

Withdrawing and Withholding Treatment

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A Response to *Withdrawing and Withholding Treatment* (A Consultation Paper from the BMA's Medical Ethics Committee)

The Linacre Centre

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1. Introduction: The Scope of this Response

The Linacre Centre¹ welcomes the opportunity to respond to the Consultation Paper on "Withdrawing and Withholding Treatment" issued by the Medical Ethics Committee of the BMA. We shall not be concerned with all the issues raised in that paper. We shall not be concerned with empirical questions about, for example, the actual practice of particular clinicians. Nor will our principal concern be with such procedural issues as how wide-ranging consultations about clinical decisions should be. Our principal concern will be with a substantive ethical framework for decisions about withdrawing and withholding treatment.

Since it is the Medical *Ethics* Committee of the BMA which has issued the document to which this Response is made, it seems reasonable to assume that an emphasis on a substantive ethical framework will be deemed appropriate. It is not, however, always clear in the consultation document that this is what is sought. For it is certain that one cannot arrive at an appropriate framework for decisions about withdrawing and withholding treatment by empirical enquiries into the current practice of clinicians or what specific codes of

¹ The Centre is a national Catholic bioethics centre of which the Trustees are the five Roman Catholic Archbishops of England and Wales (Senior Trustee: Cardinal Hume). It should be noted that none of the views advanced in this Response are advanced on the basis of specifically religious beliefs.

practice may enjoin. Nor does the English common law any longer provide an appropriate framework for such decisions. The *Bland* case is widely thought to be a key case in the relevant area of the law. The Consultation Paper indeed appears to rely on a distinction on which the judgement in the *Bland* case hangs: between an *act* intended to end a person's life and an *omission* (or course of omissions) decided upon with the very same purpose in mind. The former the *Bland* judgement treats as unlawful, while treating the latter as capable of being a lawful part of a doctor's discharge of his duties of care for a patient. But in so deciding the Law Lords rightly opined that the distinction they drew is morally indefensible and leaves the law "misshapen" or "almost irrational".² Since the law is in this condition it can provide no sound basis for settling on a framework for decisions about the *omission* of treatment ("withdrawing and withholding").

It is appreciated that this state of affairs does present peculiar difficulties for a body such as the BMA that exists to look after the interests of doctors who must keep an eye on the law. This is not a cynical observation, for it is recognised that the task of looking after the interests of doctors properly understood is inseparable from a concern for the interests of patients. But precisely because it is in the interests of doctors to have a clear-

² Lord Mustill, at [1993] 2 WLR pp.388-9: "the distortions of a legal structure which is already both morally and intellectually misshapen"; "the morally and intellectually dubious distinction between acts and omissions" (p.399); Lord Browne-Wilkinson at p.387: "the conclusion I have reached will appear to some to be almost irrational ... I find it difficult to find a moral answer ... "; Lord Lowry at p.379: "... a distinction without a difference ..."

headed understanding of what they are properly committed to if they are truly to serve the good of patients they should disentangle their understanding of their professional duties from the current confusions of the law.

These observations bring us to one respect in which this Response cannot allow its concerns to be limited in the way the Consultation Paper wishes. At 2.7 (p.11) it is said that "Euthanasia and physician assisted suicide are excluded from this paper on treatment withdrawal". But some of the lines of reasoning advanced in the paper for treatment withdrawal are euthanasiast in character: they envisage the purpose of withdrawal not to be the ending of futile or burdensome treatment but *the ending of the patient's life* on the grounds that that life is no longer worthwhile (or that it falls below a certain 'quality of life' threshold). There is no morally significant distinction between an act intended to end a life and an omission intended to end a life. It is not intellectually honest to seek to evade the implications of this truth by stipulating that euthanasia is *to be defined* as "a prompt and intentional action by a doctor to end a patient's life".³ A stipulative definition could not possibly settle what is at issue here. Euthanasia by omission is not a subject one can sideline in any discussion which aspires to be adequate to the ethics of withdrawing and withholding treatment.

Unfortunately, the BMA's position on precisely this issue has been evasive and consequently instable for at least a decade. An earlier analysis of the 1988 BMA Working Party Report *Euthanasia*⁴ showed that it took "no

³ Consultation Paper, p.11.

⁴ *Euthanasia. Report of the Working Party to review the British Medical Association's*

principled stand against killing by planned omission, and [allowed] that comprehensive and adverse quality of life judgements may provide grounds for making a patient's death the proper object of clinical management.... All this means that, despite their protestations to the contrary, the Working Party have conceded grounds on the basis of which doctors might well feel they are justified in carrying out euthanasia on an extensive scale."⁵

It is the contention of this Response that an ethical framework for decisions to withdraw and withhold treatment must recognise, if it is to be adequate, the fundamental requirement of justice in the doctor-patient relationship: the requirement that the doctor should never aim - by act or omission - to end a patient's life. The making of exceptions to this requirement standardly relies on the judgement that certain patients no longer have worthwhile lives, that their lives have fallen below some 'quality of life' threshold. Such judgements are essentially arbitrary and incompatible with recognising the dignity of every human being. But recognition of the dignity of every human being is indispensable to justice in society.

There is no rational basis for thinking that doctors should be exempt from the basic requirements of justice, though rationalizations for such exemptions abound. To concede the exemptions is not in the interests either of doctors or of patients; tragic historical experience has demonstrated the profoundly corrupting effects of rationalizing the killing of those whose lives were

deemed to be not worth living. When Sir Sandy Macara, the recently retired Chairman of Council of the BMA, reviewed some eleven years ago Robert Jay Lifton's *The Nazi Doctors* he asked: Could it happen here?⁶ In response the *BMA News Review* received a large postbag in which a majority of correspondents declared that it certainly could, some finding plenty of evidence that the slide in that direction was well underway.

