

## **Minutes of evidence taken before the Select Committee on Medical Ethics.**

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MINUTES OF EVIDENCE  
TAKEN BEFORE THE  
SELECT COMMITTEE ON  
MEDICAL ETHICS

Tuesday 18 May 1993

**VOLUNTARY EUTHANASIA SOCIETY**

*Mr Malcolm Hurwitt, Mr John Oliver and Dr Colin Brewer*

**LIFE**

*Mr Keith Davies, Dr M Heley and Professor J J Scarisbrick*

**HOPE**

*Dr Andrew Fergusson, Dr Robert Twycross and Ms Prue Clench*

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MEDICAL ETHICS

Tuesday 18 January 1983

FOR THE CHAIR: BARON BENTLEY

MEMBERS: BARON BENTLEY, BARON BRIDGE, BARON CARRON, BARON GARDNER, BARON HODGSON, BARON KEENE, BARON LORRINE, BARON MURPHY, BARON PHIPPS, BARON RUSSELL, BARON SLETT, BARON THORP, BARON WATSON

THE

REPORT OF THE SELECT COMMITTEE ON MEDICAL ETHICS

1983

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TUESDAY 18 MAY 1993

Present:

Colwyn, L.	Mischon, L.
Flather, B.	Mustill, L.
Kennet, L.	Rawlinson of Ewell, L.
Jay of Paddington, B.	Walton of Detchant, L. (Chairman)
Llewelyn-Davies of Hastoe, B.	Warnock, B.
McColl of Dulwich, L.	York, Abp.
Meston, L.	

**Memorandum by The Voluntary Euthanasia Society**

Although the literal meaning of euthanasia is simply "a good death" without reference to how it comes about, in terms of the present debate it is generally accepted as indicating a death which is deliberately sought, as being desired by or desirable to the person concerned, but which may only be achievable by the assistance of a third party. The misuse of the term euthanasia, as in Germany in the 1930s, to indicate the destruction of disabled members of society without regard to their own wishes, departs diametrically both from the original meaning of the word and from the sense in which it is used by the *voluntary euthanasia movement*: it is therefore irrelevant here. It should however be mentioned that convinced opponents of any shift in the law sometimes employ emotive arguments drawn from this other, aberrant use of the word, and that such arguments serve only to confuse the issues in what is already a complex debate.

Essentially, the euthanasia issue which is confronting all developed societies today is driven by modern concepts of *personal autonomy*, choice and the rights of the individual. The phrase "the right to die", which is favoured by many of the thirty-odd campaigning societies around the world, is not a particularly useful one, since in law as in nature there is no such absolute right any more than there is an absolute right to live. But it is an irrefutable fact that in the course of this century, and particularly in the latter half of it, expectations about the degree of control an individual may exercise over his or her own life have risen greatly. In a world where birth control is an accepted and indeed indispensable part of life, where individuals aspire to make their own choices about education, career, marriage and lifestyle, and the common parlance is not of fate and God's Will but of opportunities and personal responsibility, a quiescent attitude to life's ending seems less logical than it did to previous generations. In addition, access to efficient medical treatment is now regarded as a norm: this has the dual effect of enhancing people's expectations of control over their own destinies while making it paradoxically more likely that the process of dying may be prolonged beyond their real wishes and needs.

The part played by *developing medical technology* in the growth of the euthanasia debate is almost impossible to over-estimate. Those who hope that if they simply ignore or rebuff the debate it will go away have failed to understand that this is an issue on which the clock cannot be put back even if we would wish to. Having created the situation in which lives are routinely saved, transformed or prolonged by medical intervention, we can hardly pretend that the process of dying, and that alone, must be "left to nature". Simplistic aphorisms, which might have had more general truth fifty years or even twenty years ago, such as "while there's life there's hope" or "killing is killing", are inadequate to address the present state of medical expertise, which is capable of keeping technically "alive" irreparably sick or damaged patients, who in the recent past would not have survived at all. The Tony Bland case represented a classic example of this iatrogenic dilemma. Although this case did not fall directly within the VES area of concern, the Society welcomed the policy-decision to test the law in this matter through all the appropriate courts; the resultant publicity has helped to concentrate both specialised and lay opinion on the exact nature of the issues involved.

Since medical science can no longer subscribe to the simple concept of death as one indivisible event, the VES takes the view that the concept of the "*sanctity of life*" needs careful evaluation also. In inviting submissions, the Select Committee has asked us to comment on "the respective weight to be attached to the sometimes conflicting moral principles of the sanctity of life and the right to personal autonomy". We would suggest that the implication that these two principles stand in natural opposition to each other should in itself be questioned. In practice, neither is an absolute. Hardly anyone has total choice over their own death; it is a matter of degree. Similarly, there appears to be no genuinely comprehensive concept of the sanctity of life. Even those who invoke the phrase as if it pre-empted further discussion, usually in the context of an avowed religious belief, do not in fact present a consistent front. All the major religions find certain categories of killing justifiable (war, capital punishment etc.) with varying degree and emphasis. Even Roman Catholics, who are well known for their stated opposition to both abortion and euthanasia,



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[Continued

do not in practice act as if they believed the products of a miscarriage were the vehicle of the human soul: similarly, the results of repeated NOP polls (See Below) have indicated that Roman Catholicism has, in practice, no bearing on an individual's readiness to concede that euthanasia may in some circumstances be acceptable.

In addition, the phrase "sanctity of life" tends to by-pass the issue of the individual's moral remit to *waive the right to his own life*, with which the voluntary euthanasia movement is essentially concerned. It has always proved hard to construct any absolute philosophical argument against this, except by reference to a personal God against whom one would be offending. A belief of this nature is very much a minority cult today, and it is significant that the law of England and Wales, like that of comparable countries, has been adjusted some time ago to recognise this fact. Attempted suicide ceased to be a criminal offence in England and Wales in 1961, though it was then felt prudent to retain the charge against assisting a suicide.

The phrase "respect for life" may reflect the present day consensus on the matter more accurately than the absolutism of "sanctity of life". It was used by Lord Justice Hoffman, one of the Appeal Court judges in the Bland case. He remarked "In my view, the choice which the law makes must reassure people that the courts do have full respect for life, but that they do not pursue the principle to the point at which it becomes empty of any real content and when it involves the sacrifice of other important values such as human dignity and freedom of choice."

That there is an informal *humane consensus* on this matter is now beyond doubt. Since the early 1960s, *National Opinion Polls* have been conducted at intervals on the following question: "Some people say that the law should allow adults to receive medical help to a peaceful death if they suffer from an incurable physical illness that is intolerable to them, provided they have previously requested such help in writing". "Agree" responses accounted for fifty per cent of the sample on the first occasion. By 1976 this had risen to sixty-nine per cent, and by 1989 to seventy-five per cent. This year (1993) after the Bland case and the trial of Dr Cox, the Winchester specialist, the figure is seventy-nine per cent. At no time, incidentally, has there been any statistically significant difference between the responses of those professing a *religious belief* and those without.

The fact that doctors often act to help suffering patients out of life and always have, has long been an open secret in medical circles, but till recently the profession's policy was not to make open acknowledgement of this. The British Medical Association reviewed the matter in 1988; so unsatisfactory did the Institute of Medical Ethics find the BMA report that it formed a working party to issue its own. (See "Assisted Death" *Lancet*, 1990; 336: 610-13). The majority view of this group was that for a *doctor to assist death*, if the patient has sought such help and all else has failed, was ethical.

An international consensus effort based in the United States (the Appleton conference) reached the same conclusion in 1992. (See *Journal of Medical Ethics*, 1992; 18 (suppl) 3-22). In several American states the legality or illegality of *assisted suicide* has been the subject of lively debate in the last two years. In Europe, at present, it is unequivocally legal only in Germany and German-Switzerland. The liberal approach in the Netherlands is, however, well known: for some dozen years now there has been an informal concordat between doctors, coroners and public prosecutors which has effectively allowed medical help in dying to take place provided certain conditions are fulfilled. The Dutch government has recently encoded some but not all of this agreement in law. (It should perhaps be added here that the persistent suggestion that widespread "involuntary" euthanasia is practised in the Netherlands derives from a misreading of the Rummelink Report, "Euthanasia and Other Medical Decisions Concerning the End of Life" from Erasmus University, Rotterdam 1992. This misreading depends on using the word "involuntary" as a catch-all term regardless of the attendant circumstances: included in it are those many cases in which the central participant was terminally comatose when the decision not to prolong life was taken).

While each country will no doubt have to find its own way through the maze, it must be obvious that this is not an issue on which the United Kingdom or any other developed country can take a parochial stance.

In this country, after the Cox case last year, the editor of the British Medical Journal published an informed and tightly argued article of his own in that paper stating the *case for legal reform* (see British Medical Journal, 26 September, 1992 "Euthanasia—Time for a Royal Commission"). Elsewhere at the same time, he wrote "Most doctors have hastened patients' deaths. The commonest pattern is that doctors give ever increasing doses of opiate drugs ... to patients with terminal illnesses. The drugs are given to relieve pain or suffering, but often the patients die sooner than they would have done had the drug doses been titrated more carefully. Is this euthanasia? If so, it's illegal. "Yet it happens all the time". (EDit, the University of Edinburgh Magazine, Issue 3 Winter 1992/Spring 1993).

*The Nursing Times* said in its editorial Comment (30 September, 1992): "We must ... be able to respond to the wishes of patients: we cannot support their empowerment on the one hand and then on the other say they have no right to be involved in life and death decisions. A code is needed, enshrined in legislation, which gives choice to terminally ill patients".



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[Continued

Such open and unequivocal statements in mainstream professional organs and from established figures indicate the distance the euthanasia movement has come from the days when it was often regarded as marginal and dissident. Even the *hospice movement*, which for some years maintained the view that it was "against" euthanasia, has now conceded that in many respects its aims are identical to those of the euthanasia movement—the achievement of a tolerable death on the patient's own terms. It is also admitted that in a small proportion of cases even the best palliative care is inadequate to control pain or other physical distress. The view of the VES is that, admirable as many hospices are, they should not claim to offer a total solution. To quote an editorial in *The Lancet* of 26 September, 1992 (Vol. 340; 757), "Even if hospice care could be arranged for all who were eligible there would remain a minority of patients who still do not think that it is the answer for them and who wish to retain control not just of the manner of their deaths but also of the timing".

The several texts quoted above all suggest, directly or by implication, that the law be *brought into line with good medical practice*, so that doctors acting in the best interests of their patients and in the best traditions of sympathetic care may do so without fear of prosecution or the need to dissemble. The VES very much supports this view; it is clear that this issue is now too much one of public concern to be left to the traditional discretion of the medical profession behind closed doors. Talk of a "new law", however, may be misleading, as well as alarming to the wary and susceptible of wilful misinterpretation by the hostile. What the British euthanasia movement has sought, since its inception in 1935, is not so much to "legalise voluntary euthanasia" as to *decriminalise* it, and this may be achievable by relatively minor adjustments to existing law or to its interpretation.

We ourselves incline to the view, however, that although case law has always been important in this country, it is not really desirable that a matter which evokes such profound feelings should be decided by a series of court confrontations. Certain formal modifications to existing Acts will be needed. For a start, the concept underlying the *mandatory life sentence for murder* needs to be reviewed. (This was recommended by the Nathan Report in 1989, but rejected by a House which did not seem to grasp the reason for the recommendation). The crudity of the mandatory sentence, and indeed of the charge, no way reflects the enormous moral gulf which in reality separates the aggressive murder from the "mercy killing" carried out in response to a sufferer's own wish. The present rigidity of the law has led to *hypocritical and degrading pleas* which obscure the true facts of cases: for instance, a defendant who has acted rationally and from the highest motives is induced to plead "Guilty to manslaughter by virtue of diminished responsibility" in order to allow the court some flexibility in sentencing. This brings the law into disrepute.

It has also been widely held, following the evident distress of the jury in the Cox case, that for Dr Cox to be tried and sentenced as a criminal at all has made the law look foolish. To quote the editor of the *British Medical Journal* "The law is in effect the codification of the will of the people, and where there is such tension between a legal verdict and the people's thinking it is time to reconsider the law." (Op. cit.) The same point was made in more colloquial terms in numerous newspaper articles and in *The Police Review* (2 October 1992). It is not, therefore, in a spirit of reforming zeal, but rather in a desire simply to bring the law into line with current thinking on right and wrong, that the VES have drafted a Bill at present under discussion.

The concept of euthanasia as a *response to a patient's own wish*, therefore "voluntary", has always been a cornerstone of the Society's view, but we recognise that this poses its own problems. For instance, a case such as that of Bland, in which death may be achieved by the mere withdrawal of futile medical treatment ("passive euthanasia") may seem ethically simple, since it may fairly be said that no reasonable person would wish himself to be kept "alive" on such terms—but since Tony Bland was a previously healthy young man who had never expressed a view on the matter, strictly speaking his death must be classed as "involuntary". In the case involving Dr Cox, on the other hand, his terminally ill patient Mrs Boyes was in great pain which was not responding to drugs and was begging him to cut short her suffering. This was a classic case for voluntary euthanasia, and it is quite possible to take the view (as did *The Lancet*, 26 September 1992) that Dr Cox would have been morally reprehensible had he not responded to his patient's urgent request. However, since he ended her life by means of a drug which could have no other therapeutic effect, this was unequivocally a case of "active euthanasia".

The distinction between passive euthanasia (allowing to die) and active euthanasia (causing death) is one to which some debaters are much attached, but in practice the distinction may be blurred (see the editor of the *British Medical Journal* as quoted above—"the drugs are given to relieve pain or suffering, but often the patients die sooner than they would have done ..."). In any case, the idea that passive euthanasia is readily defensible whereas active euthanasia is not is itself questionable. As Lord Browne-Wilkinson commented in the House of Lords on the Bland case, "How can it be lawful to allow a patient to die slowly, though painlessly, from lack of food but unlawful to produce his immediate death by lethal injection ... ? I find it difficult to find a moral answer to that question." (The same conclusion was reached in a closely argued article by the editors of *The Harvard Law Review* Vol. 105, June 1992). If the whole issue of the patient's "right to choose" is properly confronted, then it seems likely that the distinction between active and passive euthanasia will be seen to be morally specious.



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The concept of patient self-determination, impeccable in theory, produces its own practical problems. The terminally ill but conscious patient who declares himself unwilling to undergo further suffering is, in these terms, the simplest of cases. Harder is the demand posed by the person who has suffered massive physical handicap as the result of an accident or degenerative disease but whose condition cannot be regarded as terminal. In natural justice, should he not have the same choice? The most difficult problem, however, is presented by the common situation in which an irreparably sick or seriously damaged person is *incompetent* either to judge his own state or to express a view on it or both. Doctors and family alike may feel that further treatment is inhumane and indeed that euthanasia would be appropriate: they may believe that this is what the patient would request were he in full possession of his faculties. But in the absence of any indication to this effect, how is the requirement "voluntary" to be fulfilled?

It is with this eventuality in mind that the VES, in common with equivalent American and European "right to die" organisations and also the Terrence Higgins Trust, have applied themselves to the drafting of documents variously described as "advance directives" or (in the USA) "living wills". (See attached copy of the VES version.) Essentially, the aim of the advance directive, which is intended to be lodged with a patient's GP and known to any close relatives, is not to bind a future doctor to one specific course of action—it is hard to see how, either in principle or in practice, this could be achieved. Rather, it seeks to give clear expression to the individual's considered wish, while of sound mind, in the hope, firstly, of influencing future medical decisions, and, secondly, of offering some measure of legal protection to any doctor involved in these. If, as is now being widely conceded, the patient has a right to be consulted about his own death, then the advance directive should be seen as a logical and valid expression of this right. (It has this status now in *Denmark*, where provision has also been made to ensure that the existence of an individual's advance directive is known to any doctor treating him.) There are, as Lord Justice Butler-Sloss pointed out during the Bland Appeal, additional Common Law rights, such as the right not to be subjected involuntarily to invasive physical treatment, and this too the Advance Directive covers.

Till recently, the advance directive has not been regarded as having legal status in this country, but it was informally stated at the Bland Appeal that all counsel had agreed that the right not to accept treatment extended to the right to decline it in advance. The still more recent Law Commission Report on Decision-making and Incompetent Adults has come out in support of this, and the same view is now, in a significant change of policy, supported by the British Medical Association. A Bill entitled "Medical Treatment (Advance Directives)" has recently been presented by Lord Allen of Abbeydale in the House of Lords for a first reading; as drafted, this Bill also directs itself to the recognition of a competent person previously appointed by the patient as *proxy* to state his views for him.

