

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

Contributors

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MINUTES OF EVIDENCE
TAKEN BEFORE THE
SELECT COMMITTEE ON
MEDICAL ETHICS

Tuesday 15 June 1993

SIR ROBERT KILPATRICK

UNITED KINGDOM CENTRAL COUNCIL FOR NURSING, MIDWIFERY
AND HEALTH VISITING

Professor G Castledine, Professor S McLean and Mr R Pyne

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HOUSE OF LORDS
COMMITTEE OF MEDICINE
SELECT COMMITTEE ON
MEDICAL ETHICS

Twelfth Session 1992-1993

SIR ROBERT KILPATRICK

UNITED KINGDOM CENTRAL COUNCIL FOR NURSING AND MIDWIFERY
AND HEALTH VISITING
The Council is a body established by the Nursing and Midwifery Order 1991.

(Witnessed on 20 January 1993)

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TUESDAY 15 JUNE 1993

Present:

Colwyn, L.	McFarlane of Llandaff, B.
Flather, B.	Meston, L.
Hampton, L.	Mishcon, L.
Jay of Paddington, B.	Walton of Detchant, L. (Chairman)
Llewelyn-Davies of Hastoe, B.	York, Abp.
McColl of Dulwich, L.	

Examination of witness

Sir ROBERT KILPATRICK, President of the General Medical Council, called in and examined.

Chairman

353. Thank you very much for agreeing to come and talk to us. We do of course know that you are here in a personal capacity and not officially speaking on behalf of the General Medical Council, though we would of course hope that any experience that you may have gleaned during your term of office, may be helpful in some of the comments that you make, just as we hope that your experience as a clinical pharmacologist will no doubt also illumine some of the remarks you would like to make. I understand you would like to begin by making an opening statement, which we would be interested to hear.

(*Sir Robert Kilpatrick*) Thank you very much, my Lord Chairman. It is very good of you to ask me to come, particularly because I cannot come as a spokesman of the Council, which has never debated this particular topic. It has debated, through its Standards Committee, advance directives some two years ago, but I do know and I am sure of this, that it has not debated euthanasia in the usual sense in which I think you are considering it here. I should introduce Miss O'Brien, whom I have brought from the Council, because she is really my ethical minder and will jump on me if I say something that I really should not. I suspect that you ask me, not just because I am President of the Council (though I cannot speak for the Council at this juncture) but because I chaired the conduct panel hearing for Dr Cox? I think that we have sent you a transcript of that—

354. We all have it, thank you.

A. —and the judgment which of course is at the end of it. I have read a good deal of evidence that has already been given to you, from the BMA, Conference of Colleges etcetera and I thought it would be useful if I could just very shortly, very briefly give you my viewpoint and the viewpoint is that of an individual who has had 40 years of medical practice, as a physician and as a physician doing acute general medicine and chronic general medicine over the whole of that period. I think that my experience and the view I hold, are shared by a very large number of practising doctors, particularly those that are fairly closely related to me in age. I think it is

slightly different for the younger doctors. I could amplify that if need be. As I see the problem that you have in front of you, it is not just about the Concise Oxford English Dictionary definition of euthanasia, which is "a gentle and easy death", it is about the actions of doctors that may expedite an individual's death. That may be by acts of *omission*, which I understand and am advised is in fact lawful, and acts of *commission*, whereby something is given to the patient, something is done, which kills him and that is unlawful, and that is very well, I think, expressed in the summary of the Cox case. In summary, I am an individual who has certainly used the former method of *omission* frequently, but I have never used the second and would not wish to do so. I would like to try to explain why that is so, because I know you have had a good deal of discussion in terms of the ethical and moral background to that. My background I think is—as with so many practising doctors—that we learn in medical practice and what we learn is (particularly for individuals of my age who came into medicine just before the enormous advances in medical treatment that there have been) the natural history of disease and how and when we should intervene in the natural history of disease. The natural history of disease often ends in death. It is on that basis that I have no problem at all with omission, because it is within the natural history of disease. I will do everything I can to alleviate suffering, but I will not actively use the second method. In other words, I will allow natural history of disease to take its course. I have some difficulty over whether that can be fitted into any ethical moral analysis, but in my view it is central to the form of medical practice that we have in this country, which is related to the trust that there is between a patient and a doctor and I think that the second method will inevitably affect that in a major way. Because of that, my definition and there have been many attempts at definitions of euthanasia, would be—and I have it written down here my Lord, because I thought I should do so—"Euthanasia is an active intervention intended to cause the death of the patient, or to enable the patient to destroy him or herself. It would exclude cases where treatment is withdrawn or withheld, or where a substance is given which has therapeutic or palliative value in the care of the

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Sir ROBERT KILPATRICK

[Continued]

[Chairman *Contd*]

patient, where the intention is to relieve suffering or distress, but the treatment has the incidental effect of shortening the patient's life." That is as much as I want to say, but it may help in relationship to these questions that you sent to me and may expedite my dealing with them.