Since then it has appeared that the incoherence of the BMA's position on euthanasia has contributed materially if not intentionally to that slide. A coherent understanding of the requirements of justice is essential if decisions to withdraw and withhold treatment are to be made in ways which truly respect the dignity of patients and maintain the integrity of medical practice. What follows is intended to make intelligible an ethical framework which is both coherent and humane.

2. Justice

Justice is not simply a matter of fairness in the distribution of resources. Classically it has been understood to cover all that is owing to others both by way of action and restraint; in other words, it concerns what we have obligations to do for others and what we have obligations not to do to others.

2.1 Doctors and justice

Clearly doctors need the virtue of justice - a readiness to do what they owe to their patients and to refrain from doing what they should not do to them. They need other virtues - or

guidance on euthanasia. London: British Medical Association, May 1988.

⁵ Luke Gormally, "The BMA Report on Euthanasia and the case against legalization", in Luke Gormally (ed) *Euthanasia, Clinical Practice and the Law*, London: The Linacre Centre 1994, pp.177-92, at p.189.

⁶ See Alexander Macara, "What makes doctors kill?", *BMA News Review* July 1987, pp.18-19, reviewing Robert Jay Lifton, *The Nazi Doctors: a study of the psychology of evil*, London: Macmillan 1986.

dispositions of character - as well, in the interests of the doctor-patient relationship, but justice is fundamental.

2.2 Who are the subjects of justice?

This question asks: *To whom* is it that we have the positive and negative obligations of justice? The traditional answer to this question is: To every living human being simply in virtue of the fact that he or she is human. But it is clear from the contemporary literature of bioethics that a different answer is gaining influence, an influence clearly detectable in the BMA Ethics Committee's Consultation Paper. So we should look briefly at this answer.

2.2.1 Only 'persons' are the subjects of justice

The answer involves stipulating that the word 'person' should be used in a special sense⁷: meaning those who have acquired some level of developed and exercisable psychological abilities, more particularly of understanding, choice and communication. The motivation for the stipulation varies, some holding that one cannot be said to have a right (even a basic right, such as a right to life), unless one has a conscious desire for what it is a right to; others holding that a life has value only in so far as the person whose life it is *invests* it with value. The former position seems rather obviously mistaken;⁸ the latter is a version of a position which needs to be briefly discussed here.

⁷ The position has been labelled "personism" by the philosopher Jenny Teichmann, who points out that nothing of substance can be settled by mere stipulation.

⁸ Who would deny that I have a right, after his death, to the £200,000 my Uncle Charlie has left me in his will even though I do not know of the existence of the will, let alone desire the £200,000?

It needs to be discussed here because another version of that position clearly underpins much that is said in the BMA Consultation Paper. What is said, for example, at pp.19-20 about pvs patients assumes that a life has value only in so far as the human being whose life it is possesses certain psychological abilities. Admittedly, in its position on pvs the BMA appears to require a much lower level of psychological ability - "sentience" - than those who require cognitive abilities for a life to have value. But this position is unstable. In the 1988 Report *Euthanasia* the BMA's Working Party spoke of the "the unique ethical importance" of human beings. That can certainly not be based on sentience, which is shared with the generality of animals. That "sentience" represents an unstable position is already evident from the principal practical preoccupation of the present Consultation Paper, which is no longer with pvs but with whether the recommended code of practice for the management of pvs patients might be extended to other categories of patient, such as those with advanced senile dementia.

Is there any acceptable version of the view that only those with some degree of developed psychological ability are subjects of justice? No. Why?

Consider what is the most basic requirement we have to meet in determining who are entitled to be treated justly? It is obviously the requirement that whatever determination we make should not be arbitrary. We cannot possibly have just arrangements if the basis on which we have excluded some from entitlement to being treated justly is arbitrary.

Consider now what is involved in determining entitlement on the basis of

developed psychological ability. If we are going to continue to talk about the "unique ethical importance of human beings" then the relevant psychological abilities will have to be to some extent cognitive. And this is indeed the position of those in the bioethics literature who link human value to developed psychological abilities. But it is arbitrary to make entitlement to justice hang on some specified level of psychological ability since standardly a developmental level of psychological ability is something that many who have not achieved it will shortly be attaining. That being so, how could it be reasonable to draw the line where you propose to draw it when the effect of drawing the line is to determine that human beings who would shortly qualify for just treatment do not presently enjoy entitlement to just treatment? Basic human rights cannot be like the rights of membership of a golf club, which may indeed be determined fairly arbitrarily.

2.2.2 All human beings possess dignity: the alternative to arbitrary discrimination

Any exercise in specifying some level of psychological ability as a necessary condition for being treated as a subject of justice is inescapably arbitrary. The only alternative to such arbitrariness is to take the fact that someone is a living human being as a sufficient condition for regarding them as entitled to just treatment. This response is not simply the only available escape route from arbitrariness; it is intrinsically reasonable. It is perfectly true that the distinctive worth of human beings is given clear expression in the exercise of certain psychological abilities. But it is a fact about human beings that before we possess these abilities as exercisable abilities we have it within ourselves to develop those abilities; it is *in our nature* to do so. So a very

distinctive worth attaches to our nature - what we call human dignity. Various forms of damage and impediment may prevent the development of abilities in a given individual, or lead to their loss. But it remains the case that that human being is one of us, "one of our kind": he or she is not of a different nature, and so possesses the dignity which attaches to our nature.

It is useful to distinguish two senses in which the word 'dignity' can be used about human beings: in one sense (Dignity1) it is used of that basic worth which belongs to human beings simply in virtue of the fact that they are human, a worth in virtue of which we say that all human beings are equal, meaning: equally entitled to be treated justly by having their basic human rights respected. In another sense (dignity2) the word refers to a certain quality exhibited by some but not all in the conduct of their lives: a quality one associates with people who have so shaped their lives as to honour what is truly worth choosing and striving to achieve. But it is a fatal mistake in reflecting on human dignity to think that loss of the capacity to give shape to one's life - to continue to be in control - means the loss of human dignity *tout court*. Dignity1 cannot be lost.