It is accepted by the VES that there will still be certain cases for which it is hard to frame a coherent and non-prejudicial philosophy. It has been the experience of this Society that people often fear senile dementia more than they do life-threatening illnesses, and feel strongly that they would not wish to go on living in such an altered and degraded state. But the conflicting ethical dilemmas posed by the dementing person who is otherwise in fair physical health do not lend themselves to any ready or simple solution. This recognition should not, however, in our view, obscure the evident need to adjust and enlarge the present law as it relates to hopeless and/or terminal physical conditions. Far from undermining the *trust between doctor and patient* as is sometimes suggested, any change making it easier for doctors openly to carry out their patients' wishes can only reinforce confidence on both sides in this demanding relationship.

VES

May 1993

*Enclosures*

- (1) *The Lancet*, November 1990, "Assisted Death".
- (2) *Journal of Medical Ethics*, 1992; (suppl).
- (3) *British Medical Journal*, 26 September 1992. "Euthanasia—Time for a Royal Commission".
- (4) EDIT, the University of Edinburgh Magazine, Winter 1992/Spring 1993.
- (5) *The Nursing Times*, editorial Comment, 30 September 1992.
- (6) *The Lancet*, 26 September 1992.
- (7) *The Police Review*, 2 October 1992.
- (8) *The Harvard Law Review*, Vol. 105, June 1992.
- (9) The Advance Directive.
- (10) National Opinion Poll, 1993.

[NB. Enclosures 1–8 are not reprinted here.]



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[Continued

**ADVANCE DIRECTIVE**

TO MY FAMILY, MY PHYSICIAN AND ALL OTHER PERSONS CONCERNED.

THIS DIRECTIVE is made by me .....

at a time when I am of sound mind and after careful consideration.

I DECLARE that if at any time the following circumstances exist, namely:

- (1) I suffer from one or more of the conditions mentioned in the schedule; and
- (2) I have become unable to participate effectively in decisions about my medical care; and
- (3) two independent physicians (one a consultant) are of the opinion that I am unlikely to recover from illness or impairment involving severe distress or incapacity for rational existence,

THEN AND IN THOSE CIRCUMSTANCES my directions are as follows:

- (1) that I am not to be subjected to any medical intervention or treatment aimed at prolonging or sustaining my life;
- (2) that any distressing symptoms (including any caused by lack of food or fluid) are to be fully controlled by appropriate analgesic or other treatment, even though that treatment may shorten my life.

I consent to anything proposed to be done or omitted in compliance with the directions expressed above and absolve my medical attendants from any civil liability arising out of such acts or omissions.

I wish it to be understood that I fear degeneration and indignity far more than I fear death. I ask my medical attendants to bear this statement in mind when considering what my intentions would be in any uncertain situation.

I RESERVE the right to revoke this DIRECTIVE at any time, but unless I do so it should be taken to represent my continuing directions.

**SCHEDULE**

- (A) Advanced disseminated malignant disease.
- (B) Severe immune deficiency.
- (C) Advanced degenerative disease of the nervous system.
- (D) Severe and lasting brain damage due to injury, stroke, disease or other cause.
- (E) Senile or pre-senile dementia, whether Alzheimer's, multi-infarct or other.
- (F) Any other condition of comparable gravity.

Signed.....

Date .....

WE TESTIFY that the above-named signed this Directive in our presence, and made it clear to us that he/she understood what it meant. We do not know of any pressure being brought on him/her to make such a Directive and we believe it was made by his/her own wish. So far as we are aware we do not stand to gain from his/her death.

Witnessed by:

Signature: .....

Signature: .....

Name: .....

Name: .....

Address: .....

Address: .....

.....

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[Continued

## NOP/41431—Euthanasia

FIELDWORK DATES 31 MARCH-5 APRIL 1993

Q.1. Some people say that the law should allow adults to receive medical help to a peaceful death if they suffer from an incurable physical illness that is intolerable to them, provided they have previously requested such help in writing. Do you agree or disagree with this? (Showcard)

(Base: All)

	Total	Religion												
		Church of England Anglican	Methodist	Church in Wales	Church of Scotland	Presbyterian	Baptist	Other Protestant	Roman Catholic	Jewish	Other non-Protestant	Atheist	Agnostic	Refused
Unweighted total	2,012 100%	1,024 51%	95 5%	11 1%	131 7%	15 1%	30 1%	87 4%	213 11%	8 *	95 5%	95 5%	29 1%	85 4%
Weighted total	2,017 100%	1,044 52%	94 5%	9 *	101 5%	13 1%	30 1%	85 4%	211 10%	7 *	95 5%	105 5%	26 1%	92 5%
Agree strongly (+2)	839 42%	449 43%	30 32%	2 21%	49 49%	6 51%	6 22%	27 32%	67 32%	2 30%	22 24%	72 67%	5 19%	44 48%
Agree moderately (+1)	740 37%	391 37%	36 38%	6 61%	37 36%	4 31%	9 30%	34 40%	86 41%	2 30%	36 39%	26 24%	6 24%	27 30%
Don't know (0)	238 12%	120 12%	18 19%	1 10%	9 9%	1 5%	5 15%	8 10%	25 12%	1 15%	12 13%	7 7%	4 46%	16 17%
Disagree moderately (-1)	83 4%	47 5%	3 4%	— —	4 4%	— —	2 6%	5 6%	8 4%	— —	6 6%	1 1%	2 6%	3 3%
Disagree strongly (-2)	117 6%	36 3%	7 8%	1 8%	3 3%	2 14%	8 26%	11 13%	26 12%	2 25%	18 19%	— —	1 6%	2 2%
Mean score	1.04	1.12	0.82	0.87	1.25	1.06	0.15	0.72	0.76	0.39	0.42	1.58	1.44	1.17
Standard deviation	1.11	1.01	1.15	1.06	0.94	1.39	1.53	1.32	1.28	1.65	1.41	0.68	0.77	0.98



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[Continued

### Examination of witnesses

Mr MALCOLM HURWITT, Chairman, Mr JOHN OLIVER, General Secretary, and Dr COLIN BREWER, Committee Member, Voluntary Euthanasia Society, called in and examined.

#### Chairman

188. Good afternoon and thank you very much, Mr Hurwitt, Mr Oliver and Dr Brewer, for coming along to give evidence to us this afternoon. First, may I thank you for your written evidence, which the Members of the Committee have had an opportunity of studying in detail before this session. Do you wish to make an opening statement or do you feel that what you have sent us in writing is sufficient for us to be able to open the questioning?

(Mr Hurwitt) Thank you. I would like to ask Mr Oliver to make a very short statement.

(Mr Oliver) Thank you very much. I am very conscious that I am speaking on behalf of something like 14,000 members of the Society. They joined for a variety of reasons but one of the principal reasons they have joined is because they have had a personal bitter experience, either because they themselves are incurably ill or they have seen a loved one die in very distressing circumstances. But for whatever reason they joined, all our members are united in wanting the option of voluntary euthanasia should their suffering at the end of life become intolerable. Admittedly, only a very few will probably take up the option but the vast majority, I am quite sure, will be very comforted by the fact that euthanasia would be available if the occasion arose. Also, an awful lot of people, particularly the elderly, now are very concerned at being kept alive by medical treatment or being imprisoned, if you like, by medical technology and they want an assurance that their wishes regarding medical treatment will be honoured by the doctor, their wishes as expressed in an advance directive. Incidentally, we were the Society that pioneered advance directives in this country over the last 15 years and although a number of other organisations are distributing advance directives at this moment, we are still the principal distributors. I would like to draw your attention particularly to the large measure of support we have now from the general public and in particular the result of the latest NOP survey, which recorded 79 per cent in favour of voluntary euthanasia and a mere 10 per cent against. In addition, there has been a plethora of other surveys, albeit less scientific, conducted by a whole variety of newspapers, magazines, radio and television, and each record exactly the same, with support ranging anywhere between something like 75 to 95 per cent. The BMA in its rejection of euthanasia does not speak for the profession as a whole and I would like to draw your attention particularly to the leading articles in *The Lancet* and the *BMJ* following the case of Dr Cox, and also draw attention to the findings of the Working Party of the Institute of Medical Ethics and also the Appleton Conference. Finally, this submission was not written in a spirit of confrontation. We in fact want to see the law adjusted so that it brings it into line with current medical practice so that doctors and patients can

address the very difficult questions, very difficult decisions, at the end of life honestly and openly.

189. Thank you. Of course, you have made clear what you mean in your document by "euthanasia". We understand too that you have made clear your wish as a Society to see that the mandatory life sentence for murder should, if at all possible, be modified or, alternatively, that some alternative verdict might be possible in cases of so-called mercy killing. You have made that, I think, very clear in your document. There is also before us, incidentally, a paper that has come from the Voluntary Euthanasia Society Scotland, the VESS; it is a separate organisation, a sister organisation?

(Mr Oliver) Absolutely.

190. They make a distinction, I believe, between advance directives and living wills. Do you feel there is a significant distinction between the two?

(Mr Hurwitt) Not really, not in the way we use it. There was a distinction some years ago but it has largely disappeared. It was an ethical one. I believe that living wills are still called that in the United States but we felt it was a misnomer because the normal meaning of the word "will" is something which operates from the date of death, not before it.

191. I hope you appreciate that this Committee has made no decisions at all and has come to no conclusions. Many people argue that if voluntary euthanasia were legalised this would signal a change in society's prohibition of the killing of one individual by another which could, in time, lead to involuntary euthanasia, the so-called "slippery slope" argument. Of course, concern has been expressed by many witnesses who have come to talk to this Committee about the present situation in Holland. Indeed, you may have seen a paper in *The Lancet* on 8 May which described what the same doctors felt right to call life-terminating acts without the explicit request of the patient. How do you propose that society's concerns about these issues should be met?

(Mr Hurwitt) I think the first point we would make would be that there is simply no evidence to suggest that decriminalising voluntary euthanasia leads to involuntary euthanasia. It is something which is often supposed but the evidence from the Netherlands is to the contrary. The Rummelink Report, about which a great deal has been written, showed that Dutch doctors were asked to carry out voluntary euthanasia roughly 9,000 times in a particular year and they did it in only a third of those cases. So they have a very tight control of things and they do not give way to any demand for voluntary euthanasia even when they are allowed to do it. They also said in the course of the survey that because of their experience when they had actually done it, they would be reluctant to do it again except in the most severe and urgent cases. So it does not seem as



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MR MALCOLM HURWITT, MR JOHN OLIVER and DR COLIN BREWER

[Continued

[Chairman *Contd*]

though doctors get the bit between their teeth and rush off and start killing people willy-nilly, but what it would do would be to bring the practice which exists secretly now out into the open. It is possible to have these figures from the Netherlands because they are available; it is controlled and people know what is done. You cannot carry out a similar survey in Britain because it is done in secret. The practice would be out into the open and would be controlled. The other point I would like to make is that if there were any such change it would need a radical change in society's attitudes and would certainly need fresh legislation. It could not happen by stealth but we do not think it would happen at all.

192. You are familiar with all the counter-arguments, of course, which include, for example, the question as to whether coercion or collusion between two doctors might lead to an abuse if euthanasia were legal, and also the question as to whether requests for euthanasia were made for reasons other than a real desire for death. These might include fear of being burdensome to family or friends, or depression or anxiety which could be effectively treated. How could you ensure that the patient's motives were properly identified and causes tackled before any decision was made?

(*Mr Hurwitt*) It would be necessary to rely considerably upon the attending physician, but if he or his clinical team suspects, for example, that the patient has depression, it would be up to him to tackle it and try to treat it. He would not ignore it. If it was a very different thing, for example, the fear of being burdensome to family or friends, that is not necessarily a bad motive. It is an element of self-sacrifice and in human beings that is noble, so that is not something to be afraid of. Most of the other examples which are given are matters which the clinical team should observe and should try to deal with, but, if I may refer to the safeguards which we have put into a draft bill, the main safeguard is that at least 30 days before the actual request for euthanasia, the patient must have signed a declaration saying that this is what he wants and so you have got at least a 30-day interval and it must then of course be repeated and the more consistently and persistently the patient repeats his request, the more reassured the clinical team should be that it is genuine.

193. For the sake of the record, may I take it that the draft bill to which you are referring is not Lord Allen's bill relating to advance directives. I presume you are talking about a totally different bill that you are in the process of preparing?

(*Mr Hurwitt*) Yes, we have prepared two, one for advance directives and one for euthanasia.

*Archbishop of York*

194. Mr Oliver in his opening statement referred to the National Opinion Poll and I would like to ask if he could help interpret the question which was asked because the question was whether the law should allow adults to receive medical help to a peaceful death. Does "medical help" include, say, increasing doses of opiates, does this include the

medical help that comes from withdrawing treatment, or is it supposed to refer to agents directly designed to cause the death of patients and, given this area of ambiguity, how is it known what the general public meant by their answers to this question?

(*Mr Oliver*) The term "euthanasia" was not in fact used because it means all things to all men, but we took advice from NOP, who have vast experience of this, and this is the wording they in fact devised. I am quite sure in my own mind that people answering this knew exactly what was meant. They knew that in fact what was meant was an injection or a fairly speedy death. In fact one word was omitted from this last opinion poll and that was the word "immediate" and that was thought undesirable for one reason or another. Perhaps we should have included that, but nevertheless every opinion poll since 1969 has recorded a substantial majority.

*Baroness Jay of Paddington*

195. Could I follow that up because I had exactly the same query about whether people would have actually understood precisely what this meant. You referred to Richard Smith's article in the *BMJ* and I was very interested in the wording that was used in the vote which was narrowly defeated in Washington State in the United States, which, if I could just read that, says, "a proposal to permit a 'medical service provided in person by a physician, that will end the life of a conscious and mentally competent qualified patient in a dignified, painless and humane manner'", which does seem to me more specific and precise and it does seem to me that if you want to do another opinion poll I wonder whether it would be more appropriate to use something as overt as that.

(*Mr Oliver*) We were advised not to make the wording too elaborate, otherwise the argument then would be that it is so complex that the average man in the street would not understand it, so this is why there is an element of simplicity built into the question.

*Archbishop of York*

196. I am very surprised that you say that everybody understood what this meant because I count myself an averagely intelligent person and I honestly did not know what it meant and that is why I asked the question. I think I am not unique in feeling some confusion about this.

(*Mr Oliver*) If I added the word "immediate", would that make it any easier to understand?

197. No.

(*Mr Oliver*) To an "immediate death".

*Baroness Jay of Paddington*] I think if I could just intervene again because I have the same concern and perhaps it should be "to receive active medical help to bring about a peaceful death" because I think the words "to receive medical help to a peaceful death" could just refer to palliative care.



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[Continued

*Chairman*

198. Supportive treatment could also be covered by that terminology. Could I pursue one other point too because you have made it clear that you support advance directives and of course have drafted some of the first. Those health professionals whom we have seen, doctors, nurses and many other groups, to date, seem generally in favour of the principle of the advance directive, but yet are opposed in their evidence to having them framed in any kind of legislative way. What is your purpose in wishing to see them enshrined in law?

(Mr Hurwitt) Well, my Lord Chairman, as a result of the judgments in the *Bland* case, it is clear that they are even now enforceable documents. It was said in the Court of Appeal and in this House that doctors cannot ignore them and so perhaps we might be asked "Why are you bothering to have legislation if they are enforceable?" and the reason is that the comments in the Court of Appeal and in the House of Lords were what are called *obiter dicta* and they were not legally binding at subsequent courts, but they carry great authority so we would like to put it beyond doubt rather than have someone having to go to court to test it directly. Also it would enable other things to be done because in the bill which we have drafted to make them legally binding, we have inserted the provision for a person to appoint a proxy to take that decision if the person signing the document is in a coma or otherwise incapable of making the decision himself. The other thing which of course we would like to see in legislation and which is not in Lord Allen's bill is that if the doctor for reasons of conscience says, "I cannot do what you ask", he would be under a duty to pass the care of that patient to another doctor, so for those reasons we think legislation is advisable.

*Lord Mishcon*

199. There is of course a difference, is there not, between having regard to wishes and to a document and having the document enforceable in law? Are you advocating that the advance directive should merely be a matter which the doctor must take into consideration, but need not be bound by?

(Mr Hurwitt) No, we are advocating that he must observe it, he must observe its terms, otherwise the patient has no autonomy and he is left in the hands of the doctor.

*Lord Meston*

200. With what sanctions if he fails to do so?

(Mr Hurwitt) He could be, as the Court of Appeal said, liable in the criminal and civil law because if you treat a patient against that patient's will, you are committing a battery, assault and battery which is criminal and civil.