355. Well, you have answered, through that statement, a number of our questions and indeed some of these came out very clearly in the deliberations that were set out in the transcript of the Cox case. So just to clarify your position, you say that you are opposed personally to any action which has the sole effect of ending a patient's life, but that if treatment is given to relieve stress and suffering which has the incidental effect of hastening death, you regard that as being lawful and proper in medical practice.

A. Certainly.

356. The second point I wanted to raise for clarification is that, you talked about omission but then in the latter part of your statement you referred to withdrawal of treatment. In the *Bland* case, of course, there was a situation of withdrawing fluid and nourishment but a lot of play was made in a legal sense upon the fact that that food and nourishment were withdrawn because they had been given by the technique of artificial feeding via a tube, an invasive method which was therefore defined as medical treatment. Is that a view you share?

A. I accept now that a definition has been given, that food and drink given by the method it was given to *Bland* is defined as medical treatment. I might have argued it before, but I would not argue it now.

357. Having said that, may I raise one final point before the other members of the Committee ask you questions: the current state of the law is that if a doctor is convicted of murder then there is a mandatory life sentence. In fact, Dr Cox was convicted of attempted murder and not of murder, which allowed the judge flexibility in sentencing him. It has been suggested to us by several witnesses that there might be a case for an alternative definition, or an alternative crime other than murder that might embrace the concept of mercy killing, for example, which would not carry a mandatory life sentence. Do you have any views personally on that?

A. This would be using the method that I defined as active intervention, not in terms of withholding or withdrawal?

358. Correct.

A. I do not think I do have any strong views.

Lord Mishcon

359. I wonder, Sir Robert, if I could take that a little further. In the transcript that we read of Dr Cox's case before the tribunal, the words "razor edge" were used by counsel for the prosecution as well as counsel for the defence, and it was a definition which you did not quarrel with. The razor edge of course was the difference between administering treatment which one knew beforehand, although it would relieve suffering, was pretty well bound to cause death, and the other case of where it was administered without any hope really of relieving

suffering but it would cause death. Do you regard that difference between the two as being razor edge?

A. I think it is very narrow. The separation is very narrow in relationship to the substances that you choose. Certainly Cox chose a substance that, if you give it to a thousand people in the form it was given, will kill a thousand people. Substances that are given for therapy to relieve suffering that have a therapeutic value, even perhaps in quite large doses, although they may produce death or shorten the patient's life quite substantially, they do not have the same absolutism of one thousand out of a thousand. It comes back to what I said about natural history. Natural history, even though you think the individual is certainly dying, is on the basis of probability and the very occasional one does not do it.

360. Would you agree, forgetting for a moment the rather tragic Dr Cox case, that in a case where a doctor is called upon in circumstances similar to Dr Cox's patient and that doctor decides to use treatment which may have a slight therapeutic effect but will inevitably cause death, that you may get the razor edge difference I was referring to because you would have to weigh up, would you not, whether there was a balance on the side of administering even something which only has a slight therapeutic effect?

A. I think there are very few substances like that, which have some therapeutic effect but inevitably kill the patient. It would depend on dosage. There are substances given in a particular dosage that will still have a therapeutic effect but will kill, but with a lower dosage will have a therapeutic effect but will not certainly kill.

361. I accept that from you with great respect. I only ask one more question, if I may. Bearing in mind what the normal citizen regards as the crime of murder with the automatic effect under our present law of a mandatory life sentence which, even if lessened by the clemency of a Home Secretary, does mean against the record of that person it is recorded life sentence, murder is the charge of which you have been convicted. Would you not have thought that it was somewhat unjust, to say the least, that a doctor, in the circumstances of Dr Cox, could have been convicted of murder with a life sentence imposed?

A. I agree with you. It is hypothetical. The decision might have been otherwise if the charge had been murder. We certainly have examples and, in fact, one was quoted in a newspaper only two or three days ago where an individual was charged with culpable homicide by giving a dose of a substance that would, in that dose and in those circumstances, kill, and the jury acquitted him.

362. Would not the jury always be liable to acquit in the circumstances that I have mentioned?

A. Yes, I think they would.

363. Therefore, is that the proper way for the criminal law to be administered, that you rely on a jury not finding according to the evidence but according to their pity?

A. I do not know that it is pity; I think it is commonsense.

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[Continued

Archbishop of York

364. What I was going to ask really follows on directly from that. It relates to something said in some evidence produced for us by the Crown Prosecution Service referring to the Dr Cox case in which it is made clear that the charge of attempted murder was nothing to do with the prosecution wanting to bring in a less serious charge, but simply on the technicality that since the patient's body had been cremated it was impossible to discover the precise cause of death. It looks as though in this instance he and, I think, your Council were taken off the hook by a legal technicality. Supposing he had been convicted of murder, I am wondering whether your committee would have come to the same conclusion?

