form LawCom231Bill, followed by the number of the clause of the Bill.

people underlies at least some of the legislative proposals in a document which in its own terms is concerned that "vulnerable people may not be getting all the help and protection they need and deserve" (LawCom231: 1.2) But the suggestion will be seen not to be implausible if one considers some of the legislative proposals in the Law Commission's Bill:

that courts, donees of continuing powers of attorney, court-appointed managers, or doctors appointed by the Secretary of State may, without regard to the best interests of the patient

- discontinue tube-feeding of an unconscious patient; [LawComBill: 10.-(1)]
- authorise the carrying out "of any medical or surgical procedure in relation to a person without capacity to consent which, though not carried out for his benefit, will in the opinion of the Secretary of State not cause him significant harm and be of significant benefit to others." [LawComBill: 10-(4)]³
- to establish mechanisms to authorise non-therapeutic research on those lacking the mental capacity necessary for consent. [LawComBill: 11]

Precisely what is wrong with these proposals will be explained in Section 2 below.

³ This proposal seems particularly sinister in its implications if one considers that LawCom231 takes up [at 6.17] Lord Mustill's suggestion in *Bland* that the permanently unconscious may be reckoned no longer to have "interests". If they are to be so regarded then it may be deemed impossible to "cause [them] significant harm", and so it may be judged acceptable to remove vital organs from them for the benefit of others, thereby killing the permanently unconscious.

There are a number of other reasons for thinking that the Law Commission's legislative proposals lack adequate regard for mentally incapacitated persons:

- the Law Commission propose an inadequate conception of the "best interests" of patients; [LawComBill 3.-(2)]
- the concept of "basic care" which is proposed [LawComBill: 9.-(8)] does not adequately cover all that may be owing in the way of care for a patient;
- it is contrary to the respect owing to the mentally incompetent to oblige doctors to cooperate in the implementation of advance refusals of treatment which were made when the patients were competent and which are suicidal in character. But the wording of LawComBill 9.-(3) makes it clear that doctors would be so obliged. Such a course of conduct on the part of a doctor is not merely morally wrong but is also inconsistent with long-standing principles of the common law which should be upheld.
- it is directly contrary to the respect owing to the mentally incompetent to require doctors to implement withdrawals of treatment and care ordered by managers and others when the reason for withdrawal is the judgement that the patient no longer has a worthwhile life; and it is likewise unjust for doctors to comply with such orders. For what is then undertaken is simply non-voluntary euthanasia by planned omission. It seems to us quite plain that the effect of legislating along the lines proposed by the Law Commission will be to give statutory force to non-voluntary

euthanasia⁴ by planned omission. Were that to be thought acceptable it is difficult to see on what basis it could be consistently held that it is unacceptable to aim to bring about a patient's death by direct action (such as a lethal injection), especially since the latter course of conduct is generally likely to bring about the patient's death in a more merciful fashion.

Each of these points will also be explained in Sections 2 and 3 below.

Who Decides? is "not seeking views on [the] subject" of euthanasia [1.8], so it may be said that these last two criticisms of the Law Commission's proposals are out of place. Unfortunately they are not, and the attempt to exclude them from this consultation is unwarranted.

The Consultation Paper seeks to sideline discussion of euthanasia as irrelevant to its proposals by the device of stipulatively defining euthanasia as "a deliberate intervention undertaken with the express intention of ending a life, albeit at the person's own request or for a merciful motive". [Footnote 6 at 4.5; emphasis added; see also 1.8] The authors of *Who Decides?* appear to rely on the 'authority' of the House of Lords' Select Committee on Medical Ethics for this definition. But that Select Committee's Report is open to the fundamental objection that it evaded one of the most challenging issues facing it precisely by giving a stipulative definition of euthanasia which is neither ethically nor legally defensible. That challenging issue was the "morally and intellectually misshapen" (Lord Mustill) state of the common law resulting from the judgements in the *Bland* case to the

⁴ i.e. the intentional termination of the lives of those who, because of incompetence, are incapable of asking to be killed.

effect that it is lawful deliberately to bring about someone's death by omission while being unlawful to do so by a positive act.⁵

The Consultation Paper also seeks to deflect the criticism that its proposals in respect of advance refusals of treatment would accommodate suicidal refusals which doctors would be obliged to implement. The attempt to deflect this criticism takes the form of invoking the authority of Lord Goff's contention in *Bland* that "in cases of this kind [viz. advance refusals of treatment], there is no question of the patient having committed suicide, nor therefore of the doctor having aided and abetted him in doing so". Precisely what Lord Goff had in mind in saying this is by no means clear. But it ought to be clear that judicial fiat cannot make it to be the case that patients cannot express suicidal intentions in advance declarations and that compliance with the patient's will cannot constitute, on the part of a doctor, aiding and abetting suicide. As we have noted elsewhere: "Suppose everyone knows that the patient's directive that on a certain date insulin (or food and water) be withdrawn was motivated simply by his intention of dying before the expiry of a term life insurance policy. On what legal principle is this not suicide?"⁶

⁵ See Luke Gormally, "Walton, Davies, Boyd and the legalization of euthanasia", in John Keown (ed) *Euthanasia Examined. Ethical, clinical and legal perspectives*, Cambridge: Cambridge University Press 1995, pp.113-40, esp. p.124.

⁶ *Submission to the Select Committee of the House of Lords on Medical Ethics by The Linacre Centre for Health Care Ethics*, June 1993. [Henceforth: *Linacre Submission to the Select Committee*] In House of Lords, Session 1993-94. Select Committee on Medical Ethics. Volume III - Written Evidence (HL Paper 21-III), London: HMSO, pp.155-82, at p.174. Reprinted in Luke Gormally (ed) *Euthanasia, Clinical Practice and the Law*, London: The

Invocation of Lord Goff's *dictum* cannot serve to show that aiding and abetting suicide cannot be at issue in compliance with certain advance refusals of treatment. What it does serve to illustrate is a characteristic feature of *Who Decides?* derivative from the Law Commission Report: that of seeking to give statutory force to a number of judicial decisions of the past decade which are inconsistent with long established principles of the common law. This feature of *Who Decides?* will be highlighted in Section 3 below. In our view what is needed is statutory *reversal* of some of these decisions both for the sake of justice in the treatment of the vulnerable and for the sake of coherent and consistent development of the law.

It cannot be right to seek to exclude substantial moral and legal issues from consideration in the assessment of legislative proposals when the substance of those issues is demonstrably at stake in the legislative proposals. Administrative declaration that such-and-such matters are "outside the scope of these proposals" is incompatible with democratic deliberation about legislation.