*Lord Mishcon*

201. I only want to get my own mind clear on this. Are you literally saying that whatever the doctor may find to be conditions which are altered when he regards the patient, for example, taking your own

case of the patient who in previous years felt that to be a burden to relatives was something which she or he could not bear and, therefore, would say that in those circumstances life should be terminated if it befell her to fall into those circumstances, and then the doctor knows perfectly well with the advance directive in front of him that indeed she need not be a burden to relatives and there are other ways of dealing with her in spite of her very grave illness, are you saying that the advance directive in those circumstances should be enforceable whatever the doctor may feel at the time under changed circumstances?

(Mr Oliver) May I make this point. First of all, in our advance directive it says that "two independent physicians, one a consultant, are of the opinion that I am unlikely to recover from an illness." So they have to determine that, in fact, the patient is incurable and also likely to be under a great deal of distress or incapacity for a rational existence. So two doctors must determine that and, having determined that, then the decision is made not to prolong life.

*Chairman*

202. The problem, I think, that Lord Mishcon has raised, is that if you were to pursue this to the ultimate in strictly legal terms you would be imposing a condition in which the doctor's clinical judgment about the nature and management of the patient's condition is overridden. Equally, you could be imposing, with the caveat to which Mr Hurwitt referred, an obligation which could be contrary to the doctor's conscience. So each of these is possibly likely to arise from that situation, is that not the case?

(Dr Brewer) May I suggest an analogy from another area of medical life. There are a number of areas where one is not quite sure what the right thing to do is and what the law is, particularly in relation to the Mental Health Act. I do not do a lot of Mental Health Act-type psychiatry but I have had in the past a number of borderline cases where I have had, in effect, to say to a patient, "I think you should be in hospital. I know you do not want to go but I propose to initiate the sectioning procedure. If I am wrong, you can challenge it in the courts." I think all that is intended by this approach is to alter the balance from the present situation, where in theory either the patient who feels she has been kept alive against her will, for example, or the family of the patient who feel the patient was kept alive and should not have been, could in principle challenge the decision of a doctor, but it would be jolly difficult to do so in a situation where it is actually the doctor's job to justify any deviation from what seems to be the patient's expressed wish. It does not stop a doctor saying, "Actually, I think this is a delicate borderline case. I am going to see that the balance of doubt is resolved in favour of her staying alive rather than not, and I am prepared to answer for my actions before the General Medical Council or the courts," as we all may have to do in difficult situations.

203. But that surely would leave it open that a doctor might, for some personal or unscrupulous reason and in collaboration with a colleague for equally disreputable reasons, interpret an advance



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directive in a way which would be inappropriate? Surely that is a possibility, is it not?

(Mr Hurwitt) It probably is but then no system is going to be absolutely watertight.

204. This is one reason why people sometimes argue in favour of common law rather than statute law.

(Mr Hurwitt) To give some sort of flexibility, but this does not override a doctor's clinical judgment because it does not direct him to do anything; it just stops him doing something.

*Lord Rawlinson of Ewell*

205. I would like to ask one or two questions about your paper. You are dealing with the mandatory life sentence for murder and you go on to say: "The present rigidity of the law has led to *hypocritical and degrading pleas* which obscure the true facts of cases: for instance, a defendant who has acted rationally and from the highest motives is induced to plead 'Guilty to manslaughter by virtue of diminished responsibility'...." Could you give me the names of the cases and could you say who was the person who induced the people so to plead? Secondly, you refer to the Law Commission coming out—those are the words you use—in support of this, which I understand is the legal status of the advance directive. Could you say, is it the Law Commission's report which came out in favour of this, not an advice paper? Then my matter for comment is this, you say, talking about the belief in a personal god: "A belief of this nature is very much a minority cult today...." Why did you use the word "cult" in view of the fact, I suppose, that that is the view of Christians generally?

(Mr Hurwitt) I do not think I am in a position to say without reference to the books the names of the cases you asked for. I did not actually prepare this myself.

(Mr Oliver) There is one, Philippa Monaghan, who had her plea changed to manslaughter on the grounds of diminished responsibility and the judge was, therefore, allowed to give a discretionary sentence, whereas in fact she helped her mother to die and made lengthy preparations for this to happen.<sup>1</sup> It is the Law Commission's report.

206. It came out in February.

<sup>1</sup>Note by the witness: I was in error in quoting the case of Philippa Monaghan in response to Lord Rawlinson's question, (205) "Could you give me the names of the cases and could you say who was the person who induced the people so to plead?" She was convicted of attempted murder of her mother, who was suffering from motor neurone disease, and was sentenced to two years probation.

There have been a number of recent cases where the judge has accepted a plea of not guilty to murder but guilty to manslaughter on the grounds of diminished responsibility. One such case was that of Patricia Fairhead, (1990) who helped her husband swallow sleeping tablets then, when he was unconscious, smothered him. He was increasingly ill from multiple sclerosis and wanted to die. She was sentenced to two years probation.

(Mr Oliver) It was a consultative document, I understand.

207. That is what I thought you were suggesting. The other thing is why do you use the word "cult"?

(Mr Oliver) On the grounds that it is religious belief exercised by a minority of the population.

208. So you deliberately chose the word "cult"?

(Mr Oliver) You think that is rather emotive?

209. I just asked why you used the word "cult"?

(Mr Oliver) Because I think it is a minority.

*Archbishop of York*

210. May I come in on this point. I find this a strange position to adopt given your NOP findings, which seem to demonstrate that 85 per cent of the population belong to some cult or other?

(Mr Oliver) Very loosely based, I would say.

211. You are judging the quality of their allegiance, are you?

(Mr Oliver) How do you determine it? Do you determine strong belief by actual attendance in church?

(Mr Hurwitt) We are not going to go to the stake to defend the word "cult".

*Chairman*

212. We appreciate the point, thank you. May I take it that it is your wish to see a lesser offence, such as mercy killing, introduced into the criminal law?

(Mr Hurwitt) No, we would not.

213. You do not agree with that?

(Mr Hurwitt) No, because if you had voluntary euthanasia, as distinct from advance directives, there would be no need for mercy killing.

214. If I may put it another way then, whatever this Committee cares to recommend in the end, if society and Parliament were to be opposed ultimately to the principle of voluntary euthanasia as you define it, would you, as a Society, wish to see an alternative offence such as mercy killing introduced into the law?

(Mr Hurwitt) I suppose if it is all that is available it would be better than nothing. It is very unsatisfactory because what it does, as you can see in the Dr Cox case, is that it switches all the attention to the doctor, who might be prosecuted, and the patient is ignored.

215. Yes, we understand. The BMA has, however, suggested to us—and you have heard this argument many times—that if doctors were on occasion to assist patients in dying the relationship of trust between doctor and patient might be undermined. What is your view on this particular suggestion?

(Dr Brewer) I think that is without foundation. It surprises me that the BMA would say that because if the patient actually wants a doctor to provide any sort of help and the doctor makes it clear, subject to a change in the law, that he is willing to do so,



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I think that can only strengthen the trust. After all, I used to teach my students that it is not all that long ago that doctors went in through the tradesmen's entrance to the grander houses. We are to a degree glorified plumbers. We are the servants of our patients, not the other way round, and we do well to remember that. We do well to remember that, and if patients want us to do that sort of thing, not all patients will want that and not all doctors will want to do it, but if by mutual agreement that is thought to be an appropriate option and a doctor is willing to provide it, I think that a patient is more likely to be happy about the situation than otherwise.

*Lord McColl of Dulwich*

216. I would like to take you up on two things, the fear of prosecution by doctors and also the statement that what doctors are doing in relieving pain and sometimes hastening death is done in secret. This practice has been going on for over 100 years. How many doctors have actually been prosecuted for relieving pain under these circumstances by opiates and other similar drugs and how many doctors do you think really are living in fear of being prosecuted?

(*Mr Hurwitt*) The problem is we cannot know. We do know that it is happening because doctors will say that the profession is doing it, but there is no way of knowing how widespread it is because it is secret and doctors do not go around openly boasting that they have shortened a patient's life, but in this House in 1936 I think it was Lord Dawson of Penn who did admit he had shortened the King's life.

Chairman] Yes, we are aware of that particular comment.

*Lord McColl of Dulwich*

217. On this business of secrecy, if you go into a hospice or indeed any hospital all the drugs and the doses are recorded and there is nothing secret about it and there is nothing secret about the record. I do not understand why you think it is all done in secret. I do not think doctors should go around boasting about what they do because they are usually pretty upset when they are looking after the dying.

(*Dr Brewer*) Yes, I think the hospice point is a very appropriate one and I would like to approach it from the other end. We do not doubt that hospices do a good and a splendid job for a lot of the patients in a certain category, but hospices only take certain sorts of patients. I checked with my local hospice just a couple of days ago what sort of patients they take. Yes, they take patients with terminal cancer and over the last year or two they have taken a few patients with Aids and they have taken a few patients with strokes. Now, that does not actually deal with a sizeable proportion of people dying from the sort of illnesses that they do not want to hang around for and hospices have nothing to provide for that and nor, as far as I can see, do they intend to. It also is not very much help to that small minority of people, and we accept that in the case of terminal cancer it should be with good management, a relatively small

minority who despite the best efforts of the hospice do not actually get adequate pain relief and all the hospice can do in that situation is to mutter about pushing up the dose of morphine and so forth and that nobody ought to suffer, but the fact is that some people do suffer and a small proportion of people do suffer dreadfully and for those people hospices are not really a satisfactory option. There are also a whole lot of people suffering from conditions which are simply not amenable to any kind of medical or psychological treatment.

(*Mr Hurwitt*) I did not answer Lord McColl's point about why I said it was done in secret. Although doses are recorded, we get into the difficult area where doctors justify what they do by saying that the particularly large dose which they have used was necessary to relieve the pain and that was the primary purpose of giving it. Incidentally it might have shortened the patient's life and that is what you cannot get beyond.

Chairman] We are aware of that particular situation about which we have heard a good deal of evidence.

*Baroness Jay of Paddington*

218. I have a slightly different point about openness and secrecy. In your paper you drew attention to Lord Browne-Wilkinson's judgment on the *Bland* case and the way in which he wrote about finding it difficult to find a moral answer to the question of the difference between allowing a patient to die slowly and giving a lethal injection, and you say, "If the whole issue of the patient's 'right to choose' is properly confronted", and presumably that means openly, "then it seems likely that the distinction between active and passive euthanasia will be seen to be morally specious". I wonder if you could develop that a little.

(*Dr Brewer*) I think this is one of the oldest chestnuts which is trotted out and perhaps one could best illustrate it by asking you what your attitude would be if you were to develop a rapid and potentially lethal pneumonia which was likely to carry you off if I did not intervene. If I left you to die on the grounds that I did not like people wearing blue dresses or because of some bizarre reason or because I thought that you were not worth saving or there were other people who needed the attention more, you and your surviving relatives would be very upset about it and yet if you were suffering from exactly the same sort of pneumonia but had also been suffering for several years from a severe dementia which robbed you of what people regard as your normal faculties, I would probably be criticised if I did treat your pneumonia, so we are talking about essentially the same act which can be seen in very different ways. If you will the end, you will the means, and there are some patients who everybody agrees would be better off dead, even in the hospice. The only argument is about how we may nudge them towards that end. The hospices will nudge, but they believe in slow and rather inefficient nudges. We would like some of our members to have the opportunity of



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faster and more effective ones, but there is no moral difference between them.

*Baroness Llewelyn-Davies of Hastoe*

219. I have only a factual question. I did not understand what kind of illnesses there are which are not susceptible to proper treatment. It is obviously the terminally-ill cancer patients and so on, but what other kinds of disease?

(*Dr Brewer*) If you have the kind of progressive chest disease which makes you increasingly breathless, emphysema, for example, even though some cases are treatable now by transplant but relatively few and nobody would transplant patients beyond a certain age and fitness, you can look forward to nothing but increasing breathlessness and discomfort and there is no effective treatment, save death in some form. People with progressive, creeping paralysis, motor neurone disease, that sort of thing, there is not really any effective relieving treatment and if the distress of that condition rather than the pain, and many of them are not in pain, if people are simply distressed not only by what they experience but by what they see their relatives experiencing, I think that is a perfectly reasonable attitude to have and if some of them want to speed up their departure, as many of them do, it seems reasonable grounds.

220. But hospices do not treat them?

(*Dr Brewer*) In general not.

Baroness Llewelyn-Davies of Hastoe] I did not quite realise that.

*Lord Mishcon*

221. I believe I am right in recollecting that the Dutch procedure, which obviously one would want to look at as being a very relevant one, is this: that after various steps have been taken as between doctors and the patient is no longer here, there is a duty thereafter to register the matter with the coroner. Do you see the slightest advantage in a procedure which is post death of that kind and do you see any possibility of the court having some jurisdiction before the death?

(*Dr Brewer*) It is really a matter for a legally-qualified person.

(*Mr Hurwitt*) We would not want the Dutch system over here. The reason the Dutch have got it is because they have chosen a halfway house. Dutch law still says that euthanasia is unlawful, but there is another agreement between the medical profession and the authorities that if they follow certain guidelines they will not be prosecuted. It does not legalise euthanasia in the full meaning of the word. They have got themselves into this rather halfway zone which creates difficulties for them and we certainly do not want that over here.

222. Could you answer the second part of the question which is do you see any role at all for the court in this?

(*Mr Hurwitt*) Only I think if there was some very unusual and extreme case. Normally we would say

no and that it is a matter for the patient and his physician.

*Chairman*

223. So I take it then that you do not agree in the case of the incompetent patient who is incapable of giving an informed decision with the suggestion in, for instance, the Law Commission's document, that there might be a judicial forum?

(*Mr Oliver*) That does not fall within our remit, I am afraid. We are the *Voluntary Euthanasia Society*.

(*Mr Hurwitt*) That is a different question. I was answering Lord Mishcon on the basis that the patient has capacity to make a decision.

224. So you do not want to comment on this issue of a judicial forum or the BMA's suggestions about having local committees with legal and medical advice, for instance, that might be in a position to examine cases without their being referred, as the *Bland* case was, to the High Court? The other point is that you talk about the *Bland* case in terms of advance directives but surely a young man going to a football match would not at his age have been likely to sign an advance directive?

(*Mr Hurwitt*) Yes, that is true.

(*Dr Brewer*) I think one of the things that the Society hopes will happen more or less incidentally—and here I doubtless find myself in agreement with the Archbishop—is that it will make people more aware that we are all living for a limited amount of time, we are all going to die and we should plan for this. Many people do not plan. They do not even make a will and I do not think it is ever too young to start encouraging people to contemplate their mortality. One hopes more people will say, "Yes, this could happen. I will make an advance directive."

(*Mr Hurwitt*) It is in fact happening. As you can imagine, we get a great number of requests for speakers and we are speaking to quite young audiences at times. There is a lot of interest in these sorts of questions and courses in medical ethics are now taught of many universities.

*Archbishop of York*

225. I want to take you back to the answer you gave to Baroness Jay's question about active and passive euthanasia. This is not terminology we are very happy with so far in this Committee, but if one may talk about the difference between killing and letting die, you would recognise that although from the patient's point of view there may be very little difference morally between those two, from the doctor's point of view there may be a very important difference in terms of his own understanding of his role, whether as a healer, a carer or, in the end, a dispatcher?

(*Dr Brewer*) I think there are certainly differences in style. There are differences, for example, between infanticide and abortion late in pregnancy. There is not in some senses perhaps a great deal of moral difference between them; there are legal differences, which is a different matter, but from the doctor's point of view it may seem quite different.



[Archbishop of York *Contd*]

But if, as I believe, morally they are very similar and if, as I believe, active and passive euthanasia are morally very similar, both being varieties of assisted suicide in a sense, I think it is up to doctors to come to terms with the inherent philosophical difficulties and if they cannot then I do not think they should not be doctors but they should not be working in that field.

Chairman

226. Thank you very much for coming. If you feel there are any issues which we have allowed to slip by please do not hesitate to write. And if you so wish, please feel free to listen to the other evidence for the rest of the afternoon.

(Mr Hurwitt) Thank you very much.

#### Memorandum by LIFE

This organisation is opposed to the legislation of voluntary, non-voluntary or involuntary euthanasia on the following grounds.

##### 1. *The Case for Euthanasia is not based on Coherent Moral Reasoning*

We would argue that:

- (a) To uphold and promote the utmost respect for human life regardless of sex, race, creed, age, prosperity, physical or mental achievement, etc. is fundamental to civilisation and has been a basic principle of English law of which we are justly proud. Legalisation of euthanasia would violate that principle and represent another radical rejection of time-honoured values.
- (b) A radical breach with the past of this kind should be undertaken only if clearly justified by rigorous moral reasoning. The onus of proof rests on those who propose change. The onus therefore rests on those in favour of euthanasia to demonstrate the intellectual underpinning of their case. Mere assertion is not enough. Nor is it enough to cite others' opinions unless these are informed opinions, ie rest on coherent reasoning.