A. On the basis that he would have had to have a mandatory life sentence?

365. You were presumably making a decision which was parallel to that made by the courts but independent of them?

A. Independent but afterwards. A conviction is reported to us after the conviction. We therefore had all the information that the court had and, of course, the sentence and the judge's judgment when he read it out. That was of some significance. In fact, we referred to it in our press briefing.

366. What I am trying to do is to test the strength of your own convictions within the Committee that this man should not be disciplined and had he been convicted of murder—

A. I think it is a common confusion between what we do and what is done in the criminal court in relationship to sentencing. A criminal court is of course exercising or using punishment. What the General Medical Council does in every instance when we make a judgment (whether it is conduct, health, etcetera) is to make that judgment in the public interest. That is how we were set up. These were the words that were used. We are making a decision on this doctor's registration, a decision, having accepted or had it proven what he did, we consider what should we do about his registration for the future, in other words, to safeguard the public. That I can certainly tell you, was in the minds of every one of the panel, that Dr Cox would under no circumstances ever do this again. He stated it very clearly; it is in the transcript. In that respect I think that was a major influence on our decision, which is always what is in the public interest. How do we safeguard the public from this doctor, if we have to?

Chairman

367. Thank you. It was said during the hearing of Dr Cox's case, and we have heard this in other circumstance, that there are certain patients in whom, despite all the skills of modern pharmacology and despite all the benefits of hospice care and palliative care, in whom distress, pain and suffering cannot be fully relieved. There were in the transcript words with which I confess I was not familiar, namely "paradoxical pain" or "allopinia"; the question I would have to put to you is, what would be your personal view (not now as President of the General

Medical Council, but as a physician and clinical pharmacologist) about the appropriate course of action to take in a patient whose distress, pain and suffering cannot be relieved, even by massive doses of analgesic?

A. Can I answer that two-fold?

368. Please.

A. One in relationship to individuals with pain, but I would also like to portray other individuals who have as extreme suffering, but not pain. As to the first, I think it is very unusual in these days not to be able to control pain, and the whole of the hospice movement would certainly back me in that respect. I think this was an extremely unusual circumstance and was another reason why the judgment was given as it was. I do not think he will ever see this again and there were many expert witnesses who testified that they had never seen it. It was very, very unusual. Whether it was paradoxical pain or whether it was due to very rapid development of tolerance to heroin, which it could have been, plus the fact she had herself insisted that all therapy be stopped two weeks before, which meant the doses of steroids she was having to control her rheumatoid arthritis were suddenly stopped and sudden cessation of steroids often gives massive rebound pain. So in this particular circumstance—I have never seen anyone like this myself and I think it is very rare—what I would have done (which is what was portrayed by for instance Sir Raymond Hoffenberg) would have been in some way to have rendered the patient unconscious.

369. With major sedation?

A. Yes, either by chlorpromazine or there are many substances. If she had been put in intensive care, she would certainly have been rendered unconscious. That is what they do in intensive care. I do think it is very important because pain usually can be controlled—but there are a group of individuals who do not have pain, but who present a worse scenario than any pain I have ever had to deal with. You will be familiar with that, Chairman, because for instance, motor neurone disease is dreadful. Following the view I have given, you may say to yourself: "How on earth can he possibly cope with that?" seeing an individual slowly, inexorably unable to breathe, unable to swallow, cannot swallow saliva etcetera etcetera and they are in dreadful distress. They do present the worst case. That is the case I thought I should bring in front of you, because it is easily the most difficult and what I do is the same as I would do with the patient in the Cox case, I would sedate them and I would sedate them more and more heavily and that sedation will inevitably mean that they will inhale saliva, they will get pneumonia and the natural history of disease will take its course.

Baroness Flather

370. A couple of things I am just trying to get clear in my own mind, you said about the Bland case about withdrawing the fluid and nourishment, you said you would have argued before, but you would not now and I just wanted to pursue that, because what you said has required (for me) some kind of explanation?

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[Continued]

A. I think it is on the basis that I am familiar with patients who are not in the persistent vegetative state that Tony Bland was, but are so brain deprived or damaged, usually deprived from birth, that they will not take food and fluid unless they are persuaded.

371. Persuaded?

A. Yes. You put a cup in front of them; they will not take it, because they are so deficient and I have difficulty in seeing much difference between that, where they have to have it in effect poured into them by a nurse, but not by a tube. That was really what I—perhaps it was unwise to bring it up.

Baroness Flather

372. At least for me it is important to understand what you were thinking about.

A. There are certainly an appreciable number of individuals within the description I have given in the United Kingdom now.