2. Some moral considerations which should govern legislation

The previous section has highlighted a number of issues raised by *Who Decides?* and by the Law Commission's Report and Bill (LawCom231). All these issues concern, in one form or another, both (i) the value to be recognised in the lives of those lacking mental capacity to make decisions for themselves and (ii) what is therefore owing to them, especially by carers. This section of

our response is therefore concerned to explain the fundamental considerations which ought to govern the understanding of these matters and some practical implications of those considerations. The explanation offered is in terms which are intellectually accessible to anyone and which ought, in our view, to commend themselves to anyone who recognises the need for an ethic of sufficient content to secure at least the basic requirements of justice in society.

1. It is necessary to begin with the recognition that every human being, however immature or impaired, possesses a fundamental worth and dignity which are not lost as long as he or she is alive. Contrary to the view of some, human worth and dignity do not depend on acquiring and retaining some particular level of understanding or capacity for choice or for communication. On that view of human worth and dignity, it turns out that the relevant level of developed understanding or of capacity for choice always requires to be determined in an arbitrary fashion. In making the possession of human worth and dignity depend on an arbitrary discrimination between individuals, this view destroys the indispensable foundation of justice in society. For basic human rights belong to us precisely because of our worth and dignity, and if our possession of the latter is to be determined arbitrarily so will be our possession of the former. But there cannot be a framework conducive to just relationships in a society if *who are to count as the subjects of justice* is determined in an arbitrary fashion. That is why recognition of the fundamental worth and dignity of

Linacre Centre 1994, pp.111-165, at p.158.

Subsequent references to the Submission are to its reprint in this volume followed by, in brackets, the reference in HL Paper 21-III.

every human being is the indispensable foundation of justice in society.⁷

It follows from recognition of the fundamental worth and dignity of every human being that it can never be consistent with justice intentionally to kill a human being because his or her life is judged to be without value - because it is judged to be "not worthwhile". So it is certainly absolutely impermissible intentionally to kill the innocent.⁸ That moral prohibition is the core of the principle of the sanctity of life,⁹ and respect for the principle is an indispensable condition of respect for human beings.

2. We should distinguish between the inalienable worth and dignity proper to every human being and the kind of dignity exhibited most conspicuously by mature human beings in full possession of their powers of understanding and choice. The loss or diminution of these powers or of other abilities may result in what is experienced as a 'loss of dignity'. But it would be a serious error to speak of the lives of those who have suffered such loss as wholly lacking dignity and the fundamental worth which that dignity imports.

⁷ For a fuller explanation see *Linacre Submission to the Select Committee*, esp.pp.118-126. [HL Paper 21-III, p.156]

⁸ If a person is killed because he is found guilty of some grave crime the reason for killing him is not inconsistent with recognition of his worth and dignity.

⁹ The principle of the sanctity (or inviolability) of life therefore imposes an absolute *negative* duty, not a positive duty to prolong life whatever the circumstances. Failure to recognise its true character, on the part of some judges in recent cases (e.g. Lord Goff in *Bland*), partly explains the false *dicta* about autonomy overriding the principle of the sanctity of life. See *Linacre Submission to the Select Committee*, at p.119, esp. footnote 2. [HL Paper 21-III, p.156, and footnote 7 on pp.177-8.]

This kind of error is exhibited in two kinds of judgement which one frequently encounters in discussions of the mentally incapacitated.

3. It is exhibited, first, in the view that those who have suffered severe brain damage, resulting in permanent loss of consciousness or of cognitive abilities, no longer possess worthwhile lives. But this view of certain gravely impaired human beings is incompatible with recognition of their basic worth and dignity. It is the view which underlies the claim that it is reasonable to aim, at least by omitting treatment and care, to end the lives of these persons when they are patients. This judgement may also be arrived at on the basis of the assertion that such persons, being unaware, no longer have any 'interests',¹⁰ so that, there being no positive good of theirs at which one could aim, one may rather aim at ending their lives. But none of us has to be conscious of all prospective benefits to be the recipient of those benefits. And if we can be the recipients of benefits unawares we can have an interest in being benefited without that interest being a conscious interest. All of us, indeed, have an interest in not being treated in ways which are inconsistent with recognition of our dignity as human beings, whether or not we are aware of that interest.

4. A second way in which the error of denying worth to certain human lives is exhibited is in the judgement that the value of a life depends wholly on the value a person *gives* to his or her life through their choices. If that were so, then loss of the capacity to choose would bring about a state of affairs in which the only value one's continued existence would have would depend on

¹⁰ A view entertained by *Who Decides?* at 5.24, following LawCom231: 6.17, following Lord Mustill in *Bland*.

the value one had chosen to attach to it when competent. This is the understanding of the value of a life behind the view that, in respect of a person's own life, his or her choices made prior to loss of competence should be allowed to determine when his or her life is to be ended -- at least when that may be purposefully achieved by omission of treatment or care.

5. Exercises of autonomy (i.e. of the capacity for self-determining choice) are not the fundamental source of worth and value in a person's life. Human beings possess an ineradicable value prior and subsequent to the possibility of exercising autonomy. Autonomy itself as a capacity 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. But it is plain that many exercises of the 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.

6. Since justice in society rests on belief in the ineradicable value of *every* human life, whatever its condition, a just legal system cannot look favourably on choices to kill a person based on the judgement that his or her life is no longer worthwhile. Whether explicitly or implicitly, this is the judgement which standardly

underpins the choice of suicide in the context of medical care,¹¹ the choice to assist a patient's suicide, and the choice of euthanasia. In the case of suicide, a person is persuaded that his life is now (or will be) no longer worthwhile. In cases of assisting in suicide and euthanasia, the person assisting or carrying out the killing is persuaded that the life of the person to be killed is no longer worthwhile; if he were to think otherwise he would have a conclusive reason for *not* killing.

7. Both suicide (including assisting in suicide) and euthanasia may be carried out by omission as well as by action if what one aims to bring about by omitting, say, nourishment or some treatment, is precisely the death of a person. The Consultation Paper *Who Decides?* is mistaken in defining euthanasia as a "deliberate intervention undertaken with the express intention of ending a life, albeit at the person's own request or for a merciful motive". [Footnote 6 at 4.5; emphasis added; see also 1.8.] It likewise fails to confront an issue central to its area of concern in overlooking the reality of suicidally

¹¹ The character of a suicidal type of refusal of treatment is well described by Mrs Justice Hale in her 1995 Hamlyn Lectures: "A person who is able to make his own decisions may be horrified at the prospect of losing that capacity and so refuse quite ordinary treatments on the ground that he would be better off dead." (The Hon Mrs Justice Hale, *From the Test Tube to the Coffin. Choice and Regulation in Private Life*. London: Sweet & Maxwell, 1996, p.116. Emphasis added.) Believing that life in such-and-such a condition would no longer be worthwhile, a person deems he would in the circumstances envisaged be better off dead, and for that reason (i.e. to hasten death) refuses treatment. Mrs Justice Hale (as Professor Brenda Hoggett) chaired the Committee of the Law Commission responsible for its work on mental incapacity. As the suicidal nature of certain refusals of treatment was resolutely refused recognition by the Law Commission it is unsurprising that it does not receive recognition in the 1995 Hamlyn Lectures.

motivated advance refusals of treatment.