However:

- (i) The case for *voluntary* euthanasia rests on the claim that an individual has the right to suicide and the right to determine the circumstances in which his/her life shall be deliberately ended by another person or persons. But the existence of such human autonomy is not self-evident. Where does it come from? How do we know it exists? How can it co-exist with the manifest lack of complete control over their lives which many human beings are constantly experiencing? Claims to "autonomy" have to be carefully assessed. Some have laudable purposes—eg rejection of slavery or determinism. Some may be used to justify degraded or irresponsible behaviour. Some are simply muddle-headed. So it is not enough merely to assert that "autonomy" justly entails a right of self-destruction. Established concepts of autonomy entail no such right. Simply to appeal to "autonomy" is merely to appeal to an equivocal word and to repeat, rather than to explain or justify, the claim at issue. It similarly begs the question to say that the right is axiomatic. This right, like others, must be established by reason.
- (ii) The case for *non-voluntary* euthanasia is being argued on the ground that it can be in a person's best interests to be dead and that it may therefore be permissible deliberately to procure that person's death by withholding treatment and/or supply of food and liquid. But to claim to know that it is in someone's best interests to be dead is to claim to know the unknowable, as is argued in Appendix A to this Submission.

Thus, in our view, both the case for voluntary euthanasia and the case for non-voluntary euthanasia are intellectually incoherent. Each is based on mere faith: faith in the existence of human autonomy and faith in the knowability of unknowable "best interests". Such faith, being without grounding in reason, is blind faith, and hence difficult to distinguish from fashion, hunch or guesswork—or mere assertion.

Furthermore, there is absurdity in appealing to "self-determination" and "autonomy" on the one hand and, on the other, asserting that people who are incapable of choosing or have never chosen this course may be killed.

- (iii) We are opposed to *involuntary* euthanasia, where the expressed wishes or refusal of the patient are overridden, on the ground that this involves an overt act of aggression against an individual and violation of his/her legitimate right of self-defence. It is yet more obviously incompatible with claims to "self-determination" and "autonomy" than is non-voluntary euthanasia.

We submit that the Select Committee cannot proceed to details of legislation allowing euthanasia unless and until it establishes the intellectual foundation of the euthanasia case.



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[Continued

## 2. *The Euthanasia Lobby Confuses Issues*

(a) The pro-euthanasia lobby, in our view, commonly blurs the well-established distinctions between ordinary and extraordinary means of managing the gravely ill, the terminally ill and the dying. These distinctions provide clear guidelines for all concerned and protect the duty of those in medical charge of such cases to judge each one on its own merits.

(b) The pro-euthanasia lobby commonly rides roughshod over careful and coherent reasoning concerning intentions and (foreseen but not intended) side-effects—reasoning which is basic to the practice of good medicine and protects both clinician and patient.

(c) The pro-euthanasia lobby often caricatures the views of its opponents by asserting that the latter insist that every means always be used to sustain human life—whereas they have always rejected such extreme “vitalism” and denied any duty to provide treatment which is futile, overburdensome, “heroic” or dangerous.

(d) In trying to re-define as medical treatment the supply of nourishment and liquid, the pro-euthanasia lobby erodes the crucial distinction between the basic care due to any human being simply because he/she is human and medical support. It confuses nursing with doctoring. Matters are made worse by use of the term “persistent vegetative state” (see Appendix B).

(e) At the same time the pro-euthanasia lobby frequently attempts a false distinction between active and passive killing, by trying to argue that a patient who is being deliberately starved to death (with or without use of sedatives) is merely being *allowed*, and not caused, to die. There is no real distinction between causing death by deliberate omission (starvation or withdrawal of routine medical care) and actively procuring it.

## 3. *Euthanasia is Morally Repugnant*

(a) Euthanasia is morally repugnant because it *either* consists in the violence of suicide *or* requires doctors and nurses deliberately, and as their direct and immediate intention, to kill patients. This is contrary to the true vocation of doctors and nurses. It is sometimes claimed that by withdrawing treatment or food in obedience to an advance directive or living will the doctor is simply allowing (passively) the patient to do what he/she has freely chosen; but, as has been said, this is tendentious. In such a case the doctor is not only abdicating his duties precisely when he should be exercising professional and moral judgment; he is doing something morally indistinguishable from procuring his patient's death. It is no defence to say that he was doing what someone else asked him to do.

(b) Moreover death by starvation and dehydration is a horrifying, slow death. It is distressing for all concerned—and a far cry indeed from the much-vaunted “death with dignity”. The pressure on any doctor involved in such “mercy-killing” to deliver the patient from a long agony with a lethal injection will be difficult to resist. So in practice “passive” killing will often become “active”.

## 4. *Legalisation of Euthanasia Unnecessary*

(a) The growth of the hospice movement and provision of home-based care for the terminally ill, together with remarkable advances in pain and symptom control, are achievements in which all should rejoice. No one need now die in pain. Cheshire Homes, hospices, Macmillan and Marie Curie nursing provision and the spectacular growth in palliative medicine are transforming the care of the chronically and terminally ill and dying. The euthanasia campaign is an affront to all these. Had euthanasia been with us a couple of decades ago few of these advances would have happened. Rather than succumb to the defeatism of the euthanasia campaigners, society should rejoice in and promote the hospice movement and all that goes with it, thus ensuring that no one need die alone, that the last days need not be “lost” days, and that all may truly be allowed to die in dignity in their due time—naturally.

(b) It is a lamentable irony that the euthanasia lobby should mount its fiercest attack precisely when the need for it has never been less urgent—and that its victory could undermine so much that has been achieved, often by heroic voluntary effort. The call for euthanasia comes from the past. It is yesterday's cause. It belongs to a world which, thankfully, has been overtaken by medical progress and people of vision. To legalise it would be retrogressive.

(c) Euthanasia is unnecessary because those ethical principles concerning ordinary/extraordinary treatment, etc. noted above provide adequate guidelines for all concerned—while also allowing and requiring of doctors and nurses full exercise of their professional judgment. They respect the rights and duties of all concerned. The claim that recent advances in life-support techniques have created new dilemmas for doctors is misleading. The principles are well defined and straightforward. The Tony Bland case, for instance, created no *new* dilemma. Doctors still have no duty to prolong the dying process and no right directly and deliberately to accelerate it.

## 5. *A Little will Inevitably Mean More*

(a) However carefully circumscribed by the legislators, the legalisation of euthanasia will inevitably open floodgates. Once the idea is established that it is not enough simply to be a human being to qualify for



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basic care such as nourishment or routine medical treatment, the temptation to start raising the "qualifying line" will be irresistible. Once we have accepted that a judgment can be made that it is in someone's "best interests" to be dead, no one is safe.

(b) The message will go out to the comatose, the severely disabled, those afflicted with incurable genetic and congenital diseases (including victims of cerebral palsy, epilepsy, etc.) that they would be better off dead. Many people will be afraid to go to hospital. There is a terrifying danger that even hospices may be corrupted. Vital trust between patients and those who care for them will be jeopardised.

(c) If feeding by tube is regarded as "extraordinary" medical treatment, the range of "disposable" people will be enlarged to include newly born premature or disabled children, and most patients in intensive care.

(d) All this will not only erode public trust in doctors, nurses and hospitals. It will open up immeasurable opportunities for manipulating, bullying and conspiracy by third parties who expect to gain from another's demise. It will be difficult in practice to protect the right to change minds or rescind advance directives at the last moment, and even more difficult to guarantee that those who signed them in the first place did so in full knowledge of what they were doing. The living will could easily do irreparable damage to relations between children and ageing parents, or younger and older siblings—if, for example a son agreed to take in a widowed mother on condition she agreed to be "put down" when she became an "unacceptable" burden.

(e) Once living wills or advance directives were authorised, the pressure would mount to make it a criminal offence on the part of a doctor not to comply with them, as it already is in Victoria, Australia (and various *dicta* in *Bland* suggest that it would be at least a civil wrong not to comply). The doctor's clinical judgment would therefore be allowed no role. Inevitably doctors would err on the side of caution and interpret living wills (and "best interests") ever more permissively.

On these grounds, therefore, we urge that the Select Committee should not dilute further the law on homicide to accommodate the demands of the euthanasia lobby. On the contrary, we urge that legislation be passed to reverse the decision of the House of Lords in the Tony Bland Case.

If, however, despite these entreaties, the Select Committee decides to advance the cause of euthanasia in legislation we urge that it recommend the following:

- (a) That any such legislation contains a "conscience clause" which gives full protection to all doctors, nurses and other hospital or hospice staff who have a conscientious objection to euthanasia.
- (b) That hospitals and hospices be free to "opt out" of providing euthanasia (ie be free to disregard living wills or advance directives and not to kill in the name of patient's "best interests") and to advertise the fact that they have done so. Every patient entering that hospital and hospice shall be informed of its policy.
- (c) That all hospitals and hospices which "opt in" and hence accept advance directives, living wills and killing in the name of patients' "best interests" be required to make this policy public knowledge. Every patient entering that hospital or hospice shall be informed of its policy.
- (d) That, regardless of whether he/she has signed a living will or advance directive, a patient shall at any time be free to choose to go to a hospital or hospice which has "opted out".
- (e) That no one shall sign an advance directive or living will without having received adequate, disinterested counselling.
- (f) That next of kin shall not give their consent to the killing of a patient on the ground that this is in his/her "best interests" until they have received adequate, disinterested counselling.
- (g) That no next of kin giving consent as per (f) above shall stand to benefit from any substantial bequest or insurance payment or in any other way under any will of the deceased made less than seven years before that person's death.
- (h) That the term "persistent vegetative state" be avoided henceforth (see Appendix B).
- (i) That every encouragement and increased financial support be given to the hospice movement and the advance of palliative medicine.

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## APPENDIX A

*Whose "Best Interests" are They Anyway?*

An action can be said to be in someone's best interests if it makes the person concerned

- (a) healthier
- (b) wealthier
- (c) better informed
- (d) wiser
- (e) happier.

No one could argue that, to be dead, is to be healthier, wealthier, better informed or wiser.

Could it be claimed that someone would be made happier by being dead? To know that a person would be happier if dead requires

- (a) knowing how much happiness he/she enjoys at the present (ie before death); and
- (b) knowing what is going to happen to him/her after death.

Since it is impossible to have an exact idea of (a), especially if the person is unconscious or senile, and since it is impossible to have an exact knowledge of (b); and since many proponents of euthanasia deny that there is any life after death, it is impossible to prove that the amount of happiness after death will exceed that enjoyed by the patient beforehand, and it is therefore absolutely impossible to know that it is in someone else's best interests to be dead.

To claim to know that it is in someone's best interests to be dead is to claim to know the unknowable.

Whereas a doctor may reasonably claim that it is in a patient's best interests to be hospitalised or undergo this or that treatment—because past experience indicates that patients benefit from such actions—no empirical evidence exists to sustain the claim that to be dead is to the patient's benefit. To ask a doctor or anyone else to know what of its nature is unknowable is ludicrous.

The truth, of course, is that it is not the *patient's* best interests which are being consulted here—but other people's. It would be more honest to state this clearly.

What the euthanasia lobby is really wanting (but dares not say openly) is that it should be permissible to kill someone who has become overburdensome to others and/or expensive to sustain.

The civilised response to such problems is, of course, to increase the supply of (for example) hospice care and to refuse to put a price on human life.

## APPENDIX B

## PERSISTENT VEGETATIVE STATE

We urge that the term "persistent vegetative state" (PVS), as applied to severely brain-damaged or otherwise disadvantaged human beings, should be disallowed—on the following grounds:

- (a) A human being cannot, by definition, ever be possessed of a merely vegetative life.
- (b) The term is offensive and discriminatory, and immediately predisposes others towards devaluing the victims of the conditions concerned. It therefore clouds and confuses discussion.

Our society is (rightly) concerned to purge its vocabulary of prejudicial and discriminatory language—whether sexist, racist, ageist, or hurtful of anyone "challenged" in any way. The term PVS should be unhesitatingly expunged, therefore.



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## Examination of witnesses

Mr KEITH DAVIES, PR Executive, LIFE Campaigns, Dr M HELEY, Secretary, LIFE Doctors, and Professor J J SCARISBRICK, National Chairman, LIFE, called in and examined.

## Chairman

227. Thank you very much, Dr Heley, Mr Davies and Professor Scarisbrick, for coming and also for your written evidence, which we have read with interest. Is there any opening statement you wish to make at this stage?

(Professor Scarisbrick) No, thank you.

228. So we can go straight ahead with the questions. You say that "there is no real distinction between causing death by deliberate omission... and actively procuring it". One appreciates that it may be difficult to see a moral distinction between the two but it is on such a distinction that the law currently relies and most ethical codes are based, so what do you feel is the position of the doctor who for a terminally ill or severely demented patient fails to prescribe antibiotics for the treatment of pneumonia or does not recommend active resuscitation in the case of a terminally ill patient? What is your view about that situation?

(Professor Scarisbrick) May I comment first on the first half of the question and say I am not a lawyer but I understand that if someone who had a duty of care of, say, a child deliberately withheld food from that child in order that that child should die, that omission would be the equivalent of deliberately causing the death of that child by, say, smothering the child or giving it a lethal injection. If the intention is to cause death, then it seems to me there is no significant distinction between omission and commission, and I believe that that is a strong tradition of common law and is, indeed, supported by statute, for example the Offences Against the Person Act 1861.

229. There are, of course, a number of legal judgments that have been made in various parts of the world which have suggested that there is a distinction between the provision of food and fluid by mouth and the provision of food and fluid by artificial means requiring an invasive technique to get the nourishment into the body. Do you see any distinction between those two?

(Professor Scarisbrick) No, I think the word "artificial" in such circumstances is slightly tendentious because if an individual is in such a condition that the only way to feed him or her is via a tube or whatever, that is the normal way of feeding that person, even as it is a normal way of feeding a child through a bottle.

230. It could, nevertheless, be argued that it is so invasive that in the absence of valid consent the insertion of a tube could be regarded as an act of battery?

(Professor Scarisbrick) It could be so argued but I believe that an action which is designed to supply food and drink in order to sustain life could scarcely be equated to battery. If we can move to the second half of that question, it seems to me that the crucial

thing here is, what is the intention of the doctor. If the intention is not to undertake unnecessarily burdensome, heroic, futile treatment, then clearly it is permissible, but if the intention is directly to cause death, then that is unacceptable. Perhaps Dr Heley might like to comment.

(Dr Heley) If I could put this in context, I am a GP and when one is looking after a patient throughout the course of an illness which is life-threatening, it runs in two phases. In the first phase the object and intention of treatment is cure. All one's efforts go towards cure and, therefore, one may subject one's patients to unpleasant, painful or even themselves life-threatening treatments, provided that cure is the intended result, but over the course of time it may become obvious that one is not going to win and that cure is not possible. Then there is a complete reversal and all one's attitude towards treatment and the objective and intention of treatment becomes comfort, the alleviation of symptoms, the production of a contented patient with a comfortable, pain-free life, able to enjoy the days as they go. In this context one views the prescription of antibiotics for infection thus. If a patient has got a painful infection, like a kidney infection, then it would be perfectly reasonable to treat it with antibiotics because to suffer that pain would be worse perhaps than the natural termination and, therefore, you cannot really say that it is right or wrong in any particular set of circumstances.

231. Forgive me, I am sure we all accept that for the relief of pain and suffering it is absolutely right that everything possible should be done, but in the case of a comatose patient or a patient who has no evidence of any perception of pain or of suffering, an individual, say, in the terminal stages of any illness, is it right, using the platitude, to strive officiously to keep alive such an individual by prescribing antibiotics?

(Dr Heley) No, of course not.

232. So you would see circumstances where it is perfectly proper to withhold such treatment in the terminal stages of an illness?

(Dr Heley) Yes, absolutely.

233. Thank you, that was the point I wished to clarify. Before other Members of the Committee ask you questions, may I just ask you this: you in your appendix urge that the term "persistent vegetative state" should be abandoned. It is clearly defined in medicine referring to an individual who has lost the cerebral cortex but still has a functioning brain stem and, therefore, is in a state of wordless, mindless wakefulness (it has also been called the aphasic state, and a whole lot of other terms have been used); if you dislike "persistent vegetative state", what term would you put in its place?

(Professor Scarisbrick) We would prefer "persistent non-responsive state".



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[Continued

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(*Mr Davies*) I think the point is we have to recognise that human beings can never become vegetables and no matter how brain-damaged they are, they still deserve and require to be treated with the utmost respect which does in fact recognise that humanity. For example, in the *Bland* case, we recognise that Tony Bland would never again have been the active, lively, athletic young man that he was before the Hillsborough tragedy, but we believe that for him to be denied food and fluid was in fact condemning him to death by starvation and dehydration and to try and mask that fact by talking about renal failure is in fact slightly dishonest because if you or I were denied water for 11 days, then would we not also die from renal failure and would not our death have been deliberately caused?