In neither use of the word 'dignity' is it just vaguely honorific; it imports worth. And the worth we should recognise as belonging to every human being should prevent us from presuming to think of any human life as "not worthwhile". To judge a life to be not worthwhile is to deny worth to the person whose life it is; for the reality of a person is not something distinct from his or her life. It should be clear, then, that assessments of certain lives as not worthwhile are incompatible with justice.

2.3 Justice and intentional killing

To kill a human being is to bring about his or her death. One may do this either by something one does (e.g. by shooting him) or by something one fails to do (e.g. by failing to give an incompetent diabetic the insulin he needs).

One may bring about someone's death either intentionally (i.e. on purpose), or foreseeably but without intending it, or without either intention or foresight. Sometimes a failure to foresee that what one does or fails to do will cause death (or is likely to cause death) is culpable, because one could and should have foreseen this outcome. What should be said about culpability in relation to intending and foreseeing one's causation of death will be discussed below.

2.3.1 Intentionally ending lives because they are judged to be not worthwhile

From what has already been said it should be clear that to aim to end a human being's life because one judges it no longer worthwhile⁹ is indefensible. It can only be made to *appear* rational by denying the very truth we have to recognise if we are to uphold justice. The foundational truth (for justice) that all human beings possess an ineliminable worth and dignity is not obviously incompatible with every reason for intentionally killing human beings. To kill someone, for example, for the reason that he deserves death (as in the judicial execution of criminals found guilty of

⁹ This is in effect the judgment frequently made about the lives of so-called pvs patients, of patients with advanced senile dementia, of severely handicapped babies, and others, and which is invoked as the reason for withdrawing / withholding various forms of treatment or care from them. The *point* of withdrawal / withholding is then simply to put an end to their lives.

capital crimes), though it may be criticisable on other grounds, is not to be faulted for being incompatible with recognition of human dignity. That kind of justification for intentional killing in fact assumes a rather high conception of human dignity, thinking of human beings as answerable for their choices. But it is not necessary to enter into any discussion of the merits of this type of justification for killing since it is irrelevant to what doctors may do to *patients*. Patients *as patients* do not have the status of guilty criminals and doctors *as doctors* do not have the status of agents of the judicial system. If doctors think there is a justification for killing what they have in mind is some consideration or combination of considerations which leads them to conclude that a patient's life is no longer worthwhile. And that cannot justify killing.

2.3.2 Why it is only intentional killing which is absolutely impermissible

Consider the circumstance in which there is a slim chance that a person's life can be saved by surgery but there is a very high probability that the outcome will be the death of the patient. The patient, let's say, consents to surgery as the only measure that could possibly save his life, and the surgeon undertakes it on the remote chance that it might. Both, however, foresee that the likeliest outcome is the death of the patient. It is clear, nonetheless, that the patient's attitude is not suicidal and the surgeon's attitude is not murderous. On the contrary, the aim of each is the preservation of the patient's life, remote though the chance of succeeding might be.

This kind of scenario makes clear why we cannot always be obliged to refrain from causing death, even foreseeably

causing death. For there are some things we have good reason to aim to achieve even when we know they are very likely to cause death: but causing death is not what we are aiming to achieve. It is when death is no part of what one purposes to achieve that it is spoken of as a "side effect".

But, as we have seen, there is no such thing in the medical context as having a good reason to aim at bringing about someone's death. Not only can one always refrain from acting with such an aim, one should always refrain from acting with such an aim since there is no good reason for having such an aim.

2.3.3 What is the scope of intention?

Intention has been explained here by reference to the reason or purpose one has in acting. Now the reasoning which leads us to choose to act in a particular way (and so the reason we have for acting in the way we do) includes reference not only to the objective we aim to achieve but to the method we adopt to achieve our purpose. And our reasoning about a choice of method refers precisely to what it is about it that appears to make it appropriate for achieving our purpose. In the case of the high-risk surgery referred to in the previous section, patient and surgeon opted for it precisely in so far as it might be efficacious in saving life not in so far as it was all too likely to be efficacious in ending life. Its efficacy in the latter respect was no part of their reason for choosing it; in other words it was no part of what they intended.

2.3.4 Intention and 'double effect'

'Double effect' is jargon to refer to a particular kind of dual outcome of action, in which apart from the intended effect of one's action one brings about a 'side-effect': an outcome one causes which it is no part of one's intention or purpose to cause in acting.

The term 'double effect' is also used to refer to what is sometimes spoken of as a 'principle' (the principle of double effect) and sometimes as a 'doctrine' ('the doctrine of double effect'). 'Doctrine' is perhaps the more appropriate nomenclature since we are here concerned with a package-deal of considerations rather than a single principle. For it is not the traditional view that provided you are not aiming at a bad effect it is acceptable to cause it. Not at all. The traditional view is that only in certain circumstances may you foreseeably bring about a bad effect. What you are aiming for has to be sufficiently important for you to run the risk of unintentionally causing death. And if the death you may cause is someone else's then you should be sure both that your choice to proceed is compatible with respect for that person's dignity and that it is fair to that person. You may test for the latter consideration by asking yourself whether, if you were the likely victim, you would think it reasonable for someone else to proceed as you are proposing to proceed.

Considerations of this order make it clear, for example, that a surgeon who carries out high-risk experimental surgery on a dying child not to benefit the child but to perfect his surgical technique is acting wrongly even though it is not precisely his aim to cause the child's death. For he shows contempt for the dignity of the child, treating him as disposable for his own purposes.

With these explanations in mind it ought to be possible to see the reasonableness of applying 'double effect' considerations to situations in which death foreseeably results from withdrawing or withholding treatment but is no part of one's purpose in doing so. The key question will be: Why has

treatment been withdrawn? We shall consider the relevant reasons in Section 3. But to briefly anticipate: it is generally accepted that one may reasonably seek to discontinue (or refuse to embark on) treatment that is gravely burdensome; if that is one's reason for withdrawing treatment then it is clear that any resultant death of the patient which may occur is not only no part of one's purpose in acting but also involves no lack of respect for the dignity of the patient or a failure in fairness to the patient.