In the absence of an adequate understanding of the moral and legal reality of euthanasia and suicide, the repeated assertions of *Who Decides?* [as at 1.8, 1.15, 2.6, 4.5] that the Government does not propose to change the law relating to euthanasia offer inadequate reassurance. In so far as current judicial practice is now governed by the judgements in *Bland*, and specifically the ruling by a majority of the House of Lords that, provided it is not 'positive action', it may be lawful (and indeed legally required) to adopt a 'course of conduct' deliberately and precisely with the aim of terminating life, that judicial practice needs to be restored to a sounder legal basis. For the common law is now in the "morally and intellectually misshapen" [Lord Mustill] condition of prohibiting active euthanasia yet permitting *euthanasia by planned omission*. This incoherent state of affairs needs to be rectified by legislation reversing the ruling in *Bland*.¹²

8. It is often falsely asserted by advocates of euthanasia that our legislators have declared suicide to be lawful behaviour, as if our society could endorse the assumption that a person might reasonably think *any* human life, even his own, no longer worthwhile. As we point out in Section

¹² We would again urge, as we urged in 1993, the enactment of a Bill along the following lines:

"No person may, in or in connection with providing to another person medical, nursing or other treatment, service or care, do or omit anything with the intention of terminating that other person's life. A person who by any such act or omission with such intention causes the other's death shall be guilty of murder."

See *Linacre Submission to the Select Committee*, p.157. [HL Paper 21-III, p.174.]

3 (at 6), this is a wholly unwarranted misreading of the *Suicide Act* 1961. That the law continues to take an adverse view of suicide is evident if one considers the seriousness of the penalty which attaches to assistance in suicide. Because of the fundamental truth about the ineradicable value of human life which is implicitly denied in the committing of most suicides, we believe it is important that the law should continue to discourage assistance in suicide, even when the assistance takes the form of omitting care and treatment, in accordance with the terms of an advance refusal of treatment.

9. It is one thing for the law to prohibit any assistance in suicide, including assistance in suicidal refusal of treatment or care. It would be a quite distinct requirement were it to oblige doctors always to *override* suicidal refusal. Doctors would satisfy the prohibition of assisting suicide by, for example, discharging from their care competent patients who persistently refused and suicidally refused the care needed in order to live. Compliance with this prohibition does not entail that doctors are required to do all they can to override suicidal refusal. There may, for example, be considerable physical difficulties which make force-feeding impracticable.

It is important to distinguish between the prohibition and the positive requirement mentioned here. Failure to attend to the distinction has led to the false inference that because there is in truth no obligatory requirement to *override* all suicidal refusals, the prohibition of assisting suicide is not valid or binding, or is subject to exceptions.

10. If part of the rationale for criminalizing non-consensual touching

is that consent to having things done to one is a general condition for the exercise of autonomy, then the strict requirement of consent can rightly cede to other considerations with the loss of the capacity for self-determination, especially when what is proposed to be done is for one's bodily good. The view of the common law has hitherto been that the 'necessity' of preserving the life or health of an incompetent patient was sufficient justification for medical interventions without consent.¹³ This view reflected a proper regard for the value of human life and for an objective and substantive conception of the 'best interests' of patients. We believe that it should continue to be a carer's duty to act on an objective understanding of the best interests of the mentally impaired patient even if it means acting contrary to an advance refusal of treatment which is clearly contrary to the patient's best interests. As we have said [5 above], autonomy is not the fundamental source of worth in a person's life and invocation of autonomy should not be allowed to trump more basic considerations.

11. A patient's refusal of life-prolonging treatment need not be motivated by the desire to end his life. It can be reasonable to refuse such treatment on the grounds that it offers too little benefit for the burdens it involves, or because, whatever the benefits, the attendant burdens either of physical pain, or psychological stress, or social dislocation, or economic hardship make the treatment intolerable. Given the great variation in

¹³ See the statement by Lord Brandon in *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1: "The operation or other treatment will be in their best interests if, but only if, it is carried out in order either to save their lives, or to ensure improvement or prevent deterioration in their physical or mental health."

dispositions and circumstances between individuals, it is clear that what is intolerable or excessively burdensome to one patient may not be to another. In assessing the likely burdens of a course of treatment for a mentally incapacitated patient account will often have to be taken either of the testimony of relatives and friends about the patient's dispositions and circumstances or of written testimony provided by the patient when competent. Advance declarations which are not binding can play a useful role in informing doctors of a patient's dispositions and circumstances.

12. The foregoing considerations are relevant to a correct understanding of what is at issue when it is said that the duty of the doctor (or other responsible carer) is to act in the "best interests" of the patient. The understanding of 'best interests' advanced by *Who Decides?* [3.22-3.25], following the Law Commission [LawCom231: 3.24-3.28], lacks those objective ingredients which are necessary in order to avoid abuse of the mentally incapacitated.¹⁴ As noted in 11 above, it is indeed

¹⁴ The four factors listed in 3.23 as "guidance for determining what is in a person's 'best interests'" all relate to the person's subjectivity as someone with *wishes*, *ability to participate in decision-making*, and *freedom of action*. They are:

" the ascertainable past and present wishes and feelings of the person concerned and the factors the person would consider if able to do so;

" the need to permit and encourage the person to participate or improve his or her ability to participate as fully as possible in anything done for and any decision affecting him or her;

" the views of other people whom it is appropriate and practical to consult about the person's wishes and feelings and what would be in his or her best interests; and

" whether the purpose for which any action or decision is required can be as effectively achieved in a manner less restrictive of the person's freedom of action."

[For further critique see Section 3 at 4. below]

appropriate, in seeking to establish whether treatment is likely to be unduly burdensome to a patient, to consult relatives and others well-placed to know. But the views of others on a patient's "wishes and feelings and what would be in his or her best interests" (3.23) should be allowed to influence decision making for the patient only if they are consistent with an objective, substantive conception of the 'best interests' of patients.