234. I do not know whether you saw an article in *The Tablet* on 13 March 1993 by a Roman Catholic priest and moral theologian called Kevin Kelly who concluded his article by saying, "I have suggested that the decision of the Law Lords in the *Bland* case was fully in line with mainstream Roman Catholic traditional medical evidence saying that the withdrawal of artificial nutrition and hydration in the case of Tony Bland should not from an ethical standpoint be regarded as killing him".

(*Mr Davies*) We are not a religious organisation.

235. I know and appreciate that.

(*Mr Davies*) We are certainly not a Catholic organisation.

236. No, I appreciate that and I am not suggesting that for one moment, but is this a point with which you disagree?

(*Professor Scarisbrick*) I think he is factually wrong in saying that the *Bland* decision is in line with traditional Roman Catholic moral teaching. I think he is factually wrong.

*Lord Mishcon*

237. Would you not have accepted in the *Bland* case that the medical evidence and the specialist medical evidence was that Tony Bland could not feel any pain at all and could know of no reaction which was painful to him in the slightest by reason of food and drink being withheld? Do you still say it is objectionable if that medical evidence is correct?

(*Professor Scarisbrick*) Yes, because we say we object to doctors deliberately procuring the death of their patients by denying them food and drink.

238. What, if I may ask you, if you had the right to impose your judgment in that case, what would you have wanted the doctors to do in regard to Bland?

(*Professor Scarisbrick*) To sustain him by the ordinary method of merely supplying basic food and so simple a thing as water. If he were to have suffered some severe virus attack, then, I think, as Dr Heley has indicated, there would be no moral objection to not striving heroically to keep him alive. Clearly if he had had a cardiac failure, there would have been no question of a heart bypass or anything like that, but we are not dealing with high-tech medicine when

we are talking about giving a fellow human being food and drink.

*Lord Colwyn*

239. Can I take up an item in subsection 4 of your memorandum where you say that no one need now die in pain. Now, we have just heard from the Voluntary Euthanasia Society that in fact they felt probably quite a lot of people are actually dying in pain. We obviously are aware of the fact that progressive doses of opiates are permitted by law and could you give your view on that, and also the differential where the opiates are pain-relieving and then may hasten death?

(*Professor Scarisbrick*) We have no problem whatsoever with the management of a case in which progressive doses of pain-killer, whose intention is to relieve pain, may indeed hasten death and, as Dr Heley may remark, sometimes of course they postpone death. We have no problem with that question, therefore. As regards the statement that there are still patients whose pain and distress cannot be fully relieved, I will ask Dr Heley to comment.

(*Dr Heley*) Speaking yesterday to the director of our own hospice, she remarked that pain was really the least of their problems and that pain was a symptom which they could control. She said that pain could be relieved, provided the patient was prepared to be made sleepy or drowsy, and she said those who wished to remain conscious very often have to put up with more pain and these are usually the younger people; they are not the people who are asking for euthanasia and they are the people who want to stay alive and be conscious as long as possible. She said that distress was a more difficult problem because it involved things like loneliness and fear of the dying process and wanting to get it over with. But she felt that these could be coped with by counselling and befriending and other human techniques.

*Chairman*

240. Do you think the principles which have dominated hospice care and the methods of relieving pain and distress have been sufficiently widely disseminated throughout general practice and the medical profession?

(*Dr Heley*) Far from it, far from it, I am afraid.

241. But it is a fact that education in this field is nevertheless improving, is it not?

(*Dr Heley*) Yes, but it has a long way to go.

(*Mr Davies*) Could I just come back to the question of pain control and pain management, and draw the Committee's attention to the report produced by the World Health Organisation on cancer pain relief if I may quote from page 55 of that, "The Committee there adopted the position that with the development of modern methods of palliative care, legalisation of voluntary euthanasia is unnecessary. Now that a practical alternative to death in pain exists, there should be concentrated efforts to implement programmes of palliative care rather than a yielding to pressure for legalised euthanasia". Later on in the same page they actually say, "Drugs in doses



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[Continued

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required to control pain and other symptoms should not be withheld solely because they may shorten a patient's life". I think that is the viewpoint we would support, that even if powerful pain-controlling medication were to be administered in such large doses that it had an unavoidable secondary effect of bringing on and hastening the dying process, that should not be confused with euthanasia, and it should not be confused with deliberate killing.

Lord Mustill] I would like to ask a question about withholding antibiotic treatment. Could I preface it and take the opportunity to put in a word for somebody long dead, Arthur Hugh Clough, who wrote *The New Decalogue*, in which the distinction between killing and striving to keep alive is constantly being drawn wrongly? I do not think I need say any more.

Chairman] The next stanza is perhaps relevant in stressing the satirical character of the poem.

*Lord Mustill*

242. It would be inappropriate in a serious matter like this to quote the next one anyway. I was looking for the opportunity to say that. I would like your help on this question of the withholding of antibiotics as distinct from more far-reaching methods, which is a puzzle. Speaking for myself, I find large tracts of this branch of law on ethics a puzzle. We need not look at the law for present purposes but it is overlaid by the distinction between acts and omissions and the valid distinctions between sustenance and treatment, but what about withholding antibiotics? It is a commonplace of ordinary medical life that if a person develops a condition which yields to antibiotics, if there are no contrary indications you give him or her antibiotics, and that is just as much a fact of ordinary medical life as ensuring the nurse provides proper nutrition and hydration. As I understand your evidence, you would say that the withholding of antibiotic treatment which would normally be a matter of course is in a special case acceptable. Can you explain how you get there?

(Dr Heley) I do not think it is the same as nursing treatment, as food and drink. It is a definite medical intervention. Food and drink and nursing care are not an intervention, they are a basic right. But antibiotics intervene in the course of an infection, which you may or may not want to do.

243. But let us take a situation where you had a 12-year-old who had a condition which would yield to antibiotics and the doctor would normally prescribe that. It would be in ordinary circumstances a wrong thing to do to withhold. Forget that it is criminal. It would be morally wrong, most people would say, absent some powerful reason, yet you would accept that in the special case under consideration it is not morally wrong. What makes the difference?

(Professor Scarisbrick) Because the patient is dying.

244. Anyway?

(Professor Scarisbrick) Yes. The antibiotics might or might not win for that patient another few

hours of life. It might not, in some cases, hasten death but the most you could hope for is a few more hours, and this might be the 20th, 30th, 50th time you are administering these antibiotics and the virus is getting stronger and stronger and the dosage is getting stronger and stronger. There comes a point when you simply give up. You are not causing the death of the patient; you are allowing that patient to die in his or her own time as a result of the disease that has overtaken that patient.

*Chairman*

245. Could I follow up that point. Let us go back to the *Bland* case for a moment. Everyone agrees that as a matter of medical experience, being in a physical state of dehydration is also thoroughly unpleasant and starvation is thoroughly unpleasant, but that is the case in the conscious, sentient patient. The argument in the *Bland* case that was put at the time was that he had no perception of the world around him and was incapable of understanding or even of having any awareness of the state of dehydration if the nutriment and the fluids were withdrawn. The point that Lord Mustill is making is, is there a distinction between withholding that and withholding antibiotics?

(Professor Scarisbrick) I think there is always a distinction between withholding food and drink and not continuing to strive with very powerful drugs. The distinction is one I have already tried to draw. When what is being offered to a person as a human being is food and drink one does not take into account whether or not that patient is conscious or highly intelligent or whatever. A newly-born child may not understand the meaning of food and drink but you are still required to give it to that child. An unconscious person recovering from an operation has long since lost contact with the outside world but one would still feed that person.

*Baroness Flather*

246. Is there anything else in the category of food and drink or is that in a category of its own, in your mind?

(Professor Scarisbrick) I would strongly argue that the courts did no service to society by saying that food and drink were a form of medical care. That confuses nursing with doctoring.

247. I did not ask that question. In your categorisation you make that a distinct category on its own?

(Professor Scarisbrick) Yes.

248. And nothing else falls into that category?

(Professor Scarisbrick) But there can be other genuine forms of medical care and treatment which are perfectly ordinary and normal and routine in some situations but become extraordinary in others.

*The Committee suspended from 5.31 pm to 5.37 pm for a division in the House*

*Chairman*

249. I do not think we are going to have to detain you for much longer, but just to follow up the point



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[Continued]

[Chairman *Contd*]

you were making then, it would be put to us, I think, by others that a new-born baby or a small child, would be capable of feeling shock and distress, on becoming dehydrated. However, others have made the point that there is no evidence to suggest that a patient in what you would prefer not to call a persistent vegetative state (whatever you call it) would experience any distress or suffering if food and nutrition were withdrawn.

(*Professor Scarisbrick*) With respect, I cannot see that that is significant because the fact remains that the person concerned is still a human being and it is the humanity of the patient not the quality of sensation and so on which is fundamental, I would have thought.

250. So you would not, in that situation, subscribe to what has been suggested as being in the patient's best interests, for example?

(*Professor Scarisbrick*) We would regard claims to know what is in the best interests of a patient who is insensate and so on as bogus. It is impossible to know that it is in the patient's best interests to be dead.

*Baroness Warnock*

251. I quite agree it may well be impossible to talk about the best interests of a patient who has no experiences, just as I think it is impossible to talk about the best interests of a very young foetus. It does not make sense. You cannot possibly know or talk about it. So I agree with you, if I may, we should drop the "best interests" terminology but it does seem to me that if you are right in what you have just said to us, that the quality of the life of the patient is perfectly irrelevant to what we are talking about, it is that the patient is a human being and alive, which is what I think you said, then I cannot see why you do not think that it is necessary for a doctor to pay attention to the extra life that a patient, however sick, can have. If what is valuable, what is absolutely valuable is human life in whatever form, and presumably for however long or short a time it persists, then I cannot see how you can justify not resuscitating a patient or giving him antibiotics if he will continue to be alive in whatever state for even five minutes because you are then degrading that which you have said is intrinsically valuable in itself.

(*Professor Scarisbrick*) No, I do not think that the length of the person's life is material here, whether you can win another ten minutes or half an hour or a day, which is of course very uncertain whether you can because there is evidence on both sides that some opiates may shorten life and others simply by relieving the pain may extend the life.

252. But could we stick to the example of withholding antibiotics for a patient who might be, or there is a good chance he would be, saved from death even if only for two or three days. Let us take that example where the probability is he would live if he had antibiotics, but you have told us that you do not think it is wrong to withhold antibiotics in that case and I cannot quite understand why.

(*Professor Scarisbrick*) One is not discriminating against that person. One is not saying, "You are not

worth bothering with". Our main complaint against the euthanasia lobby is that it is purporting to discern certain human beings who have become inferior, disposable, sub-standard and, therefore, you do not bother with them any longer and you write them off. I think that that is incompatible with civilisation. We would say that a civilised society gives the utmost respect, and I am nervous of the word "absolute", the utmost respect to all human life, regardless of age, sex, condition, intelligence, et cetera, et cetera, and it is entirely compatible with showing the utmost respect for a human being who is dying not to go on reviving and pumping in antibiotics and so on, but to let that person die.

253. I think there are two senses of the word "life" being used here. One is that one respects the life of someone who is alive, whatever their colour, race and so on and so forth, but I thought you were arguing that one has to respect just the spark of life, so to speak, which is in somebody whether that person has any enjoyment or pleasure in life or not. I would have thought, and I still think, but I will not pursue the matter, that you do slightly switch the use of the word "life" when you talk about not making any discrimination about people of either a certain race or colour or what-not.

(*Professor Scarisbrick*) A human being is a human being is a human being, full stop.

254. But for how long?

(*Professor Scarisbrick*) Until such time as natural death overtakes that person. There is a point at which one may legitimately cease to strive to postpone that moment when you know that the battle is lost, that death is around the corner and that person has now every right to die quietly in his/her own time and way.

*Chairman*

255. Thank you very much for letting us have that point of view, but I think you can, however, see the moral problem which Baroness Warnock has put so carefully.

(*Mr Davies*) Well, with respect, I think Baroness Warnock is actually implying that we would wish to see officious means used on every occasion and that is not the case. Those of us who oppose euthanasia would not like to see patients who are in terminal conditions or who are in the process of dying being wired up to machines and kept artificially alive. That would in fact be equally repugnant.

256. With respect, I think Baroness Warnock was referring not to heroic intervention to prolong life, but she was referring to something that would be regarded in other sets of circumstances as being part of normal medical practice.

(*Mr Davies*) But in the terminal phase of some patients, it might be regarded as heroic and officious.

(*Professor Scarisbrick*) What is normal in one situation will become heroic and extraordinary later on in perhaps the same patient's condition or story.

257. With respect, the same argument could be applied to the provision of artificial food and nourishment in a non-sentient individual.



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[Continued

[Chairman *Contd*]

(Mr Davies) Well, I think food and fluid should never be regarded as medical treatment. It is the most fundamental of all human requirements and I do not think it should ever be deliberately denied to any patient.

258. You will be aware that in various jurisdictions across the world, not just in this country, such treatment has been accepted as being medical treatment.

(Mr Davies) With respect, that does not make it right.

Chairman] Right, thank you, you have expressed your view.

*Baroness Jay of Paddington*

259. May I just ask a very brief question which is not nearly so complicated as those just asked. I think you were in the room when we discussed with the Voluntary Euthanasia Society the basis for their 79 per cent pro their position in the opinion poll and the question they had asked. Obviously a great deal of what you have said reflects a very definite, basic moral view and I am wondering if you have any perception of how widely that is supported in this country.

(Professor Scarisbrick) They began by saying that they represent 14,000 people. Perhaps I might return the compliment by saying that Life has 30,000 members and we regard ourselves as quite a large organisation. I do believe that the Archbishop put his finger exactly on the point, that that was a highly ambiguous question and that the majority of doctors, I think, find the idea of themselves being turned into killers repugnant.

260. With respect, I am not really asking you to comment on the discussion we had before, but I was simply asking you whether you had any sense perhaps through opinion polls or whatever it may be of the strength of feeling in the country for the moral position which you present.

(Mr Davies) I think the opinion polls on occasion are misleading anyway because they are asking the wrong questions. They talk about death with dignity and are we not all in favour of death with dignity and are we not all in favour of death free from pain and death free from distress? However, that is different from saying, "We support procedures which are designed deliberately and intentionally to kill".

Chairman] Well, thank you. We are grateful to you.

### Supplementary Memorandum by LIFE

Following our appearance before the Select Committee on Medical Ethics on 18 May last, we would like to make the following additional submission.

#### 1. General remarks

(a) To rob someone of his/her dying days is to deprive that person of an important part of life. The dying person should be helped to be as aware and accepting of what is happening as is possible, so that the "last days are not lost days", and he/she is able to use precious last hours to settle affairs, to effect whatever reconciliation is due and, by ending in the most positive and happy way, to leave behind the most loving memories. Thus will the dying person and all around him be most helped.

(b) Behind every request for euthanasia is fear and poor self-image, and a need for self-affirmation. It is a doctor's duty to help allay fear, not to run away from it. Fear faced is fear diminished. For a doctor to accept a patient's low self-image is to reject, not to try to heal.

(c) We may all want doctors to be more responsive to patients and their relatives. But the pro-euthanasia lobby would do much more than improve doctors' "sensitivity". It would do even more than take away their clinical discretion and reduce them to technicians. It requires a role-reversal. It requires that doctors become direct and deliberate killers. It would turn doctors into despatchers.

#### 2. To Lady Warnock

Please may we reiterate what we said: It is entirely consistent with the utmost respect for human life to accept that a time may come when the struggle to preserve that life is so obviously futile and burdensome that it is permissible to discontinue treatment.

Indeed, it is entirely consistent with such respect to say that a time could come when that treatment ought to be discontinued—for the patient's sake, ie so that he/she can indeed die with dignity.

#### 3. To Lord Mustill

Please may we reiterate what we said: There is a fundamental moral difference (because a fundamental difference of intent) between withdrawing treatment (say, antibiotics) from a patient who is dying or is grievously and irreversibly stricken, and denying a patient food and drink. In the former situation the intention is to spare all concerned what has obviously become futile and "heroic" intrusion, and to admit



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defeat and the inevitability of death. The patient's death is foreseen but is not the purpose of withdrawing the antibiotics. When food and drink are denied to a patient death is not being allowed, it is being deliberately caused. Medical treatment is not being withheld (hunger and thirst are not diseases). The doctor's intention is to procure death, a death which is the direct and immediate result of a deliberate action.