The invocation of the doctrine of double effect is frequently held to involve hypocrisy, especially in its application to the use of analgesics which may have the effect of causing death. But that it is possible for a doctor to dissemble his intentions in administering analgesics no more counts against the importance of the distinction between what is intended and what is merely foreseen, than the possibility that we can use language to lie counts against the importance of the distinction between telling the truth and telling lies. Just as language-use is not inescapably mendacious so use of analgesics is not inescapably murderous.

Talk about the 'hypocrisy' of the doctrine of double effect rests in part upon a failure to see the moral significance of the distinction between intention and foresight, and in part upon

" ... a failure sufficiently to distinguish problems in the analysis of intention from problems about what is to count as admissible evidence for intention. The use of an essentially lethal substance provides the sort of *prima facie* evidence of an intention to kill which is not so clearly available when planned killing is by an opiate which

has palliative uses. But in so far as standards of medical practice are established in the control of pain, a doctor whose intention (i.e. aim) is to kill a patient by the use of pain-control medication is likely to become more readily detectable. Nonetheless there is bound to remain a grey area in practice. But difficulties over establishing a person's intention should not lead to confusion over what intention is. Nor should those difficulties, as they arise in relation to the doctor who dissembles his intention, lead us to conclude ... that 'the law endorses, indeed entrenches, hypocrisy'."¹⁰

2.3.5 Intention and the character of doctors

Intention serves to identify the character of choice: your choices are

¹⁰ The quotation is from a long endnote to 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.113-140, at pp.139-140. The final quotation internal to the quoted passage is from Professor Ian Kennedy's 1994 Upjohn Lecture. Kennedy's highly influential writings are strongly marked by the misunderstandings and confusions identified in this passage. The objection relating to evidence for intention was met head-on by the House of Lords Select Committee on Medical Ethics, who concluded: "... juries are asked every day to assess intention in all sorts of cases, and could do so in respect of double effect if in a particular instance there was any reason to suspect that the doctor's primary intention was to kill the patient rather than to relieve pain and suffering. They would no doubt consider the actions of the doctor, how they compared with usual medical practice directed towards the relief of pain and distress, and all the circumstances of the case. We have confidence in the ability of the medical profession to discern when the administration of drugs has been inappropriate or excessive." House of Lords, Session 1993-94. Report of the Select Committee on Medical Ethics. Volume 1 - Report. (HL Paper 21-I), London: HMSO 1994, p.50 (para.243).

shaped by the goals to which you are committed and by what you are committed to doing by what reason identifies as the efficacious means for achieving your goals. Now it is precisely such commitments which shape character. Once you choose to lie, for example, as a way of getting what you want you make yourself more disposed to lie (unless you repent of what you did). Once you make killing a means to your chosen end (however worthy that end may be) you make yourself more disposed to be a killer (unless you repent of what you did). What we are talking about here in referring to the development of dispositions is not, of course, the acquisition of some mindless behavioural reflex. What is acquired is the mind of a liar or the mind of a killer - the disposition to help oneself to rationalizations for such choices when they seem to serve one's ends.

For a doctor to acquire either kind of mind-set is a disaster for his or her patients. Think what is involved in acquiring the mind-set of someone disposed to kill: it means being disposed to help oneself to the rationalization that at least some human beings have no claims to just treatment from one. A doctor who is so minded is no longer governed by considerations of justice but perhaps merely by considerations of what is socially respectable or acceptable.

2.3.6 Withdrawing or withholding treatment and intentional killing

From all the foregoing two things should be clear: first that one can aim to bring about someone's death precisely by deliberate omission of some form of treatment or care; i.e. one can intentionally kill a patient in this way. Secondly, that to do so is, morally speaking, as gravely wrong as intentionally killing them by giving

them a lethal dose of poison or a fatal wound.

But what about 'legally speaking'? As we saw in the Introduction, the judgements in *Bland* rely on a distinction between acting with a view to bringing about someone's death and deliberately failing to do something with the very same intention. But there is no reason to take this distinction seriously, particularly as the Law Lords themselves could offer no reasoned defence of it.

Two things ought to be clear about intentional killing in English law. First, it emerged in the mid-1980s that judicial understanding of intention sharply distinguishes it from foresight.¹¹

Secondly, that decided cases in English law¹² make it clear that those with duties of care for a person cannot aim to end that person's life by a course of deliberate omissions. *Bland* is not merely a moral anomaly but a legal one too. Ethical guidelines for the medical profession should ignore it.

3. The purpose of medicine

Ethical guidelines about withdrawing and withholding treatment cannot, however, afford to overlook consideration of the purpose or goal of medicine. For a clear view of what would make such decisions reasonable depends on a view of what the proper purpose of medicine is.

¹¹ This is documented with analysis in J M Finnis, "Intention and side-effects", in R G Frey and C W Morris (eds) *Liability and Responsibility. Essays in law and morals*, Cambridge: Cambridge University Press 1991, pp.32-64. For an authoritative exposition see Lord Goff of Chieveley, "The Mental Element in the Crime of Murder" (1988) 104 *Law Quarterly Review* 30.

¹² *R v Bubb* (1850) 4 Cox C.C. and *R v Gibbins and Proctor* (1918) 13 Cr.App. R. 134.

The profession of medicine combines a distinctive ethic with expertise based on a unified (or potentially unified) body of knowledge. Both ethic and expertise are warranted by the human good which medicine exists to serve. What is the human good which medicine serves on the basis of a unified (or potentially unified) field of knowledge of natural causes? The answer is *somatic* health,¹³ in the sense of the well-ordered organic functioning of the body. This well-ordered organic functioning is both an instrumental and an ingredient good of human well-being. In other words it is something we enjoy for its own sake as well as something we need in at least some measure in order to share in some of the other basic ingredient goods that make for living well (such as the acquisition of truth, the appreciation of beauty, growth in friendship, the exercise of skills, the maintenance or establishment of justice in political community, and so on).