13. Truly objective criteria of what is in a patient's best interests exclude the thought that it can ever be in a person's best interests to have his life ended through conduct ('action' or 'omission') *intended* to end his life. For the intention which such conduct carries out treats the life thus deliberately suppressed as no longer a good to be respected; in that way it treats the patient's very being as no longer worthwhile. It thus denies the inherent worth and dignity of seriously incapacitated human beings. If an advance refusal of treatment is clearly motivated by the view of the person who made it that in such-and-such conditions his life would be no longer worthwhile and for that reason he would want doctors to end treatment and care precisely to end his life, then it should not be permissible for doctors to comply with that refusal.

In the area of healthcare, the concept of 'best interests' should be understood to include the standard objectives of healthcare practice: the restoration and maintenance of health, or of whatever degree of well-functioning can be achieved, the prolongation of life, and the control of symptoms when cure cannot be achieved. It is in serving these ends that doctors serve the good - - and, therefore, the best interests -- of their patients.

If the understanding of 'best interests' fails to include objective, substantive requirements there will be no non-arbitrary way of judging whether the testimony of relatives and others about a patient's "preferences" is self-serving, no non-arbitrary way of settling differences of opinion, and no objective criteria for determining whether a regulatory system is operating to really protect patients.

14. The attitude of *Who Decides?* to non-therapeutic experimentation on mentally incapacitated persons and organ transplantation from them treats those persons as means to be used, on characteristically utilitarian grounds, for the ends of others. No doubt useful knowledge can be gained from experimenting on people without their consent, and functional capacity can be restored to others by transplanting organs from those who cannot consent to parting with their organs. But the moral justification for such procedures is *voluntary* solidarity with others, i.e. a willingness to meet the needs of others in ways which involve some cost to oneself and no comparable benefit. If one subjects people to non-therapeutic experimentation or to removal of organs or tissue without their consent one is failing to respect them as persons and treating them as merely useful.

Those charged with making decisions for the mentally impaired should not think they have any moral warrant, independent of an advance statement offering specific warrant, to authorise non-therapeutic experimentation or removal of non-vital organs or tissue from patients.¹⁵ Vital organs should never be removed prior to ascertaining

¹⁵ For one limited type of circumstance which provides an exception to this requirement for organ donation see Section 4 at 2.2 below.

that the person from whom they are to be removed is certainly dead.

3. Legislating in accordance with fundamental principles of the common law

1.¹⁶ In order fully to understand the main principled objections to *Who Decides?*, it is helpful to have some appreciation of the extent to which the law has historically enshrined the ethical fundamentals advanced in Section 2 and how in recent years decisions of the courts have tended seriously to weaken the law's adherence to those principles. For it is against the background of, if not under the influence of, these recent decisions that the Law Commission Report and the Consultation Paper have been drafted.

This Section will, firstly, sketch the law's adoption of the principle of the inviolability of human life and its recognition of the important yet subordinate value of individual autonomy before, secondly, tracing the inversion of these values in recent judicial decisions.

2. The principle of the sanctity or inviolability of life holds that, because the lives of all human beings share the same fundamental worth simply in virtue of their humanity, regardless of their physical or mental abilities or disabilities, it is always wrong *intentionally* to kill another person for reasons other than the requirements of

justice. This principle, a hallmark of civilised societies, is enshrined in Article 2 of the *European Convention for the Protection of Human Rights and Fundamental Freedoms* which provides that:

" Everyone's right to life shall be protected by law. *No one shall be deprived of his life intentionally* save in the execution of the sentence of a court following his conviction of a crime for which this penalty is provided by law." [Article 2 (1)] (Emphasis added.)

It has also long been enshrined in our criminal law. In particular, intentionally to kill an innocent person constitutes the offence of murder. And it is well established that murder can be committed by an act or by an omission in situations where there is a duty to act. It is also clear law that it is murder regardless of the request or consent of the victim. Further, suicide was, until relatively recently, a criminal offence and assisting suicide remains an offence.

In short, the criminal law has traditionally held that the value of human life transcends the value of individual autonomy. Life is valuable in itself, whether or not the individual possesses certain physical or mental abilities, and whether or not the individual, or others, considers his or her life to have worth. The law has steadfastly refused to discriminate between those thought to have "worthwhile" and those thought to have "worthless" lives.

3. Autonomy is, therefore, trumped by the inviolability of life. But it is also commonly trumped by other principles and policies. Indeed, individual autonomy is extensively restricted by the criminal law, often in the interests

¹⁶ For a fuller discussion see John Keown, "Restoring Moral and Intellectual Shape to the Law after *Bland*" (1997) 113 *Law Quarterly Review* 481; John Finnis, "Living Will Legislation" in Luke Gormally (ed) *Euthanasia, Clinical Practice and the Law* (London: The Linacre Centre, 1994) 167; Stuart Horne, "Advance Directives: A Legal and Ethical Analysis" in John Keown (ed) *Euthanasia Examined* (Cambridge: Cambridge University Press, 1995) 297.

of others, but sometimes solely in the interests of the individual. Not only, therefore, does the law prohibit murder and rape; it also prohibits the possession of certain drugs, even for one's own use, and the infliction of actual bodily harm, even with the victim's consent. And it sometimes requires positive conduct largely if not exclusively in the individual's own interests, such as the wearing of seatbelts when driving or being driven in a vehicle. In short, the law has historically accorded individual autonomy an important, but subordinate and qualified status, a status consistent with the understanding of its ethical value sketched in Section 2 rather than with the inflated significance uncritically accorded to it in the Law Commission's Report and in *Who Decides?*

4. Unfortunately, in recent years the courts, as a result of misunderstanding some of the ethical fundamentals underpinning the law, have arrived at decisions which effectively undermine the inviolability of human life and exaggerate the significance of autonomy (sometimes doing the former *by* doing the latter).

In a series of decisions culminating in the landmark case of *Airedale NHS Trust v. Bland*,¹⁷ the courts have fatally compromised the law's adherence to the principle of the sanctity of life. They have done so by holding that, while it remains murder for a doctor intentionally to kill a patient by an act, in certain circumstances a doctor may (if not must) intentionally terminate a patient's life by deliberate omission. As Lord Mustill noted in *Bland*, this has left the law in a "morally and

intellectually misshapen" state.¹⁸ Yet the Law Commission's Report and the Government's Consultation Paper, far from proposing that the law be returned to its former, coherent shape, have advanced proposals which would serve only to perpetuate its inconsistency.