### Memorandum by HOPE (Healthcare Opposed to Euthanasia)

#### INTRODUCTION

HOPE is a coalition of organisations and individuals involved in healthcare and united in opposition to euthanasia. We support the highest standards of healthcare and are convinced that there are always better solutions than euthanasia to the sensitive situations at the end of life. We recognise that these issues seem to be becoming more complex and we are grateful for the invitation to provide written and oral evidence to the House of Lords Select Committee.

#### PRELIMINARY CONSIDERATIONS

##### *Rights and Responsibilities in the Professional-Patient Relationship*

In the background to these discussions are the increased ability of medical technology to treat patients, and a change in attitude to the role of patients themselves in decisions about healthcare. These two major developments, which have taken place over the last 20–30 years, have affected both parties in the healthcare partnership, and we will briefly consider these effects in turn.

As professionals, we welcome the advances in medical treatment and nursing care which have taken place, but we do not feel we have the *right* or the *responsibility* to use every such advance, on every patient, in every situation, just because such facilities exist. We feel that it is the over-treatment of some patients (perhaps particularly in the USA) which has justifiably led to the concerns expressed by many. We reject meddlesome medicine and support healthcare which recognises that life has a natural end.

However, we do believe that as professionals we have the *right* to treat every patient in a way which accords with ethical standards. Further, we believe that we have a *responsibility*, or duty, so to treat them.

We also welcome the move over the last couple of decades away from paternalism in doctor-patient relationships and towards involving the patient as much as possible in the decision-making process. Some describe this as a move towards greater patient autonomy and the exercising of the patient's *rights*. However, patients too have *responsibilities* as they participate in decision-making. This will be discussed further in answers to specific issues, but we wish here to emphasise our conviction that we live in a society that is more than just a group of autonomous individuals. To go forward ethically in this whole area, society must rediscover that delicate balance of rights and responsibilities which is the hallmark of civilisation.

Our general position can perhaps best be summed up in the concept of healthcare as a partnership of expertise—*between the healthcare team who are experts in their own specialties, and the patient who is an expert in how he feels and what he would prefer.*

#### THE QUESTION OF "COMPASSION"

Apart from autonomy, the other key argument for euthanasia is "compassionate" killing. Is it ever necessary to kill the patient to kill the symptoms? Our commitment to good healthcare leads us to believe it is not, and we will argue below from the hospice experience that if the will is there, intentional killing in healthcare is never necessary on grounds of compassion.

Our comments in these two areas should give an indication of our perspective on the difficult issues before the Committee, and we will now respond in turn to the nine specific issues mentioned.

For the sake of brevity, we will not comment further on the Terms of Reference of the Committee, but our answers to the specific questions will touch in passing on points explicit or implicit in those Terms.

#### SUMMARY

*We believe that professionals and patients are in a partnership in healthcare, and that both parties have rights and responsibilities. We do not believe that intentional killing is ever necessary on the grounds of compassion.*

(1) "The respective weight to be attached to the sometimes conflicting moral principles of the sanctity of life and the right to personal autonomy"

(a) "Sanctity of Life"

As indicated in the Preliminary Considerations above, we have sought to encourage and obtain the highest possible standards of healthcare. Such an approach inevitably requires a high view of the unique



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value of every individual human life. However we also recognise that life has a natural end, and it is a responsibility of healthcare professionals to recognise when that natural end is drawing near.

Thus while we believe it is always morally wrong and always unnecessary intentionally to kill patients, we also believe that a time may come in any particular case when death is near and interventionist treatment need not be started or continued. The patient should be allowed to die naturally, although care will always continue to be given.

We do not believe that this is euthanasia, which we define as the intentional killing of a patient as part of his medical care, either by act or omission. This omission does not have the intention to kill, but rather to maximise the quality of life remaining to the patient. We will address this in more detail under (3) below.

(b) "Personal Autonomy"

We have also expressed our general position on autonomy under the Preliminary Considerations above. Some suggest that the "sanctity of life" concept is a religious one and the "autonomy" concept is a secular humanist one. We see this as an unnecessary distinction and an artificial polarisation. HOPE has members from a number of different religious faiths and none, and we would argue that it is possible in principle and in practice to balance a very high view of individual human life with a proper respect for personal autonomy, whatever one's own personal ideology.

We are relieved that the emphasis on *rights* in the first paragraph of the Committee's Terms of Reference is balanced by concepts of *responsibilities* and *restrictions* implicit in the final paragraph on "the likely effects of changes in law or medical practice on society as a whole".

(c) Further Considerations on Autonomy

(i) Autonomy is not Just About Choice, but About Choice that is Free, Fully-Informed, and Rational

We have argued extensively elsewhere<sup>(1), (2)</sup> that society could perhaps never be sure that a sick and frightened patient near the end of life was fully in a position to make such a choice. Could we be sure they were not:

*Depressed*—with a pathological sense of worthlessness? It would be argued that psychiatrists would be involved in the medical decision-making process, and that requests should be persistent and durable, but there is evidence from the Netherlands,<sup>(3), (4)</sup> where euthanasia is permitted, that insufficient attention is paid to this aspect.

*Confused*? Inadequately investigated or inadequately treated physical illness can lead to temporary confusion which could cloud judgment.

*Demented*? Diagnosis of early dementia can be difficult, and of course, euthanasia here would by definition not be voluntary.

*Suffering*?—It is difficult to make a free and rational choice when one feels awful, yet good healthcare has taught us that pain and other unpleasant symptoms can be eliminated or substantially relieved. Patients who achieve such relief almost invariably stop asking for euthanasia.

*Feeling a sense of burden*? Many elderly people feel they are a burden to family and to society. We would argue that proper provision must be made for good care so that this sense of burden is removed, as far as possible. We are concerned that if voluntary euthanasia were legalised, an *option to choose death* might become an *obligation to choose death*. We draw the Committee's attention to the fact that the mere existence of any permissive legislation would send a strong signal to the vulnerable. That signal would state that society had agreed that there was a category of people the quality of whose lives was deemed to be so low that they had lost the former absolute right to the protection of their lives.

*Under pressure from family and friends*? It might be possible to safeguard against pressure from motives of financial benefit, which we believe would be relatively rare anyway, but we are more concerned about pressures conscious or unconscious arising from the issue of burden addressed above.

*Under pressure from healthcare attendants*? There have been a few examples of disgraceful lapses from ethical standards, but these are rare and again we are more concerned about subtle signals of which the doctor or nurse might be unaware. If voluntary euthanasia continued to be prohibited by law, these particular signals would not be generated.

*Under pressure from a society short of resources*? As healthcare professionals we are only too aware of the need to operate within resource constraints, but we insist that resource considerations should never lead to the intentional killing of patients.

These eight examples illustrate ways in which the patient might not be able to make a free and fully-informed choice. Where choice is constrained in these ways, patient autonomy is not respected.



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## (ii) The Exercise of the Patient's Autonomy Affects the Autonomy of the Doctor

Unlike suicide, euthanasia is not a private act. It involves another. It could be argued that a "conscience clause" as seen in Clause 1 (5) of Lord Allen's Medical Treatment (Advance Directives) Bill would protect doctors with objections, but there is evidence<sup>(5)</sup> from the House of Commons Social Services Committee that such clauses may not be very effective. If euthanasia was practised we are concerned that specialties like geriatric medicine or palliative care, for example, might lose some otherwise first rate recruits. Those who did work in these fields could well be seen as the administrators of death, therefore increasing patient fear rather than reducing it.

We are also concerned about the effect on the character of the "healer" who becomes the "killer", however rarely and with whatever good intentions.

## (iii) What about Reasonable Requests?

Despite the eight objections recorded under (i) above, we accept that a very small percentage of requests for euthanasia might seem reasonable and genuinely reflect autonomy. Why should these patients not be allowed their wish and the law changed?

The answer lies in our mutual responsibilities in relationships in society. If the law is changed to allow X his reasonable "right" to be killed by a doctor, then society would have moved away from a black-and-white situation of absolute protection of all patients to a grey area of arbitrary decisions about "quality of life". There would be inherent injustice in these decisions<sup>(6)</sup> about quality of life.

Patient X's 1 in 100 request might seem reasonable, but for him to be allowed euthanasia the law would have to be changed and up to 99 cases of injustice might occur. We would therefore argue on the grounds of justice that X's responsibility to society means that he should give up his "right" to euthanasia.

We readily accept restrictions on our liberty in ordinary areas of everyday life because of respect for the good of the majority—we all agree, for example, to drive on one side of the road only, and society rightly has legal penalties for transgressors. In other words, we accept that rights are not absolute.

## (iv) The Slippery Slope Argument

Evidence from The Netherlands (see<sup>(4)</sup> and Section 9 below) makes it clear that where voluntary euthanasia is sanctioned, euthanasia which is not voluntary will follow. This is clearly not autonomy but paternalism of the worst possible kind.

These four main arguments mean for us that respect for autonomy is a powerful argument against voluntary euthanasia, and we trust that the Committee will give them full consideration in their deliberations on the second paragraph of their Terms of Reference.

## SUMMARY

*We accord human life very high value but recognise that it has a natural end, and so we have no duty to prolong dying. We respect autonomy and by four main arguments therefore reject voluntary euthanasia.*

## (2) "The extent of a doctor's duty of care to a patient"

We are surprised and concerned that this issue has been expressed here as "a doctor's duty of care". As a multidisciplinary organisation we recognise that healthcare nowadays usually involves many people. Whether in hospital or the community it involves doctors, nurses, specialised therapists, technicians, social workers, administrators, chaplains, clergy of different faiths—and, of course, family members and voluntary carers.

All these have a "duty of care". Whilst doctors unquestionably have such a duty, they also perhaps primarily have a responsibility for medical treatment. Currently there is considerable confusion between treatment and care, as the recent Tony Bland debate shows. We believe that this confusion must be clarified.

We do not believe the Courts needed to be approached about *medical treatment decisions* such as whether antibiotics could be withheld in the event of Tony Bland getting a chest infection,<sup>(7)</sup> but we endorse the nursing profession's view<sup>(8)</sup> that feeding (even by naso-gastric tube) is always part of the *basic care* of all patients except at the very end of life. This should have been given more consideration.

It should be clear from our Preliminary Considerations and (1) above that we believe there are limits to the doctor's duty to give medical treatments. We repeat that it would be morally wrong to prolong dying, but would argue that care always continues. This is vital to the maintenance and further development of the relationship of trust between patients and healthcare workers. We are concerned that unless the current confusion between treatment and care is clarified, there will be less encouragement for those professional and lay carers who do so much for patients.



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## SUMMARY

*Medical treatment and care are different. Medical treatments may become inappropriate; care always continues. We acknowledge and applaud the team approach to healthcare and believe the work of those who provide care for patients should not be undermined.*

**(3) "The distinction between the withholding or withdrawal of medical treatment, and deliberate intervention to end life"**

We have elaborated our definition of euthanasia as the intentional killing of a patient as part of his medical care, either by act or omission. We believe the concept of *intention* is crucial. We find the concepts and language of active and passive euthanasia unnecessary and unhelpful (and are grateful that the Committee has not used them), but believe that the idea of intention is very helpful both in principle and in practice. What did the doctor intend when he or she performed the act? What did he or she intend in omitting to act?

A deliberate intervention to end life is unnecessary, is wrong and is unlawful. We are convinced it should remain so. An omission would be wrong if its intention was solely to cause death and that is why we would not support Lord Alport's Bill Clause 2 (1a). An omission could be an example of good healthcare if its intentions were, for example, to respect the wishes of the patient and his family and to maximise the quality of life remaining. It is the intention that is critical ethically.

This concept also clarifies distinctions in the use of high doses of powerful painkillers. These high doses may be necessary to control pain, and may incidentally shorten life by depressing respiration. (In practice, hospice experience is that adequate pain control even with very high doses of such drugs usually prolongs life, and life which is of a good quality). Even if life were shortened by such drugs, that would not be the intention of giving them. The alternative, of not giving the drugs, would lead to unrelieved suffering which would not be acceptable.

There is obviously the danger that perhaps only the doctor knows what his or her true intention was, which opens the possibility of abuse. For this reason we would advocate such decisions (about drug doses or about the withholding or withdrawal of medical treatments) being taken after the widest discussion possible with the patient, the family, and all relevant members of the healthcare team. The decisions would also be taken according to accepted medical practice, formalised in Codes of Conduct if necessary.

We do not find helpful those academic debates which examine the philosophical questions implicit in this issue in a vacuum, using artificial examples. Such medical ethics decisions will always have to be implemented in a real world, and we do not pretend they are easy. We are convinced though that the concept of intention is very helpful here, and it is of course enshrined in our present law on homicide, as the judge in the Dr Cox trial made clear.

We repeat here that while medical treatments can legitimately be withheld or withdrawn, care always continues and this is the fundamental flaw with both Lord Allen's *Medical Treatment (Advance Directives) Bill*, and Lord Alport's *Termination of Medical Treatment Bill*.

## SUMMARY

*Deliberate interventions to end life are always unnecessary and always wrong. Intention is the critical concept in decisions concerning withholding or withdrawing medical treatment.*

**(4) "The different considerations arising in the case of patients who are legally competent and of sound mind, and of patients who are unable to express their own wishes about treatment"**

We accept that competent patients can refuse medical treatment and care, though the latter will continue to be offered. This is the position under common law and is in clear guidelines to healthcare professionals. Furthermore we understand that common law does not accept that patients have the right to require doctors to kill them.

Cases of patients who cannot express their own wishes are clearly difficult. Such patients by definition are in a particular category of the disadvantaged and require extra-special consideration. Because we totally reject intentional killing, we would always rule out acts or omissions whose main intention was to bring about death in either group.

Questions about withholding or withdrawing medical treatments should be taken broadly on the same basis as outlined in (3) above, though obviously with the added difficulty that discussion cannot be held with the patient. In other words, maximum possible discussion should be held, and the decision should be in line with accepted medical practice. There may be a limited role for advance Directives or proxy decision-makers—see (5) below.

We would make the point that if there is any doubt, the patient should be given the benefit of it, and



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that because such patients are particularly disadvantaged, they should be shown positive discrimination if necessary.

We take this opportunity to comment on the mention of "best interests" in the Committee's Terms of Reference. Whilst recognising that decisions have to be made on some basis, we are concerned about the dangers of abuse of such concepts.

We would consider that the following factors should be taken into account when attempting to assess the best interests.

- The views of the patient should be sought, and attempts at communication should be made.
- Where communication is difficult then the ascertainable past wishes and feeling of the patient should be considered.
- The views of doctors and other members of the healthcare team.
- The views expressed in an advance Directive or through a proxy decision maker, even though these should not be legally binding.
- There may be a need to consult an independent review body with members of the general public represented.

We note the recently published Law Commission Paper on the matter and are concerned that the section referring to this is given thorough consideration.<sup>(9)</sup>

#### SUMMARY

*There is no fundamental difference of principle in the approach to competent and incompetent patients, though the incompetent deserve special protection and the benefit of any doubt. Intentional killing should never be considered for either group, but treatment decisions are more difficult with the incompetent. We recommend caution with arguments based on "best interests".*

#### (5) "The role of advance Directives and proxy decision-makers"

##### (a) Advance Directives

We seek to involve our patients as much as possible in their own healthcare and therefore believe that advance Directives can be of some help in indicating a patient's wishes. However, we agree strongly with the British Medical Association<sup>(10)</sup> that they should never be given the additional status and force of legislation. Our reasons are as follows:

##### (i) Issues of Timing—When Should They be Implemented?

A clearly identifiable trigger-event would be needed—either the onset of incompetence, or the occurrence of a new event in the already incompetent. Could all those involved agree on this? Would incompetence have to be permanent or temporary? (Many medical conditions would be readily reversible.) If permanent, how is permanent to be defined?

##### (ii) Issues of Informed Consent—How Could People Precisely Foresee Future Situations?

No-one could foresee all future possibilities, nor how new medical treatments might change them in years to come. No-one could possibly document their views on all such eventualities. It is probably unlikely that people would update any documents sufficiently regularly.

##### (iii) Changed Minds

The healthy do not make their choices in the same way as the sick. An important review<sup>(11)</sup> of a recent paper from Canada states:

"The authors conclude that:

- an advance Directive prepared by a healthy person is not a valid indicator of the preferences of a similar person when sick;"

This is not necessarily an argument against advance Directives, but it is an argument against them having the force of law. Our experience is that people change their minds when they become unwell, but an earlier advance Directive might still be in force.

##### (iv) Difficulties of Diagnosis and Prognosis

We believe these difficulties (best summed up in the title of a British Medical Journal paper<sup>(12)</sup>: "'Patients with Terminal Cancer' who have neither Terminal Illness nor Cancer") are a powerful argument against euthanasia, and they are a powerful argument against advance Directives having the force of law.