It is because health in the sense explained is of such central significance for human well-being that there is an ethic *internal* to the practice of medicine. In other words, the practice of medicine itself, if it is to be well-adapted to the achievement of that goal, imposes certain ethical requirements on doctors and demands certain dispositions of them.¹⁴

¹³ This answer is explained more fully in Luke Gormally, "Medicine as a profession and the meaning of health as its goal", in *Briefing* Vol.27 (special issue, October 1997), pp.14-19.

¹⁴ Of course there are those who reject the view that medicine exists to serve any distinctive good of human beings and so reject the view that there is any ethic internal to the practice of medicine. They think of medicine as simply offering to satisfy those individual desires which can be satisfied through the deployment of technical skills based on

At various points the BMA Consultation Paper refers to medical goals so it would be as well to clarify how the standard goals of medicine relate to what has been identified here as the overall purpose of medicine.

3.1 The purpose of medicine and the goals of medicine

Medicine is often thought of as having disparate goals:

- the restoration and maintenance of health;
- the prolongation of life;
- and, the alleviation of pain.

The first clearly coincides with what has been identified as the controlling purpose of medicine. Of course health is not an 'all or nothing' condition. It varies in relation to age and other factors. And often the best one can achieve is some approximation to health, in the sense of some approximation to that organic well-functioning which is necessary to our sharing in other human goods.

The other two goals are only rightly understood in relation to the controlling purpose of somatic health; they are not, so to speak, free-standing goals.

Prolongation of life is a proper goal of distinctively medical treatment in so far as it goes along with some continuing capacity, however exiguous, for integrated organic functioning. That is why when we are confronted with a patient in the terminal phase of dying, who is, so to speak, in process of irreversible disintegration, efforts to prolong life are inappropriate. Prolongation of life

knowledge of how to control and modify the body.

is not to be understood as an independent goal of medical practice but as dependent on the achievability of some measure, however depleted, of the kind of organic functioning which makes possible our sharing in at least some other human good.

The alleviation of pain through palliative medicine is also best understood precisely as a goal of medicine by reference to the controlling purpose of somatic health, and more particularly somatic health as an instrumental good.¹⁵ As we have already noted, we require well-ordered organic functioning to achieve some of the other ingredient goods of human life. Now if that well-ordered organic functioning is not achievable in ways important to our achievement of other goods then medicine can at least aim to mitigate the effects of *disordered* organic functioning. Much medical treatment has to settle for mitigating disorder - typically manifested in pain - when the restoration of well-ordered functioning is not achievable. Palliative *treatment* of the dying - the control of the symptoms of irreversible organic disorder and disintegration - is an extreme form of a standard element of medical practice in its service of somatic health as an instrumental good:

" ... given that not even an approximation to health can be achieved, one aims to secure as *tolerable* a state of the organism as possible so that conscious living (with family and friends and others) may

continue. Thus palliative medicine, in deploying techniques of pain control, is focussed, just like other forms of medicine, on the organic component of our aptitude to share in other human goods."¹⁶

3.2 What in general terms restrains doctors from aiming to achieve the goals of medicine? Futility, burdensomeness and the veto power of the competent patient

First, and most obviously, the fact that the only available treatments prove incapable of achieving the goal one had set out to achieve for a particular patient. The treatments one has tried (or perhaps merely contemplated) appear to be clearly futile.

Secondly, the treatments one contemplates or tries, though they may promise some medical benefit, in the sense of securing one of the goals of medicine, will impose grave burdens on the patient in doing so. These burdens may be unacceptable either because, independently of other considerations, they are excessively difficult to bear, or because bearing them does not seem warranted by the amount of benefit the treatment promises.

Sometimes, since the extent to which certain side-effects are burdensome will depend very much on the dispositions and circumstances of the patient, one needs evidence (directly from the competent patient, or by way of testimony from those close to an incompetent patient) about those dispositions and circumstances in order to assess the extent to which what will be experienced as burdensome will be warranted by the likely benefits of treatment.

¹⁵ The following understanding of the rationale of palliative medicine is explained more fully in Luke Gormally, "Palliative Treatment and Ordinary Care", unpublished manuscript of paper prepared for a Conference on *The Dignity of the Dying Person* to be held under the auspices of The Pontifical Academy for Life, Rome, 24-27 February 1999.

¹⁶ Luke Gormally (ed) *Euthanasia, Clinical Practice and the Law*, London: The Linacre Centre 1994, p.134.

We should allow a wide interpretation to the notion of 'burdens of treatment': they may be physical (as in pain); psychological (as in mental distress); social (as in disruption of life-style); and economic (as in the financial burdens they impose on others). But this wide interpretation of the *scope* of the notion of burden should be combined with a *strict* interpretation of what is meant by talking of 'the burdens of treatment'. 'Burdens of treatment' means: burdens *caused by treatment*. A patient's *life* is not caused by his treatment, even though it may be true to say that a patient is enabled to stay alive through treatment. So survival with disability should not be counted among the burdens of treatment. If it is, and if it is regarded as a reason for ceasing treatment, then you make the aim of ceasing treatment to be that of putting an end to the existence of the patient.

On the other hand, the fact that a person is disabled in a particular way may make it predictable that a particular course of treatment will be excessively burdensome. Disability can be relevant in that way to a reasonable decision to withhold some course of treatment. This illustrates one way in which a particular type of 'quality of life' judgement is relevant to decisions to withhold and withdraw treatment. The type of judgement in question is one which focuses on the condition of the patient as that is relevant to assessing the prospective benefits and burdens of treatment. One's interest is in determining those benefits and burdens. There is a quite distinct kind of Quality of Life judgement for which the focus is not on the worthwhileness of treatment, as one may assess that in terms of its benefits and burdens, but rather on the worthwhileness of the patient's life. As we have already seen, to shift focus in

that way is already to have embarked on a potentially euthanasiast line of reasoning. To engage in judgements of that kind is incompatible with recognising the dignity of the patient and his or her entitlement to just treatment.¹⁷ It is precisely such judgements, unfortunately, that the BMA's Consultation Paper envisages (at 2.9.7 and 2.11, no.7) as the appropriate basis for withdrawing and withholding treatment in certain types of case.