By failing to prohibit the withholding or withdrawal of medical treatment with intent to kill, the proposals in the Consultation Paper would appear to accommodate the intentional killing of patients by the deliberate withholding or withdrawal of treatment on the basis of a judgement that their lives lack worth and they would be better off dead. There is nothing in the Consultation Paper to prohibit such judgements. In particular, the proposed concept of "best interests", although foundational to the entire edifice of the proposals, lacks substantive content and ignores the fundamental proposition that it can never be in a patient's best interests to be intentionally killed. It appears that the patient's "best interests" are, essentially, whatever he or she *thinks* (or, even more questionably, *would* think if able to do so) is in his or her best interests, and / or whatever "other people" *think* he or she thinks and what they *think* is in his or her best interests. Leaving aside questions about how a doctor is to ascertain what an incompetent patient would have thought (particularly if they have *never* been competent), or how a doctor is to resolve disagreements between what the patient thought (or would have thought) and what other people think, a fundamental objection to the Consultation Paper's concept of "best interests" is that, in a rather Alice-in-Wonderland way, it collapses into whatever people happen to think it is.

¹⁷ [1993] AC 789.

¹⁸ At 887.

Such a concept is both erroneous and dangerous. Erroneous because it is quite possible for competent individuals, when making decisions for themselves, to be *mistaken* about what is in their own best interests, and no less possible for someone acting on behalf of incompetent individuals to be *mistaken* about what is in their best interests. In short, some things (like being fed and kept comfortable) are in an incompetent patient's best interests and some (like being exhibited as a public spectacle or being killed) are not, regardless of what the patient, or others, happen to think.

Not only is the Consultation Paper's proposed definition (or explanation) of "best interests" erroneous; it is also dangerous. For if the best interests of incompetent patients are to be determined largely if not exclusively simply by the "views of other people", then what is to prevent others judging that the patient would be better off dead and that his or her life should be intentionally terminated, albeit by the withholding or withdrawal of treatment?

Similarly, if the determination of the incompetent patient's "best interests" is to be arrived at on the basis of the patient's past wishes, and it is thought that the patient's past wish was for his or her life to be terminated by the withholding or withdrawal of medical treatment in the situation which has materialised, doctors will be placed in the position of being legally required to implement such a wish, even if it was an unambiguously *suicidal* wish.

5. As we have argued in Section 2, *Who Decides?* not only undervalues human life but also exaggerates the importance of individual autonomy. This exaggeration is evident not only in the unqualified importance accorded

to the patient's present or past "wishes and feelings" in the quasi-definition of "best interests" (3.23) but also in its proposals in respect of advance refusals of treatment. The Consultation Paper, like the Law Commission Report before it, seems to adopt the view that patients have a virtually unqualified right to refuse medical treatment, even in advance of incompetence.

Here too, it is instructive to view the proposals in the light of judicial decisions which have accorded an exaggerated scope and significance to the patient's right to refuse treatment. It is uncontroversial that competent patients have a right to refuse treatments which offer no reasonable prospect of benefit or which they would find excessively burdensome. But the courts have gone much further than this, holding that competent patients have an "absolute right" to refuse treatment "*notwithstanding that the reasons for making the choice are rational, irrational, unknown, or even non-existent ...*",¹⁹ and that (provided certain conditions are satisfied) this right *can be exercised in advance of incompetence*.²⁰ The courts appear, with respect, to have largely overlooked the problems of principle and practice that these propositions raise.

One fundamental objection of principle is that recognition of such a sweeping right to refuse treatment undermines the law against assisted suicide. For if the right to refuse treatment extends to cases where the patient's intention (that is, purpose) is to hasten his or her death, then it accommodates suicide.

¹⁹ See *Re T* [1992] 3WLR 782 at 786, *per* Lord Donaldson M.R. (Emphasis added.)

²⁰ *Ibid* at 787; see also *Re C* [1994] 1 All ER 849; *Airedale NHS Trust v. Bland* [1993] AC 789 at 864 (*per* Lord Goff).

And if doctors act lawfully when they intentionally assist a refusal of treatment (by, for example, withdrawing a life-saving treatment), knowing that that refusal is suicidal in intention and effect, then the law against assisted suicide has been seriously compromised.²¹

²¹ We do not say that the sweeping legal right to refuse treatment *entails* abandoning the distinction between such refusal and assisting in suicide-by-omission. The judgement of the Supreme Court of the United States in *Vacco v. Quill* (1997) 65 United States Law Week 4695 gives powerful reasons (see 4697) for thinking that, where law-makers, courts and other relevant bodies have a clear grasp of the way in which differences in *intention* really and authentically differentiate kinds of conduct, it is possible to give legal force to such refusal (as recent New York legislation does) while maintaining the law's prohibition on assisting in suicide including suicide-by-omission. In such a situation, the breadth of the legal right of refusal will have the result (foreseen but in no way intended by the clear-headed legislator) that -- just as allowing doctors to use pain-killers facilitates some covert voluntary euthanasia (murder) under the guise of palliative care -- sometimes a patient will exploit his right of refusal to commit covert suicide-by-omission. Where such a patient is still competent, the Supreme Court suggests (4697) that "a physician who withdraws, or honors a patient's refusal to begin, life-sustaining medical treatment purposefully intends, or may so intend, only to respect his patient's wishes ... " (and not to kill or assist in suicide). This analysis clearly covers the usual case, where the doctor has no real knowledge of his patient's motives for refusing treatment; in other cases, where he is morally sure that refusal of treatment or care is motivated by a suicidal purpose (intention of terminating life), the doctor has to respect not only the statutory prohibition of imposing medical treatment on unwilling patients but also the law's prohibition of assisting in suicide (including suicide-by-omission). Legislative guarantees of patient autonomy have their proper limit at the point where the patient demands assistance in his autonomous purpose of self-destruction (including suicide-by-omission), and the Supreme Court's judgement makes it clear that the law is coherent in drawing such a line.

As we have said above (Section 2 at 9), the obligation *not to assist* in suicide (including

In short, the court decisions asserting an unqualified right to refuse treatment have served to outflank the prohibition on assisted suicide just as the decisions on the withdrawal of treatment have outflanked the prohibition on homicide. The criminal law's consistent prohibition on intentional killing and intentional assistance in suicide has been replaced by a "morally and intellectually" misshapen prohibition on *active*, but not *passive*, killing and assistance in suicide. And it is this same, misshapen distinction

suicide-by-omission) does not entail an obligatory requirement to override refusals of treatment or even of care and sustenance. To be sure, the path between the Scylla of *assisting* suicide-by-omission and the Charybdis of force-feeding a competent patient is narrow, and opinions will differ about how precisely to proceed along it.