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## (v) Little Difference in Practice

A recent review of initial experience in the USA, where advance Directives have been encouraged by force of law since December 1991, confirms that they make little difference in practice, and therefore just waste time:

"The authors conclude that the piece of paper itself does little, positive or negative: it will only be useful if it encourages doctors and patients to discuss the options more fully."<sup>(13)</sup>

## (vi) Breakdown in Communication

There are those who hold the view that in the long term advance Directives will result in a reduction in the communication between the doctor and the patient. Where communication with a patient may be difficult, then the healthcare team may choose to use the Directive rather than make the effort to communicate directly.

For these reasons we are opposed to advance Directives being legally binding, but in addition we are concerned that *the language used in them reinforces negative attitudes to illness and disability and feeds people's fears.*

Finally, we question the real reason behind Lord Allen's Bill, and its sponsorship by the Voluntary Euthanasia Society. The VES Advance Directive<sup>(14)</sup> states "that any distressing symptoms (including any caused by lack of food or fluid) are to be fully controlled by appropriate analgesic or other treatment, even though that treatment may shorten my life". Legal powers are being sought to dehydrate and starve people to death. If these powers are obtained, we believe it would soon be argued that this mode of dying was not "compassionate" and that a lethal injection should rather be given as soon as the decision was taken. Thus we are concerned that legalised advance Directives would sooner or later lead to euthanasia. This is the aim of the Voluntary Euthanasia Society as stated by one of their members in a letter to the New Scientist:

"Whether such advance Directives become legally binding on doctors may be decided by the new Bill proposed by an all-Party group headed by Lord Winstanley. Once acceptable guidelines and safeguards have been established for passive euthanasia, similar studies can be done to enable physician aid-in-dying or active euthanasia."<sup>(15)</sup>

We oppose advance Directives having the force of statute law.

## (b) Proxy Decision-Makers

We recognise that some strategy is needed for the special problems posed by the incompetent. In principle, we would see proxies as safer than pieces of paper completed years earlier, but there would have to be many safeguards in practice.

We note with interest the comments regarding this matter in the Law Commission Consultation Paper No. 129. We would here express concern that in the long-term the appointment of proxies may concentrate decisions regarding the welfare of a patient in the hands of one individual rather than as a matter for the multidisciplinary team.

## SUMMARY

*Advance Directives have some value as indicators of patients' wishes, but they should not have the force of law. We oppose Lord Allen's Bill. We are cautious of any changes that would place too much power in the hands of proxy decision makers.*

## (6) "The Role of the courts in interpreting the law in the light of changing medical technology and practice"

We perceive the role of the courts working within the following framework.

The issues of principle have to be settled by Parliament. Parliament's role is to provide the principles through legislation. At times, in the light of developments, legislation has to be reviewed and it is the role of the Medical Ethics Select Committee to review present legislation.

Once the legal framework has been established by Parliament then healthcare professionals work within that framework. Codes of Conduct or Codes of Practice are often devised by the various professional bodies in order to clarify the law for healthcare professionals.

Difficult cases may arise, however, where a decision regarding medical practice or nursing care may be challenged. Further clarification may be needed and therefore the need arises for the courts to interpret the law and consider what is the appropriate and legal course of action.

Whilst the courts are helpful in providing guidance we are concerned that their role is kept to a minimum.



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Otherwise medical practice in the UK could experience lengthy legal procedures that hinder medical practice in a number of other countries.

For the overwhelming majority of cases there is no need to seek the help of the courts. The legal safeguard that intentional killing by act or omission of a patient as part of his medical care is prohibited, provides an effective framework which enables the doctor in discussion with the healthcare team to act decisively.

#### SUMMARY

*We see the role of the courts as being to maintain a prohibition on intentional killing and occasionally where necessary, to issue judgments on difficult individual cases.*

#### (7) "The case for change in the existing law, and the nature and extent of such change"

Following from (6), we believe however that the recent series of verdicts on Tony Bland have at least the potential for removing the previous legal safeguard, and have thus confused the relationship between the law and medical practice in this area. We recognise that the verdicts were to apply to that one case only and to set no precedent, but are concerned that the law may have begun to accept the concept of intentional killing, albeit in a very difficult example of a thankfully rare clinical situation.

Statute law may therefore have to be involved further. If so, we would support legislation which clarified the distinction between treatment and care and ensured that care always continued until natural death. Such legislation would need to reaffirm the previous prohibition of intentional killing, whether by act or omission.

One example of helpful definitions which has come to our attention is that of Australian legislation<sup>(16)</sup> in which "palliative care" is defined as

*"(a) the provision of reasonable medical procedures for the relief of pain, suffering and discomfort; [and]*

*(b) the reasonable provision of food and water"*

and in which "medical treatment" is

*"(a) an operation: or*

*(b) the administration of a drug or other likely substance: or*

*(c) any other procedure—but does not include palliative care."*

However we would not want to see any other changes in law. We do not believe that there is any need for changes to be made to the existing law in relation to the charge of murder for the doctor or the healthcare professional who terminates the life of his patient. We believe that to introduce a lesser charge to try and take account of the motives, would be to encourage similar instances of medical misconduct with all the ensuing problems. We note that the House of Lords Select Committee on Murder and Life Imprisonment<sup>(17)</sup> rejected this proposal in 1989 and made no recommendation for a change in law on this point.

With regard to advance Directives there is likewise no need for any change in law. If they are granted the additional force of statute law and become legally binding on healthcare professionals then the problems discussed in 5 would follow.

#### SUMMARY

*We support the view of the Department of Health and the Home Office that there is no need for a change to the homicide laws. However we recognise reluctantly that legal guidelines may now be needed to clarify further the difference between medical treatment and care, ensuring that care could not be withdrawn.*

#### (8) "The role of the hospice movement and advances in the care of the terminally ill"

For the sake of brevity and in the expectation that our members and colleagues in the hospice movement will be making detailed submissions to the Committee, we will confine ourselves here to some general comments.

Under "Preliminary Considerations" we stated our conviction that compassion never required the killing of patients. We believe the hospice movement has demonstrated this clearly. In response to the over-simplified choice between legalised euthanasia or cancer patients dying in terrible agony, the hospice movement has by meticulous research and creative care been able dramatically to improve the quality of life of the dying. Pain and other unpleasant symptoms are now controlled in all but a very small percentage of their patients, so that it is not necessary to consider euthanasia. In the words of Dame Cicely Saunders:<sup>(18)</sup> *"You matter because you are you, and we will enable you not only to die with dignity, but to live until you die."*

The United Kingdom has led the world in pioneering the hospice concept and palliative care and there



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are now almost 200 centres. It is no coincidence that in the Netherlands, where euthanasia is sanctioned, there is very little in the way of a hospice movement. We believe that if euthanasia were to be legalised in the United Kingdom there would be little incentive to be creative in caring when we can no longer cure.

So successful has the hospice movement been that the drive for euthanasia now persists from those who are ignorant of the scientific basis of symptom control which allows "death with dignity". Whilst fully recognising that some diseases produce very distressing symptoms which can in a small number of patients be hard to control, we would argue that dignity "is in the eye of the beholder" and is reflected in the way in which the healthy view the sick and care for them. A person's perception of dignity is the way they are viewed by those around them and creative approaches to care will allow patients to maintain dignity. It is these creative approaches to care that society should encourage.

We do not pretend that all is well. We recognise that some patients at home or in hospital are still (unnecessarily) having "bad deaths". We want "good deaths" for them and argue that "bad deaths" represent bad healthcare. The answer to bad healthcare is not killing patients but is good healthcare and society should fund this adequately. There is widespread support for the movement in Parliament with two recent Early Day Motions obtaining support of over 150 MPs.<sup>(19)</sup>

The success of the hospice movement in terminal illness gives us confidence that the healthcare professions could achieve similar successes in problem areas like AIDS, or dementia. There are already some exciting initiatives, and we believe they deserve every encouragement. Pro-euthanasia legislation would discourage those very developments which would make our society even more civilised.

#### SUMMARY

*The hospice movement has demonstrated by compassionate care that euthanasia is unnecessary and hospice care should be given every encouragement. Similar initiatives need to be developed in other areas. Pro-euthanasia legislation would discourage this.*

#### (9) "The experience of other countries, in particular in Western Europe and the USA."

##### (a) *Western Europe*

The Netherlands is notorious for its sanctioning of euthanasia. As revealed<sup>(20)</sup> in 1991, 1.8 per cent of the nearly 130,000 deaths in 1990 were due to "euthanasia", 0.3 per cent to "assisted suicide", and 0.8 per cent to "life-terminating acts without explicit and persistent request".

We believe that 2,300 cases of what may have been "voluntary" euthanasia are a grave indictment of a misguided profession, but 1,030 cases of euthanasia which are not claimed by the Dutch themselves to be voluntary are far worse. In these official statistics is unequivocally demonstrated the reality of the "slippery slope"—that where voluntary euthanasia is tolerated, euthanasia that is not voluntary will inevitably follow. We believe this evidence alone should stop the United Kingdom legalising euthanasia.

Further evidence of euthanasia which is not voluntary occurs with the newborn. Professor Versluys admits<sup>(21)</sup> that "about 10" babies are killed every year by acts of commission. This year *The Independent* reported<sup>(22)</sup> that:

"a male child born with deformed genitalia is put to death because the doctors and his parents concur that he will have a poor quality of life."

Those who advocate euthanasia make much of strict safeguards and guidelines. There is ample evidence<sup>(4)</sup> that the Dutch guidelines are not followed. For example, one criterion is notification after death to the appropriate authority so that compliance with the guidelines can be confirmed. However, of the 3,300 officially recognised euthanasia deaths in 1990, only 454 were reported.<sup>(4)</sup>

We believe there is substantial evidence here to justify our conviction that euthanasia should never be permitted because it cannot be policed. One of the main reasons for this is that the key witness is dead. We recommend the Committee assess the Dutch situation very carefully and could provide expert witnesses later if required.

##### (b) *The USA*

Experience here varies because of the different policies of the different States on, for example, assisting suicide. We have already commented on the different medical culture in the USA and the possible tendency to over-treat patients, and also mentioned their early experience that advance Directives are unhelpful.

We would further draw the Committee's attention to the outcome of referenda in two States. In November 1991 the voters of Washington State rejected euthanasia by 54–46 per cent, and in November 1992 California similarly rejected it, coincidentally by the same margin.

Michigan has temporarily banned assisting suicide<sup>(23)</sup> because of the practice of Dr Kevorkian with his "suicide machine", which has been condemned by most commentators, and is reviewing its State law.



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We are glad that from its fine traditions of healthcare and medical ethics the United Kingdom is reviewing through the Committee all these matters, and trust that the right lessons will be learned from overseas.

## SUMMARY

*We deplore the situation in the Netherlands, which confirms the truth of "slippery slope" arguments against euthanasia. We share the increasing concern about recent developments regarding assisted suicide in the USA.*

## SUMMARY OF SUMMARIES

We believe that professionals and patients are in a partnership in healthcare, and that both parties have rights and responsibilities. We do not believe that intentional killing is ever necessary on the grounds of compassion.

We accord human life very high value but recognise that it has a natural end, and so we have no duty to prolong dying. We respect autonomy and by four main arguments therefore reject voluntary euthanasia.

Medical treatment and care are different. Medical treatments may become inappropriate; care always continues. We acknowledge and applaud the team approach to healthcare and believe the work of those who provide care for patients should not be undermined.

Deliberate interventions to end life are always unnecessary and always wrong. Intention is the critical concept in decisions concerning withholding or withdrawing medical treatment.

There is no fundamental difference of principle in the approach to competent and incompetent patients, though the incompetent deserve special protection and the benefit of the doubt. Intentional killing should never be considered for either group, but treatment decisions are more difficult with the incompetent. We recommend caution with arguments based on "best interests".

Advance Directives have some value as indicators of patients' wishes, but they should not have the force of law. We oppose Lord Allen's Bill. We are cautious of any changes that would place too much power in the hands of proxy decision makers.

We see the role of the courts as being to maintain a prohibition on intentional killing and occasionally where necessary, to issue judgments on difficult individual cases.

We support the view of the Department of Health and the Home Office that there is no need for a change to the homicide laws. However we recognise reluctantly that legal guidelines may now be needed to clarify further the difference between medical treatment and care, ensuring that care could not be withdrawn.

The hospice movement has demonstrated by compassionate care that euthanasia is unnecessary and hospice care should be given every encouragement. Similar initiatives need to be developed in other areas. Pro-euthanasia legislation would discourage this.

We deplore the situation in the Netherlands, which confirms the truth of the "slippery slope" arguments against euthanasia. We share the increasing concern about recent developments regarding suicide in the USA.

May 1993

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[Continued

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#### Examination of witnesses

Dr ANDREW FERGUSSON, Chairman, HOPE, Dr ROBERT TWYXCROSS, MacMillan Clinical Reader in Palliative Medicine, University of Oxford, Patron of HOPE, and Ms PRUE CLENCH, Director, Thames Valley Hospice, called in and examined.

#### Chairman

261. We have read all that you have put before us and have studied it carefully. Of course you have heard much of the discussion which has gone on earlier this afternoon, so I do not think we need necessarily to cover all of the items you have raised in your document which I think was very full and complete. Are there any items in the light of what we have been discussing which you would wish to highlight for us this afternoon?

(Dr Fergusson) Just very briefly, I think we would like to draw attention to the perspective from which we come, which is that Healthcare Opposed to Euthanasia is a forum for doctors and nurses and other healthcare professionals which has arisen over the last couple of years because of concerns such as the Committee is looking at, and we, therefore, represent healthcare professionals who have much active experience in these areas recently. That is the perspective from which we would like our written and our oral comments to be considered.

262. Dr Twycross, Ms Clench, is there anything you would wish to add?

(Dr Twycross) No, I am happy to wait for the questions.

(Ms Clench) I would like to comment that in fact the point of view of nurses has not been raised in the evidence heard so far today. I think that is a very valid point, that we are talking a great deal about medical decisions and about the patient's perspective, but the people who are actually face-to-face 24 hours, seven days a week, are often the nurses and it does have very strong ethical implications for

nurses in the perspective of their role, that there are times when maybe the patient is not conscious of what these moral differences might be, but it makes a great deal of difference to the nurse as to whether they are caring for the patient or taking an active step towards shortening a patient's life, and I think it would have very great implications for the nursing profession.

263. We have heard evidence from the Royal College of Nursing and we have taken written evidence also from the UKCC, so I can assure you that in all our deliberations we are taking account of the health care team as a whole. Despite the enormous advances in the field of palliative care are there still some patients whose pain and distress cannot be fully relieved? What is the proper course of action in such a case?

(Dr Twycross) The baseline is the doctor's responsibility. The doctor has two responsibilities—the responsibility to preserve life and to relieve suffering—and you have this tension between those two responsibilities. Quite clearly, as a patient moves towards his death, his natural death, then preserving life becomes increasingly meaningless and relief of suffering becomes increasingly important. I think we have to look at the evidence from the hospices and elsewhere. I think St Christopher's have collected the largest body of data and they would say that pain which remains difficult to control is less than 1 per cent and that comes from many thousands of patients over 25 years. So given appropriate medical treatment, we are talking about a very small minority, and the reason for this persistent difficult control may be as much psychological as physical; but



[Chairman *Contd*]

because of our dual responsibilities including relieving suffering, in these very rare, extreme situations we would, if necessary, offer the patients sedation so that they slept until their natural death ensued.

264. So that effectively, other than what you heard about earlier—giving increasingly large doses of analgesics which might have the effect of hastening the patient's death—you would also be prepared, should the need arise, to give heavy doses of sedation to grant them what in literal terms is not active euthanasia but is a gentle, easy death—the literal translation?

(*Dr Twycross*) Good symptom control, I would suggest. In fact, we have got hooked on pain. I think the situation where we have to offer and administer heavy sedation is rarely due to unrelieved pain. It is due to severe mental distress. Again that is not physical pain, it is mental distress, and in these resistant situations where you cannot, with all the best support and help in the world, achieve a peace of mind, then it is in these circumstances, not unrelieved pain, that we would find ourselves having to offer increasing sedation. So the concept of ever-increasing doses of morphine or heroin is foreign to my everyday practice, but occasionally, yes, offering sedation, sedatives, is something I have to face up to repeatedly.

(*Dr Fergusson*) This is a tiny percentage of cases really. The drive for euthanasia is coming from symptoms of distress and perceived indignity, and we recognise that and we hope that we are operating in the real world. Our concern is that we get those perceptions right, because one of the reasons that we do not want to see voluntary euthanasia legalised is that we believe it would take away any incentive for us to be creative in caring when we can no longer cure. We want to see the lessons of the hospice movement in pain and in the other symptoms applied in other, more difficult areas—AIDS, dementia, the elderly and so on—and we are concerned about the perceptions that patients have, the very real fears that patients have, and the effect that any permissive legislation would have on the moral climate of the nation.