Thirdly, one may be prevented from aiming at what one regards as an appropriate medical goal in the care of a patient by the competent patient's refusal of the relevant treatment. The veto power of competent patients may be exercised on the basis of good or bad reasons. Here we can take note of one kind of good reason which does not involve either futility or burdensomeness. In the following section we will clarify why bad reasons for refusing treatment are reasonably allowed effect in the life of a competent patient, but should not be allowed continuing effect when that once competent patient has become incompetent.

A competent patient may have good reason to refuse potentially beneficial treatment not because of any burdens consequent upon treatment but because other obligations stand in the way of the patient undergoing treatment. Clearly it is down to the competent patient to say whether this is the case, and there could be no moral justification for a doctor seeking to

¹⁷ The distinction between the two kinds of 'quality of life' judgement and its significance are lucidly analysed by John Keown, "Restoring Moral and Intellectual Shape to the Law after *Bland*", (1997) 113 *Law Quarterly Review*, pp.481-503, especially at pp.486-7.

prevent a patient discharging overriding moral obligations.

Finally, one may be prevented from aiming at an appropriate medical goal by resource constraints: personnel, facilities, equipment or medication are not available.

3.3 The purpose of medicine and the 'best interests' of patients

In the practice of medicine, the concept of 'best interests' should be understood to include the standard goals of medicine as they have been presented in 3.1 above. It is in serving these ends that doctors serve that element of the good of patients which they are qualified to serve.

It is important to distinguish between those 'best interests' of a patient which a doctor is competent to judge and what one might call the 'overall best interest' of a patient. The two may not coincide even when what is under consideration is some treatment a patient needs. For as we saw in the previous section, there can be circumstances in which a patient may rightly judge that what it is good and right for him to do will prevent him undergoing the treatment he needs. But it is certainly in his 'best interests *overall*' to do what it is good and right for him to do.

But, as we also noted in the previous section, the veto power of the competent patient over proposed treatment is not always exercised for good reasons. It remains that it is regarded as near-absolute in the eyes of the law. There are defensible public policy reasons for this,¹⁸ as well as the

¹⁸ Public policy reasons may also justify compulsory treatment of a competent patient when the patient's condition poses a serious danger to public health. So even in respect of his own health a competent patient's veto powers are not absolute. In other areas of life,

reason that people need to be left free to decide what place care for their health has in relation to other obligations. But it does not follow from this fact that *whenever* a patient refuses treatment he is acting in his own best interests. The notion of 'best interests' is not so elastic as to be definable in terms of whatever desires and wishes a patient may have. Clearly some competent patients refuse treatment contrary to their 'best interests' for indefensible reasons. Given that there are good reasons for leaving people free to exercise responsibility for their health, it is unsurprising to find that many abuse this freedom. What is surprising is to find people wishing to dignify a competent persons 'wishes' as, without qualification, a constitutive component of his or her 'best interests'.¹⁹

By contrast with competent patients the incompetent patient is precisely someone who is not capable of adequately taking responsibility for his own health. So others have to take some measure of responsibility for him. In doing so they should be guided by an *objective* understanding of his 'best interests'.

of course, the law places considerable limits on the exercise of autonomy.

¹⁹ The Consultation Paper *Who Decides?* issued by the Lord Chancellor's Department in December 1997 is seriously unsatisfactory in its understanding of 'best interests' in precisely the way identified in the text. See *Who Decides?* 3.22-3.25 following the Law Commission (LawCom231: 3.24-3.28). As we remarked in the Response to *Who Decides?* prepared by the The Linacre Centre on behalf of the Roman Catholic Bishops of Great Britain and Ireland, "... 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" (p.27 of Response).

As we have noted, not any reason a person may have for refusing treatment makes refusal of treatment in that person's 'best interests'. So the fact that a person who is now incompetent made an anticipatory declaration or gave an advance directive that he should not receive treatment in certain circumstances does not as such make it to be in that person's 'best interests' that one withhold treatment. If the reason for anticipatory refusal of treatment was bad then one does not act in an incompetent person's 'best interests' by respecting that refusal. Since that person can no longer exercise responsibility for himself, the responsibility others have to act in his best interests requires that they ignore a bad reason for refusing treatment.

What sorts of bad reason for advance refusals of treatment should be ignored? Most importantly, any reason which, in anticipation of some future state of the patient, identifies that state as so unacceptable that withdrawal / withholding of treatment is demanded precisely in order to put an end to the life of the patient. The anticipatory refusal is, in other words, suicidal in character. This is a bad reason for refusing treatment because it is inconsistent with recognition of the *dignity* of the patient. If we are to say that every person possesses human dignity however 'undignified' their condition and circumstances (and, as we have seen, we must) then we are prevented from regarding any life as lacking worth. The fact that a person when competent had an anticipatory view of his own life as not worth living under certain circumstances provides no one with a reason for ending that person's life. It is neither a view of the value of his life which anyone is justified in sharing with him, nor could such a view of a person's life provide a justification for killing.

From an ethical standpoint, advance declarations (as distinct from advance refusals of treatment) do have a limited role to play in the treatment and care of incompetent patients. They can provide evidence of the sorts of consequences of treatment which a patient anticipates he or she will find unduly burdensome. It remains that such evidence should be used with caution and with a proper concern not to deny a patient the real benefits treatment can secure. For it is well-known that anticipatory views, arrived at when one is healthy, of what one will find unduly burdensome can change dramatically when one is seriously ill.