But what is quite clear is that where the patient's suicidal purpose was articulated prior to his *incapacity*, and he is now *incompetent* to make any authentic ratification or withdrawal of it, the question of respect for his autonomy ceases to be central and the decisive criteria must be his true best interests including the inviolable worth of his life. Ronald Dworkin in *Life's Dominion* [1993] has exposed fairly clearly (pp.226-9) some of the implications (which Dworkin himself there rightly describes as "very troublesome" and "shocking") of thinking that autonomy always trumps other interests and goods, and that the past wishes (or advance directives) of a now-incompetent person must be respected on grounds of "precedent autonomy" (unconditional respect for "past wishes and feelings"). Mrs Justice Hale seems much less troubled. Speaking of the person who has made an advance refusal of "quite ordinary treatments" on the grounds that "he would ... be better off dead" than being incompetent, she foresees that such a person "once he has become demented, ... may be quite content; those around him who remember how he used to be will suffer much more than he does. But he will be no longer able to revoke the refusal." On which she comments: "This, of course, is what advance refusals are all about; the right to decide while you are able to do so the extent to which you want to be obliged to stay alive. This will depend on what you think makes life worth living ... " (*From the Test Tube to the Coffin*, p.116)

which disfigures the Law Commission's Report and *Who Decides?*

6. The explanation for the courts' weakening of the prohibition on assistance in suicide is not entirely clear. It may well at least partly lie in a misunderstanding of the principle of the inviolability of life. But there is also evidence in the relevant authorities of the mistaken beliefs, firstly, that suicide was decriminalised out of respect for self-determination and, secondly, that suicide cannot be committed by omission.

For example, in the Court of Appeal in *Bland*, Hoffmann L.J., referring to the case of a person who refuses life-saving treatment, observes that the decriminalisation of suicide "was a recognition that the principle of self-determination should in that case prevail over the sanctity of life".²² However, as the Parliamentary debates leading up to the enactment of the *Suicide Act* 1961 confirm, the reason for decriminalisation was *not* respect for self-determination but rather a belief that the suicidal needed help rather than punishment. In other words, suicide was decriminalised not to help people to commit suicide, but to help them not to. The Government strenuously denied any intention to condone suicide, let alone establish a right to it. Moving the *Suicide Bill's* Third Reading, the Joint Under-Secretary of State for the Home Department issued the following warning:

" Because we have taken the view, as Parliament and the Government have taken, that the treatment of people who attempt to commit suicide should no longer be through the criminal courts,

²² [1993] AC 789 at 827.

it in no way lessens, nor should it lessen, the respect for the sanctity of human life which we all share. It must not be thought that because we are changing the method of treatment for those unfortunate people we seek to depreciate the gravity of the action of anyone who tries to commit suicide."²³

Addressing fears that decriminalisation might give potential suicides the impression that what they proposed to do was no longer regarded as wrong, he stated: "I should like to state as solemnly as I can that that is certainly not the view of the Government, that we wish to give no encouragement whatever to suicide ... ",²⁴ adding: "... I hope that nothing that I have said will give the impression that the act of self-murder, of self-destruction, is regarded at all lightly by the Home Office or the Government".²⁵ That acceptance of a right to commit suicide was not the reason for decriminalisation is confirmed by the fact that assistance in suicide was not decriminalised and remains a serious offence.

7. Equally erroneous, with respect, is any suggestion that suicide cannot be committed by omission. In *Bland*, Lord Goff stated that when a patient dies as a result of refusing life-saving medical treatment "there is no question of the patient having committed suicide, nor therefore of the doctor having aided and abetted him in doing so".²⁶ If His Lordship was referring to the refusal of treatment on the ground that it would be futile or excessively burdensome, the proposition is uncontroversial. If,

²³ (1960-61) 645 Parl. Deb. H.C. cols. 822-823. Recently, in *Kirkham v. Chief Constable of the Greater Manchester Police*, Lloyd L.J. observed: "The court does not condone suicide." [1990] 3 All ER 246 at 252.

²⁴ (1960-61) 644 Parl. Deb. H.C. 1425-26.

²⁵ At col. 1426.

²⁶ [1993] AC 789 at 864.

however, the proposition extends to the refusal of life-saving treatment in order to hasten death or, in other words, to commit suicide, it is unsupported by, and is indeed contrary to, authority and principle. As *Stroud's Judicial Dictionary* states, to commit suicide "is for a person voluntarily to do an act (or, as it is submitted, to refrain from taking bodily sustenance), for the purpose of destroying his own life".²⁷ This is, moreover, consonant with the general principles of criminal law relating to homicide. Suicide at common law was regarded as self-murder²⁸ and, just as there is no doubt that murder can be committed by deliberate omission, so too can self-murder, that is, suicide. It would indeed be artificial if it were suicide for a person to throw himself in front of a bus, intending to be killed, but not suicide to remain in front of an oncoming bus, when one could easily move out of the way, with precisely the same intent.

In *Secretary of State for the Home Department v Robb*, Thorpe J. cited *Bland* as authority for the proposition that a patient who refuses life-prolonging treatment, which results in death, does not commit suicide and that the doctor who complies with the patient's wishes does not aid or abet suicide.²⁹ Granting a declaration that the Home Office and medical and nursing staff might lawfully abide by a prisoner's refusal to take food and water, His Lordship observed "The principle of the sanctity of human life in this jurisdiction is seen to yield to

the principle of self-determination" adding that, although the state interest in preventing suicide is recognisable, it had no application to a case such as the present where the refusal of food and treatment "in the exercise of the right of self-determination does not constitute an act of suicide".³⁰

If Thorpe J. was of the view that suicide may only be committed by an act and not by a refusal of food and treatment, then he advances no argument or authority in support, beyond *dicta* in *Bland*. But this is bootstrap authority: those *dicta* are themselves either ambiguous or bereft of authority and the point was simply not at issue in *Bland*. Moreover, His Lordship's apparently unqualified proposition that the right to self-determination takes precedence over the sanctity of life is clearly irreconcilable with the prohibition on assisted suicide and murder on request. The true position is that a refusal of treatment or food may indeed be suicidal (depending on the patient's intention), and that not only may a doctor be justified in overriding such a refusal but the doctor may incur liability for not doing so. As Professor Finnis has observed: "The law firmly and rightly holds that those who have undertaken to provide treatment or nourishment are not absolved from their duty by the patient's adamant refusal if that refusal is either incompetent or unlawful. A refusal which is motivated by suicidal intent is unlawful, even though suicide itself is not a criminal offence; that is why assistance, and agreements to assist, in suicide are serious criminal offences."³¹

²⁷ 'Suicide' in *Stroud's Judicial Dictionary* 5th edition (1986) by John S James (London: Sweet & Maxwell, 1986) vol.5. p.2674. See also the discussion by M Otlowski, *Voluntary Euthanasia and the Common Law*, Oxford: Clarendon Press 1997, pp.65-73.

²⁸ See Smith & Hogan, *Criminal Law*, 8th edition (London: Butterworths, 1996), p.391.