(*Dr Twycross*) Could I add that I do work satisfactorily within the present constraints of the law, these dual responsibilities of preserving life and relieving suffering. I have sufficient freedom under the law at the moment and Dr Cox last year, in my opinion, did not have to kill his patient deliberately to ease suffering. He could have done it within the constraints of the law. I could have done it within the constraints of the law and I think this is a very important point.

Chairman] We take the point, thank you.

Baroness Warnock] I was very much cheered to hear you talking about things other than pain, and other kinds of distress. I wanted to raise a hypothetical question. Supposing there was somebody who was terminally ill but was not going to die terribly quickly and you could provide either analgesics or even sedation, and supposing that patient persistently said, and had said all her life, that what she did

not want to do was to be very expensive, to be a charge not necessarily on her family but on the regional health authority. This seems to me actually to be a very rational thing to do and increasingly likely as the average age of society gets higher. How would you deal with that? Would you insist on sedating that patient?

Chairman

265. Before you answer Baroness Warnock, I was going to ask a very similar question which follows on from what she says. It relates to individual autonomy. What would be your view about a patient who positively refused, and was competent to do so, any form of treatment, whether designed to relieve distress or whatever?

(*Ms Clench*) In the first place, I commonly meet patients who might express the view that you have put, particularly if they are elderly. I think the danger is of what we hear by that question because it almost always expresses, "How much value am I to society?" It is about the reassurance of saying that even when you can contribute nothing, in their view, you actually have a value in society, and quite small things like coming up to our day care centre, being part of a group and finding that they have a value to other people makes that question not asked later on. I would be very afraid of taking the question at face value. In fact, in all questions of terminal illness one of the things we are specially taught about and has made such a difference is to hear what people are actually saying and not to take them at the value of the words that are expressed.

Baroness Warnock

266. That terrifies me but thank you for your answer.

(*Dr Twycross*) May we come to your question. The patient who refuses any sort of treatment, either for comfort or whatever, this does happen from time to time. Some people have deep-seated fears or deep-seated beliefs which make them say, "I must tough it out. I must suffer it without the benefit of morphine," and so on. We are talking about partnership, partnership between the health care professionals and the patient, and I think this has been one of the big rallying cries of the hospice movement. Maybe everyone talks about partnership now but 25 years ago it was quite unusual to emphasise partnership, partnership, partnership, and I would accept a patient on these terms. I might say, "Look, I find it difficult because, after all, we have these natural remedies like morphine, but if that is how you feel you want to play it, then I am happy to support you. We are happy to support you through this difficult time."

(*Dr Fergusson*) Could I pick up very briefly on that word "partnership" because I think it is really the heart of what we would want to suggest. I qualified in medicine at the end of the era of paternalism, "doctor knows best" and "doctor's orders", and I welcome the move towards the greater involvement of patients in decisions about their care, very much so. It is a balanced partnership where both sides are recognising that they have rights and that they have



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[Baroness Warnock *Contd*]

responsibilities. That balanced partnership needs good communication and it needs a clear dialogue and that means that we need as much freedom as possible, and I would endorse what Dr Twycross said earlier that the present law, provided it is not altered, gives us that freedom, with that one ultimate safeguard that we should not intentionally take life, and there is room for communication and dialogue to work out many of these issues.

*Archbishop of York*

267. Can I take you up on this question of intention which you spell out in your memorandum and you will have heard the exchange earlier in the afternoon with the Voluntary Euthanasia Society. If one is going to locate a crucial moral difference in the intention of the healthcare team, how do you counter the charge that really the healthcare professionals are looking after their own moral integrity and not actually fulfilling the wishes of those patients who are asking for a different kind of exit?

(*Dr Fergusson*) There are two questions there, I think. The first issue, why do we attach such importance to intention? It is not just us, but it is the law of the land, that certainly where acts of commission are concerned intention is critical, and Mr Justice Ognall made that clear in his opening remarks to the jury in the *Cox* case and when he began his summing up and he concluded accordingly. The difficulty lies in the issue of law and intention when we are looking at omissions, and Lord Mustill in his opinion on the *Bland* case a number of times used the expression "the intellectually and morally dubious distinction between acts and omissions". We find intention a very helpful concept both in principle and in practice. It is the question we ask ourselves when we are trying to be honest with ourselves and we think it works in principle and in practice, and I think it may shed some light on this very difficult area of an excessive weighting in our law in the past on this issue of omissions being morally different. In that sense we have some sympathy with the Voluntary Euthanasia Society who say there, "Well, hang on, there is a bit of fudging in the middle ground". I think there is a sense in which I have some sympathy with that. Forgive me, I am now trying to answer the second part of your question.

(*Dr Twycross*) Could I just come in on this intention business because it is important to me as a practitioner. If I give you an aspirin, you may die, and if I give you penicillin, you may die, but it is not my intention, so what I am saying is that in all medical treatment there is a risk, and I know this may have gone off the point from where you started, but I think it is relevant, all medical treatment carries a risk and it is axiomatic that I as a doctor must minimise that risk as much as possible. For me, by the bedside, intention is very important. Whatever it is to the philosopher or the moralist, intention to me is very important in my everyday practice.

(*Dr Fergusson*) That reminds me of the second part of your question which is: is this not dangerous and how do we actually know what really was the doctor's intention and is this not just another opportunity for fudging the issues?

268. It was not quite that.

(*Dr Fergusson*) Well, perhaps I could just deal with that very briefly, if I might, and that would simply be to say that we believe such decisions should be made after the widest possible consultation with the patient, family, everybody in the healthcare team and according to accepted medical practice, but I am sorry if that does not quite answer your question.

269. If I put it more generally, we have heard quite a lot of evidence from various members of healthcare teams over the weeks and one of the strongest ethical points that has come through is that the integrity of the doctor and the healthcare team is really at stake here and we cannot change our image of ourselves. I think what the Voluntary Euthanasia Society were saying was that it is time you started changing your image of yourself because people are asking something of you which it is reasonable to ask and I wondered how you would answer that particular question.

(*Ms Clench*) I understand the question and I think it is quite justified. I think it is because of the fact that we say the healthcare professionals' perspective is based on a team approach in which the team includes the patient, so in a normal situation we would expect the patient to be the very key person in that discussion. When we actually come to a situation in which the patient cannot participate in that discussion, then I think we are saying that the integrity of the healthcare professionals is all we have actually got to be able to use and it, therefore, is very important to safeguard that integrity for society as a whole. When we have got a key witness missing, we have to make do with what we have got.

*Baroness Warnock*

270. But this is going back to the question I asked you when you gave me such a frightening answer, because it seems to me that there comes a stage when the wretched patient may believe absolutely sincerely in her own integrity and her own responses and her own wishes and you, in the hypothetical case we invented, were saying that she does not really mean that and, therefore, the integrity of the healthcare team must prevail and this is what frightens me.

(*Dr Fergusson*) She might not mean it.

271. I know she might not mean it, but she might.

(*Dr Twycross*) Usually she does not and this is the crux because if you are going to change the law to facilitate the wishes of a small minority, you are going to jeopardise the autonomy and integrity of a much greater number. This is what the hospice experience is.

Chairman] But supposing the patient persisted in her view.

Baroness Warnock] Yes, and made an advance directive.

*Chairman*

272. Would you then be prepared to override that advance directive?



[Chairman *Contd*]

(*Ms Clench*) I think just to go back to the way that you asked that, I think we were talking about a patient who said that initially and I was saying that I would want to look at what they really meant by that question, so I do not mean a once-only, but it means getting to know and building a relationship with that patient and trying to discern. If they persistently put their point of view, as Dr Twycross was saying, that has to be respected and acknowledged.

Baroness Warnock] That is useful, but it does raise the question of the advance directive because it may well be that you and I fear that when it comes to the point I shall not be *compos* and shall not be strong or intelligent enough to know what I want, but I do know now.

*Baroness Jay of Paddington*

273. And also you are arguing against the position and you are treating everybody in this process as equal members of a team and then you are saying that the patient's views and integrity are to be equally represented as the medical team's and the doctor does not know best, so you have moved on.

(*Dr Fergusson*) The stopping point for us would be: what is the patient asking us to do, and we would not accept being asked to do something which we would see as immoral and which certainly currently is unlawful, ie, to kill the patient. That would be the stopping point.

*Baroness Warnock*

274. But this would be precisely the argument the patient might use for wishing, whilst still *compos*, that the law might be changed.

(*Dr Twycross*) Can I come in here? Lord Walton, you said this was about the advance directives and I had not realised that earlier on.

*Chairman*

275. In part.

(*Dr Twycross*) I think, Lady Warnock, you started off by talking about a *compos mentis* patient and we have moved away from that. Can I talk about the advance directive as a result of the introduction of the topic? We have quoted one study in Canada in our submission which says quite clearly that if you bind yourself literally to what the advance directive says, you will not be respecting patient autonomy because people change their minds. Now, there is another study where they gave an advance directive to so many patients who were on renal dialysis and said, "If you had a stroke and this, that and the other, would you want the doctor to adhere to the words of this advance directive?" Now, roughly speaking, in round figures, 40 per cent said, "No, we would want the physician to have absolute discretion whether he follows the wording of the advance directive or not", and 20 per cent said, "We would like him to have some leeway", and it was only 40 per cent, the minority, who said, "Yes, he must obey the letter of the advance directive". The point is that if you have a mandatory or legally-binding advance directive, you are in fact going against the wishes of

60 per cent of the patients who want the doctor to continue to have flexibility of interpretation.

276. We appreciate that particular point of view because there have been a large number of organisations who favour advance directives, but who have made it clear in their view that they should not be legally binding but should give a very positive pointer in the direction of what action to take (or withhold).

(*Dr Fergusson*) That would be our view. May I just add very briefly that if there is still a question about this issue of autonomy, our written submission develops arguments, using the language of autonomy, about why we feel that very small number of reasonable requests must be denied in public policy interests.

*Lord Mishcon*

277. Did you find the judgment and the reasoning behind the judgment of the House of Lords in the *Bland* case acceptable, and have you any views about the procedure which ought to be adopted in similar cases, by way of application to the courts or otherwise?

(*Dr Fergusson*) I think *Bland* was an extreme example of a thankfully rare unpleasant clinical situation and hard cases make bad law. We do have concerns about some of the other concepts which we may take on board as a result of opinions given during that. The confusion between medical treatment and basic care has cropped up already today and previously. We are concerned that the idea that in some sense Tony Bland was dead already may be accepted without rigorous discussion. We remain concerned about the intention and we realise that this is a point that will take a lot of arguing to try and dialogue about. On the issue of tube feeding we recognise that there are arguments for and against, whether it is part of basic care or it is a medical treatment, and we would agree that it is a difficult case there. So we are certainly all of us left with concerns about the *Bland* case.

(*Dr Twycross*) But we do recognise that that is an extreme example of a very difficult situation and, as has been said, difficult cases make bad law. The point I would like to make is that, reading an article by Tony Bland's physician in the January *BMA News Review*, it is clear from that that Tony Bland was not only being given food and fluid, he was also being given antibiotics when he had an infection, and if he had been in a hospice, because he was quite clearly in a situation where he could not recover his faculties, we would have said this is the sort of situation where, biologically speaking, we should give inevitable death its chance and we would not have used antibiotics. I think if Tony Bland had been in a hospice he would probably have died 12 or 18 months ago and it would never have come to the Law Lords. If I understand the article in the *BMA News Review*, he was definitely being given antibiotics as well as food.

*Baroness Flather*

278. I have a very brief point. You gave us some figures about these patients that you asked about



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[Baroness Flather *Contd*]

whether they would want to make an advance directive which would be binding and you said 40 per cent said they would. You said 60 per cent said no, but 40 per cent said that they would leave it entirely—

(*Dr Twycross*) That is right. They wanted the physician to have absolute discretion about how they interpreted the answer, said some leeway.

279. Twenty per cent said some discretion along with their own wishes?

(*Dr Twycross*) Yes, and 40 per cent said literal interpretation, must stick to the letter of the advance directive.

280. And you think that that is an argument against advance directives?

(*Dr Twycross*) No, I agree with you.

281. That is the only point. You told us 60 per cent did not but what about the 40 per cent who did, because there is a major argument there?

(*Dr Twycross*) What I am saying is, if you make advance directives legally binding, yet in this sample of people 60 per cent said, "We want the physician to have flexibility—"

282. Twenty per cent have to be disregarded even in your equation because there was a partnership issue with the 20 per cent in the middle?

(*Dr Twycross*) With all due respect, I do not think we can ignore the 20 per cent.

283. Twenty per cent are saying with some discretion?

(*Dr Twycross*) Some discretion, yes.<sup>1</sup>

*Chairman*

284. I am afraid we must end. If you have any views about alternative mechanisms for dealing with a situation like the *Bland* case—for example, the BMA have suggested some kind of local committee rather than a reference to the High Court, and you have no doubt also seen the Law Commission's consultative document, which makes certain suggestions about the way things may be handled in the case of the incompetent patient. If you have any views about this and other issues we have not covered fully in our discussion, would you please write in and let us have supplementary evidence because this will be very carefully considered by the Committee?

(*Dr Twycross*) We shall indeed, if we may.

*Chairman*] Thank you very much indeed.

<sup>1</sup>*Note by the witness:* The study referred to is "How strictly do dialysis patients want their advance directives followed?" by Sehgal *et al*, in *JAMA* Vol. 267 No.1.

You will see from the Results section in the Summary that, for the sake of clarity, I simplified the results of the study—though in what I believe is a mathematically/statistically correct way. Thus, I merged 'a lot of leeway' with 'complete leeway'.

The fact remains that just under 40 per cent only said 'no leeway'. This is what I would expect as a physician. This study comes to the same broad conclusion as the one referred to in the HOPE submission.



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[Continued

**Supplementary Memorandum by Dr Robert Twycross**

I am taking advantage of Lord Walton's closing remark that he would be happy for Members of the HOPE delegation to submit supplementary written evidence.

This memorandum stems from an exchange between Lord Mustill and the LIFE delegation who gave evidence immediately before HOPE.

Lord Mustill asked, if I remember correctly, the LIFE delegation what was the difference between the apparent obligation to give antibiotics to a younger person with (say) pneumonia and the apparent liberty *not* to give antibiotics to a person with a terminal condition.

I hope the chapter written by myself and Dr Ivan Lichter from the recently published "Oxford Textbook of Palliative Medicine" might offer a simple and clear account of the difference.

At the heart of the matter is the self-evident truth that eventually all human beings have to die. As this is a rigid biological fact, physicians practise medicine against the background of this invariable "law of life". Thus, eventually, it becomes biologically futile/impossible/too burdensome to sustain life in the face of approaching death.

In practice, therefore, if supportive/resuscitative measures at the end of a person's life can best be described as prolonging the process or distress of dying then, from a biological point of view, they are deemed inappropriate.

To give biologically inappropriate treatment is, in my opinion, bad medical practice.

It is possibly because non-clinicians do not always remember that the doctor works against a background of a moving set of biological goal posts that the actions of a doctor at the end of life may seem arbitrary or indeed unethical.

In practice, given that there are a variety of "biological models", it is necessary to invoke the concept of "appropriate treatment". This means treatment appropriate to the patient's biological condition and biological prospects (prognosis).

21 May 1993



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27 May 1993

*Deputy's Memorandum by Dr Robert Taylor*

I am sure, whatever of Lord Wolff's closing remarks, that he would be happy for members of the HSE's delegation to submit supplementary written evidence.

The memorandum stems from an exchange between Lord Munn and the HSE delegation who were invited to participate before HSE.

Lord Munn asked if I could refer succinctly, the HSE delegation what was the difference between the present diagnosis of gonorrhoea to a simple period with (any) pathogens and the current theory as to its causation as a period with a terminal condition.

Lord Munn's query is correct and Dr van Lint's letter from the HSE delegation indeed "concludes that it is probable that there might be a simple and clear picture of the difference".

As the result of the current, the self-evident fact is that generally all tissues become infected. The HSE delegation would also provide feedback against the background of the current, the theory, is to view biologically pathogenic. Many mechanisms to prevent the in the form of appropriate death.

In terms of control of immunological response in the end of a period with the fact is that the HSE delegation is providing the process of disease of being that, after a biological point, the HSE delegation would provide.

To give biologically appropriate treatment, in any system, the medical practice.

It is possible for most of the HSE delegation do not always remember that the HSE delegation would provide a working set of biological and points that the HSE delegation do not of the HSE delegation would provide a working set of biological.

In practice, given that there are a variety of "biological models", it is necessary to consider the concept of "appropriate treatment". This means that of appropriate to the patient's biological and appropriate biological aspects (programs).

27 May 1993

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