4. The duty of ordinary care

4.1 Doctors and the duty of ordinary care

Our lives begin in a state of comprehensive dependency on others to meet our most basic needs and often end in a similar condition. In between we are all in varying degrees, and in respect of varying needs, dependent on others.

At the beginning of our lives our basic needs are standardly met by those who have undertaken responsibility for us in bringing us into the world. At the end of our lives responsibility for our basic care may devolve upon family members, such as our children. But when our needs are such that we require medical treatment and doctors undertake that treatment in a context (typically hospital) in which we are effectively removed from the care of others they also thereby undertake duties of ordinary care for us. A commitment to aim to secure the good of health, or some approximation to that good, or at least the palliation of symptoms which impede our sharing in other basic goods, hardly makes sense independently of recognition of our more fundamental claim to be cared

for in the basic ways in which human beings need care: by the provision of food, shelter, warmth and a hygienic environment, and by respect for those other basic rights which belong to us in virtue of our dignity as human beings. In the absence of severe shortages of basic resources, a decision to abandon basic care for someone who is still capable of being sustained by such care is standardly a decision to cause that person's death.

4.2 What ordinary care requires

The basic material care human beings need has here been identified as consisting in the provision of:

- nourishment;
- shelter;
- a warm environment;
- an hygienic environment.

There is an increasing tendency nowadays to question whether the first item - provision of nourishment - includes anything other than what is called "provision of direct oral nutrition and hydration".²⁰ We think the exclusion of tube-feeding from basic care is not warranted. Once a tube has been established to deliver nutrition and hydration, the actual delivery of food and fluids to a patient should be accounted a part of basic care. For what is secured thereby is not some special form of medical treatment but the satisfaction of basic needs for food and fluids. 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.

It is significant that the decisions which are made to withdraw tube-

feeding are not standardly justified by reference to the claim that tube-feeding is burdensome to the patient or is failing to achieve its end - nourishment - and *in that sense* is futile. Rather, the proffered justifications have in mind what is deemed to be the futility of the very *existence* of the patient. They therefore envisage as the purpose of withdrawing tube-feeding the ending of the patient's life. For that reason such decisions are characteristically decisions to carry out euthanasia by planned omission.

To say this is not to imply that, once established, tube-feeding may never be discontinued. There can be circumstances in which the only available methods of delivering nutrition and hydration become extremely burdensome to the patient, and that can be a sound reason for discontinuance. Furthermore, a dying person who has hitherto been tube-fed, may, in the terminal phase of dying,²¹ manifest a strong disinclination to have the process continue. That would also be a circumstance in which discontinuance was reasonable.

5. Answers to some of Section 3's "Specific questions"

(1) [*Are there gaps which need filling in current UK ethical/legal guidance about withdrawing or withholding life-prolonging treatments? Are there other*

²⁰ Thus the Law Commission in its Report on *Mental Incapacity* confines the provision of nourishment as a requirement of basic care to "the provision of direct oral nutrition and hydration" (LawCom No.231, p.79: 5.34)

²¹ By 'terminal phase' the following is understood: "The patient's condition leaves no room for doubt that death is now near and is likely to occur within a matter of days. He is: profoundly weak; essentially bedbound; drowsy for extended periods; disoriented for time and has a severely limited attention span; increasingly disinterested in food and fluids; finding it difficult to swallow medication." R G Twycross and I Lichter, "The terminal phase", in D Doyle, G W C Hanks, N Macdonald (eds), *Oxford Textbook of Palliative Medicine*, Oxford: Oxford University Press, 1993: 651.

legal and ethical problems associated with withdrawing or withholding treatment which are not mentioned in this paper?]²²

Guidance about withdrawing / withholding treatment needs to emphasise that an adverse judgement on the very existence of a patient is *never* a proper ground for such decisions. Comprehensive "Quality of life" judgements are out of place in the practice of medicine (and in human relationships generally). [See Section 3.2 above at p.24]

We urge, as on previous occasions,²³ the need for 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 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)."

²² The questions in the Consultation document are included in italics in square bracket in this version of The Linacre Centre Submission.

²³ *Submission to the Select Committee of the House of Lords on Medical Ethics by The Linacre Centre for Health Care Ethics*, June 1993. In House of Lords, Session 1993-94. Select Committee on Medical Ethics. Volume III - Written Evidence (HL Paper 21-III), London: HMSO, pp.155-182, at p.174. And *Human Dignity, Autonomy and Mentally Incapacitated Persons. A Response to Who Decides?* submitted to the Lord Chancellor's Department by The Linacre Centre for Health Care Ethics at the request of the Roman Catholic Bishops of England & Wales, of Scotland, and of Ireland, March 1998, p.38.

(2) [*Are international consensus documents such as the 1992 Appleton International Consensus used in practice when decisions need to be made? If so, is review of such guidelines necessary?*]

We possess no empirical data on the use of the Appleton Consensus document. Those guidelines in particular certainly need revision, and unsurprisingly so, since the group responsible for their drafting was disproportionately euthanasiast in its composition.

(3) [*If guidance were to be produced, are there good reasons for distinguishing between withdrawing and withholding treatment? If so what are they?*]

There is one kind of situation in which there does seem to be a significant distinction between withholding and withdrawing treatment. That is the type of situation in which what is involved in establishing or setting up a form of treatment or care (say tube-feeding) is burdensome whereas the actual delivery of the treatment or care once established is not. Hence you might have a reason for withholding a form of treatment or care which did not hold good if the question you were asking was: Should this treatment or care be withdrawn.

(4) [*Are there good reasons for distinguishing between the treatment of adults and children when drawing up guidance? If so, what are they?*]

It is assumed that the question is asked in respect of *incompetent* adults by comparison with incompetent children. Rules for treatment which distinguish between categories of patients on the basis of age are generally unfairly discriminatory. Treatment decisions for all classes of incompetent patients should be based on consideration of what is genuinely beneficial for each

individual patient. [See Sections 3.1-3.3 above.]