²⁹ [1995] 1 All ER 677.

³⁰ At 682.

³¹ John Finnis, "Living Will Legislation", in Luke Gormally (ed) *Euthanasia, Clinical Practice and the Law* (London: The Linacre

8. Two of the major, principled objections to the Law Commission's Report and the Government's Consultation Paper can, therefore, equally be levelled at recent decisions of the courts. But a third objection relates to proposals which clearly go beyond existing judicial decisions, namely, proposals to carry out procedures on incompetent adults, such as "elective ventilation", which are not in their "best interests", even in the elastic sense proposed in the Consultation Paper. The House of Lords in *Re F*³² made it clear that it is lawful to perform medical procedures on an incompetent patient if they are in the patient's best interests, as improving the patient's health or preventing a deterioration in the patient's health. But to perform a procedure on an incompetent adult not in his best interests but in the interests of someone else, constitutes a battery. The proposals in *Who Decides?* which would allow incompetent adults to be used for the benefit of others are clearly contrary to the principle of bodily integrity protected by the crime and tort of battery, and expose some of the most vulnerable persons in society to being used as a means to the ends of others. These disturbing proposals are hardly consistent with the traditional principles of the common law and the Consultation Paper's stated aim of ensuring protection for the vulnerable.

4. Observations on Specific Proposals

1. Advance refusals of treatment

1.1 Advance refusals which are suicidally motivated

As we have noted, an advance refusal of treatment may be suicidally

motivated. According to the Law Commission's Mental Incapacity Bill section 9.-(3) the presumption in favour of life may be overridden by a patient's advance refusal of treatment. This would enforce, in effect, the compliance of doctors and other carers with, among other refusals of treatment, those which are evidently suicidally motivated. We think there are compelling reasons why doctors and other carers should not comply with refusals of treatment which are known to be suicidally motivated:

- because to do so would be contrary to recognition of the patient's dignity, and so contrary to the patient's best interests;
- because to do so is corrosive of the ethic of medicine and of the dispositions we require in doctors, which are to be defined in part by reference to an objective, substantive conception of the best interests of patients;
- because withdrawal of forms of treatment and care precisely with a view to ending a patient's life is morally indistinguishable from euthanasia. Since, however, withdrawal of life-sustaining care usually subjects the patient to a protracted process of dying which is painful to onlookers if not to the patient, legalization of such conduct can only be a half-way house to the more straightforward and probably more merciful practice of active euthanasia.

Hence, we consider that where it is known that an advance refusal of treatment has been suicidally motivated, doctors and other carers should be obliged to ignore that refusal and to act with a view to serving the best interests (including sustaining the

Centre, 1994), p.168, and see the authorities there cited.

³² [1990] 2AC 1.

life) of the mentally incapable patient, just as if no such refusal had been made. We urge (as we did in 1993)³³ that there should be legislation to provide that:

"where a patient is incompetent to give or withhold consent to medical treatment or care, the existence of a declaration made by that patient at some earlier time purporting to give directions for the withdrawal of treatment or care (or of any specified form of treatment or care) shall not be taken to require those responsible for his treatment or care to follow any course of conduct (including omission) otherwise than in accordance with their judgement as to the best interests of the patient, and shall not be taken to require or authorise any person to give any assistance in suicide (including suicide by omission)."

1.2 Advance refusals and pregnancy

Advance refusals of procedures such as Caesarean section may endanger not only the life of the pregnant woman but also the life of her child. Where that turns out to be the case we believe that the refusal of such procedures should not be respected at the expense of the woman's own life or that of her child. No difference should be made to this rule by the fact that the woman anticipated death as a possible consequence of her refusal. [See *Who Decides?* 4.28-4.29]

1.3 Advance refusals and the definition of basic care

The Law Commission recommended [LawCom231: 5.34] that an advance refusal of treatment should not preclude provision of 'basic care' defined as "care to maintain bodily cleanliness and to alleviate severe pain,

as well as the provision of direct oral nutrition and hydration". We believe this definition is too narrow; in particular, we would consider that once a tube has been established to deliver nutrition and hydration, the actual delivery of food and fluids by such means should be counted a part of basic care. For what is secured is not some special form of medical treatment³⁴ but simply the delivery of what is necessary in the way of nourishment to sustain life. And the supply of what is required in the way of nourishment simply to sustain a person's life belongs to the basic care of that person.

The definition of 'basic care' proposed by the Law Commission embodies an odd inversion of values, according as it does a greater importance to comfort and hygiene than to sustaining life.

It should not be ordinarily possible for advance refusals of treatment to exclude provision of basic care defined, as we propose, to include provision of food and fluids by tube. [See 4.35-4.37]

1.4 The general proposal to make advance refusals of treatment binding in statute law.

Much of the preoccupation with making advance refusals of treatment binding by statute seems to be motivated by the false valuation of human autonomy to which we have already referred (see Section 2 at 4 and 5, and Section 3 at 3). Apart from the reasons of principle we have already adduced for thinking certain types of advance refusal of treatment to be ethically and legally unacceptable, we believe there are many prudential and policy reasons for not making advance

³³ *Linacre Submission to the Select Committee*, p.158. [HL Paper 21-III, p.174.]

³⁴ Hunger and thirst are not diseases, and tube-feeding is not directed at treatment.

refusals of medical treatment binding by statute law in the way proposed by *Who Decides?* following LawCom231:

- the proposal that an advance refusal of treatment may be made orally (4.12) seems to leave no basis for identifying false claims by interested parties that a patient made an advance refusal of treatment.

- advance directives deal with hypothetical future scenarios not present specific ones. In consequence many will raise questions about their applicability which can only be resolved by applications to the courts (4.38). The courts in consequence may well have to handle an inordinate amount of litigation, thereby consuming scarce health service resources.

- the proposed legislation contains no provision that makers of advance declarations should take relevant medical advice. If ill-informed, in what sense is an advance refusal of treatment a genuine exercise of autonomy?

- advance directives may have the effect of excluding new methods of treatment which one did not envisage at the time of making the declaration.

- 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 general, in depriving people of appropriate medical care advance refusals are likely to leave many patients alive but in a worse condition than they might otherwise be (e.g. bedridden instead of mobile).

- 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 the proposed legislation will create new areas of liability and hence of litigation.

2. Use of patients in medical research without consent and in non-therapeutic procedures.

2.1 Participation of mentally impaired adults in non-therapeutic research/experiments.³⁵

There are influential tendencies in medical and scientific circles to exploit those without relevant decision-making powers in the interests of research. We believe that research which involves *any* level of risk to which consent cannot be given should not be justified on utilitarian grounds. If the law is designed to legalise non-therapeutic research on the non-consenting on utilitarian grounds we fear that there will be increasing social acceptance of potentially ever more harmful forms of research on the mentally incapacitated.

2.2 The use of mentally impaired adults as sources of organs/tissue for transplantation.

We believe the justification for organ donation is essentially connected with the capacity willingly to *give* ; to speak

³⁵ See *Who Decides?* 5.35-5.39 and Q.48.

of 'donation' is a misnomer in the absence of consensual giving. And in the absence of consensual giving removal of organs will normally amount to exploitation of persons for ends to which they have no discernible attachment.

Normally, therefore, transplantation *inter vivos* should not involve use of those unable to give informed consent to the removal of their tissue. The carefully circumscribed exception to this should be for cases in which the 'donor', although unable to give informed consent, has some discernible attachment to the good of the potential 'recipient' as someone perceived to be integral to the good of his or her own existence. This sort of exception should not in practice be thought to exist outside the context of close family relationships. It should be a further condition of 'donation' in these circumstances that it involves no risk of significant harm to the 'donor'.

It should never be permissible even within the limits of this exception to arrange for the removal of sperm or ova for reproductive purposes or of ovarian tissue for transplantation. To do so would be contrary to the integrity of the marital relationship and to the good of children which the law should protect.

Where what is envisaged is cadaveric transplantation, it ought to be the case that organs may be removed only if (i) the person whose organs they were has made an advance statement when competent of willingness to donate organs, and (ii) the patient has been certified as certainly dead.³⁶

³⁶ We do not address in this document the controversial issue of whether the UK protocol for diagnosis of so-called 'brain-stem death' shows the patient to be actually dead as distinct from irreversibly dying.

For reasons noted in Section 3 (at 8) we believe "elective ventilation" should remain illegal. The Law Commission's readiness to recommend otherwise (LawCom231: 6.26) well illustrates the inadequacy of their concept of 'best interests' as a basis for the protection of patients.

3. The authorization of medical procedures to be carried out on the incompetent.

3.1 Abortion³⁷

The circumstances are extremely rare in which a pregnancy threatens the life of a mother. It is only in such circumstances that one might expect the law to take the view that the killing of the unborn child is a 'proportionate' means of avoiding harm -- in this case lethal harm -- to the mother.

The view that abortion is justified by the mere incompetence of the mother is cruel and callous, showing not merely an indifference to the moral claims of the unborn child but also to what may well be the deeply traumatising effects on the mother of an abortion.

Since abortion is an even graver procedure than sterilization intended to render a person permanently infertile, we believe it too should require court authorization. The second opinion procedure does not provide adequate safeguards.

3.2 Sterilization³⁸

Procedures which result in permanent sterility and which are undertaken "to relieve an existing detrimental effect of menstruation" should require a second doctor's certificate. This is because there is a tendency too readily to have

³⁷ See *Who Decides?* 5.19-5.20

³⁸ See *Who Decides?* 5.8-5.10

recourse to hysterectomy when a more conservative approach might solve the problem. The doctor responsible for giving a second opinion should be expected to consider whether a more conservative approach would be adequate.

In the care of women who are reasonably believed to have no prospect of consenting to intercourse with any adequate sense of its significance,³⁹ sterilization as such (i.e. sterilization to prevent conception) should not be considered other than a measure of last resort. It should be a measure of last resort not least because the effects of carrying it out are both to make girls and women more readily exploitable and for less care to be devoted to their proper protection. All proposed sterilizations for contraceptive purposes should require court authorization.

3.3 Donation of tissue or bone marrow⁴⁰

For reasons outlined under 2.2 of this Section we believe the grounds for authorizing transplantation of tissue or bone marrow from a mentally incapacitated adult are extremely limited. It should be for the court to determine whether it is authorized, having regard to the grounds on which we think transplantation might be acceptable.

³⁹ In such cases intercourse with the woman is properly speaking a kind of rape and the prevention of conception can be taken as a measure of protection against the rape's final effect on the woman's body. If conception does occur in consequence of rape, the distinct moral claims of a newly conceived human being then confront one. Since it is incompatible with recognition of human dignity to kill a human being for reasons other than the requirements of justice, and since the newly conceived human being is in no way answerable for what has occurred, the killing of that human being cannot be just.

⁴⁰ See *Who Decides?* 5.11-5.13

3.4 Discontinuing artificial nutrition and hydration⁴¹

Artificial nutrition and hydration should not be regarded as discontinuable for a defined *category*⁴² of patient [5.24, 5.25 and Q.42] but should be withdrawn only if in a particular case it is found to be ineffective in delivering nourishment, or if the mode of delivery proves to be truly burdensome, or if the patient in question is in the final phase of dying and withdrawal will not itself significantly affect the time of death or make dying a more distressing process. Whether these grounds for withdrawing nutrition and hydration hold good in a particular case may reasonably be decided by the clinicians responsible for the care of the patient in question. [QQ. 44a-45]

It should be reserved to the courts to determine whether withdrawal of nutrition and hydration from a particular patient on other grounds should be authorized. In making its judgement the court should proceed on the general assumption that once artificial feeding is established it should be maintained as an expression of care for and solidarity with a fellow human being in an extremely deprived condition. It is never acceptable to withdraw tube-feeding on the grounds that feeding is futile because the patient's life is itself not worthwhile, or he cannot be benefited or harmed, or he has no interests, since he is permanently unconscious. No human being's life may be characterised in those terms (see Part 2 at 1).

⁴¹ See *Who Decides?* 5.24-5.30

⁴² As it happens, the category of patients from whom *Who Decides?* suggests nutrition and hydration may be withdrawn is defined in very ambiguous terms.

4. Continuing Powers of Attorney⁴³

Legislation to create a power of attorney extending to health care and personal welfare matters is to be welcomed only if the power is exercised by reference to the best interests of an incompetent person and 'best interests' is understood by reference to a substantive conception of the good of the person along the lines indicated at 11 of Section 2 above.

No holder of a power of attorney should have the power to consent to the withdrawal of nutrition and hydration; see 3.4 of this Section.

5. Court-appointed Managers

We believe that court-appointed managers should not have power to refuse consent to particular forms of healthcare which are reasonably held by doctors to be in the best interests of patients. (7.25-7.26, and Q.78)

For reasons already explained, managers should certainly not be able to consent to non-therapeutic research procedures. (7.29-7.30, and Q.79)

Managers of residential care establishments should never be appointed managers with the power to make decisions regarding the healthcare of residents of their own or of associated establishments. Such a relationship is too likely to be affected by conflicts of interest which may be seriously harmful to the mentally incapacitated patient.

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⁴³ With particular reference to *Who Decides?*
6.9 and 6.17