(5) [*When patients lack the ability to make decisions for themselves, will not recover sentience, and there is no clear indication of their wishes, should withdrawing or withholding treatment be an issue to be decided by health professionals and families alone? If so, should the decision-making process conform to strict criteria? What kind of criteria would be appropriate? Are the ones discussed in this paper sufficient?*]

Properly medical treatment (i.e. treatment which is directed to achieving one or other of the goals of medicine [see Section 3.1 above]) may be discontinued by health professionals and families acting alone provided that the reasons for discontinuance are that the treatment is no longer securing its therapeutic goal. This Response takes the view that there is no sound defence for regarding the activity of tube-feeding as medical treatment. Given that there is a determination to regard it as such, we take the view that the decision to discontinue it, except in the terminal phase of dying or when the only available method of delivering nutrition is excessively burdensome [see 4.2 above], should be reserved to the courts. Moreover, the courts should not accept as a reason for discontinuance the view a doctor (or others) may have formed that a patient's life is no longer worthwhile, or is of unacceptable quality.

(6) [*Is there a foreseeable stage at which withdrawing nutrition and hydration from patients who have irrevocably lost sentience would no longer need to go to court?*]

No. For reasons explained in Section 1 above, decisions about withdrawing and withholding treatment are often straightforwardly decisions to kill by

omission, and are morally and legally indefensible.

(7) [*Is there a role for Ethics Committees to be involved in making decisions about withdrawing or withholding treatment from patients who cannot express their own views?*]

No. They are not sufficiently open to public scrutiny, and not adequately answerable for their decisions.

(8) [*Are there particularly problematic decisions of this type which should be made only by the courts? If so, can clear parameters be defined to differentiate those cases sufficiently problematic to require legal overview from those which could legitimately be decided jointly by families and health professionals? Would ambiguity about the terms of a patient's refusal of treatment or about competence to make valid refusal be the type of case where courts should be involved?*]

The answer to question (5) above makes it clear that, with two exceptions, all other cases of proposed withdrawal of nutrition and hydration should be reserved for decision by the courts.

(9) [*Does withdrawing or withholding artificial nutrition and hydration form a separate category of decision from any other type of treatment which might be withheld or withdrawn? If so, why? Does society need to agree clear and strict criteria for withdrawing or withholding artificial nutrition and hydration? If so, what kind of criteria? Are the criteria and safeguards discussed in this paper (e.g. a period of monitoring before a decision is made; an independent second medical opinion) sufficient?*]

Yes, for the reason that it is not medical treatment but ordinary care.

The criteria the Consultation Paper proposes are procedural criteria and on

their own manifestly inadequate. It is substantive criteria which are required. What those should be has been indicated in the answer to question (5) above [see also 4.2 above].

(10) [*When decisions about withdrawing or withholding have to be made, what are the main factors which health professionals currently take into account when discussing the matter with competent patients? When deciding how to proceed for patients who cannot express an opinion?*]

We have no data relevant to answering this question.

(11) [*How should "best interests" be defined for incapacitated people? What criteria should be taken into account?*]

The 'best interests' that a doctor is competent to identify and serve are: healthy functioning, or whatever approximation to it is achievable; prolongation of life; and palliation of symptoms where cure is not possible (see 3.1 above). These are the proper focus of a doctor's medical care of incapacitated people. He may modify the aims of treatment in the light of reliable evidence that it may have consequences which are unduly burdensome to the patient. Treatment should not, however, be withdrawn or withheld on the grounds that the patient would be 'better off dead' because lacking a worthwhile life. It is never in the interests of patients to treat them as if they lacked human dignity and their lives were in consequence disposable (see 2.2.2, 2.3.1 and 3.2 above)

(12) [*If a patient has left no indication of who should be consulted on his or her behalf, how widely should views be sought from people caring for an incapacitated adult? Should the views*

of blood relatives take precedence over others?]

What is crucial is identification of those who are familiar with the patient, have the objective best interests of the patient at heart, and who can bear disinterested testimony to the patient's sensitivities and sensibility which may be relevant in assessing any foreseeably burdensome consequences of treatment. (See 3.2 above)

(15) [*Should there be more research into how decisions about withdrawing and withholding treatment are made?*]

Yes. We need a much clearer picture of the actual influences on decision-making (particularly the ideological influences).

(16) [*Do you consider that there is broad concern about the use of the "double effect" argument concerning treatment at the end of life? If so, is the concern shared by health professionals and the public? Would health professionals welcome more debate about the implications of "double effect"?*]

In section 2.3 above the minimum necessary intellectual background to an adequate understanding of 'double effect' is provided. Some objections to the 'doctrine of double effect' spring from a rejection of the moral norm which absolutely excludes intentional killing of the innocent. One form the critique of this norm takes begins from the contention that there is no morally significant distinction between intending and foreseeing the consequences of one's choices. If there is not, then of course an absolute norm forbidding all foreseeable causation of death seems obviously untenable. And if it were true that there is no morally significant distinction between intention and foresight then the doctrine of double effect is redundant: it only makes sense on the assumption

that such a distinction exists. This kind of intellectual attack is typically mounted by utilitarians. This is not the place to explain all that is mistaken about utilitarianism as a philosophy of human conduct. But it ought to be clear that utilitarianism can have no place for the sort of ethic of medical practice which has hitherto sustained trust in the doctor-patient relationship. Other objections to the doctrine of double effect proceed from the fact that it is simply not understood. To make it intelligible one needs to offer at least the equivalent of what is offered by way of explanation in the whole of section 2.3 above.

(17) [*Are there additions or amendments that should be made to the list of general points concerning withholding or withdrawing treatment mentioned in section 2.11 of the discussion paper?*]

It should be clear from all the foregoing that extensive additions and amendments would have to be made to 2.11 of the BMA Consultation Document to provide an adequate basis for sound ethical guidance.

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