373. Would you be saying then, or are you saying, that in Bland's case, you did not see the nasogastric feeding as part of the medical treatment, but you saw it as nourishment?

A. I see it as something everyone has to have to keep alive. They have to have food and they have to have water.

374. It does not matter in what way they receive it?

A. Yes, that is what I am saying.

375. May I just ask one more thing which has come up before and I have not been able to get it clear in my own mind, this question of the best interests of the patient and at what point it starts to shift towards helping the patient along the way? If you cause a patient to move towards death slowly, is that in the *better* interests of the patient than to do it quickly? That is something which I wanted to get clear in my own mind, seeing it only from the patient's point of view of course, not from the point of view of the doctor.

A. Well, I have made myself plain I think, that in relationship to the patient/doctor relationship and trust, I am against giving a substance that kills just like that.

376. I have that point clearly.

A. But in terms of their best interests in relationship to giving them therapy, which reduces their likely span of life, that is something that we do all the time as doctors. When we make a decision to intervene in the natural history of disease we have to balance up the likely benefit of the intervention against the conceivable hazards of the intervention. It happens all the time. In most instances one is fairly clear that the intervention risks are so much lower than the benefit that you use them; but, as you get nearer and nearer to death, the balance is more difficult. That is really all I am saying.

Lord Meston

377. I just want to press a little further on the question raised by the Archbishop in the case of Dr Cox. It is right, is it not, that but for the fact that

there had been a cremation before a *post mortem* examination could be carried out you would have been dealing with a convicted murderer on exactly the same facts and circumstances as pertained?

A. I think that is hypothetical.

378. Of course it is hypothetical, but assuming that the *post mortem* examination had established the cause of death in the way that it certainly could have done, you would have been dealing with him—

A. It would depend upon the decision made by the jury.

379. All other background circumstances being the same, you would have been dealing with a convicted murderer, with all of the favourable points to be made in mitigation that undoubtedly were made before you. Could it have been that you would then have seen the case in the same way; bearing in mind, if I may follow that up, your remit to protect the public?

A. I hate to be asked hypothetical questions, on case summaries that have not come my way. In terms of the public interest, if he had had a mandatory life sentence the public would be protected while he had the sentence.

380. For a few years?

A. That is right. That in itself would be a factor that would have to be taken into account when we made a judgment. I really cannot answer how the judgment would have been.

Chairman

381. Would it have been in your power as a conduct committee, if he had been convicted of murder and had received a mandatory life sentence, to take the view that he had been punished enough?

A. Yes, certainly.

Lord Mishcon

382. But punishment, if I might say so, you excluded from your duties.

A. That is absolutely right. We do not give punishment. The sentence is the punishment by the criminal court; ours is about the future, and the public would be protected for so long as he was in prison.

Chairman

383. I should have phrased that in another way, by saying would it have been within your view to say that the punishment he had received would have meant that the public was protected as completely as you and your committee would have wished?

A. Yes, but it could of course be followed: what would we do when he was released? I would rather you did not push it!

Baroness Jay of Paddington

384. Could I go back to the case you suggested about the potential for anaesthetising a patient in acute uncontrolled pain?

A. I did not say "anaesthetise". There is a difference. I said "rendered them unconscious".

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[Continued]

[Baroness Jay of Paddington *Contd*]

385. You then went on to say, and correct me if I have it wrong because I was only making a brief note, that once you had rendered someone unconscious in those circumstances it was likely, for example, that they would swallow saliva, that that would lead to pneumonia and that, in turn, would hasten their death?

A. Yes, that is right.

386. I find it extremely difficult to understand how that is not an active intervention in the natural history of the disease, in the way you have described there being a distinction in your mind which had been a failure to act in the natural history and active intervention?

A. It can be defined very simply when you have to fill up the death certificate.

387. I am talking about real life, and am not talking about death certificates.

A. Death certificates are real life. They are very much a part of real life.

388. If we look at the instance of Dr Cox I think the question of death certificates is something which we should not go into in great detail?

A. I quite expected to be assailed on this point, and that is why I said what I did in the opening statement. I do think there is a difference between dying from the natural history of disease and someone giving a substance that will inevitably cause death—that is execution.

389. I understand that there is a difference there. What I cannot understand, and I am not pursuing this for any reason except that I genuinely do not understand the difference between an active intervention of the kind you have described when talking about the possibility of rendering someone unconscious and that then having the consequential result of pneumonia and therefore death, which you would see as the natural history progressing to a point at which death occurred, and not doing something.

A. Then I have not convinced you.

390. It seems to me an extraordinary thing to want to convince on. It is not a question of judgement but a question of fact.

A. I do not know that it is a question of fact. It is a question of what is the centrality of a patient/doctor relationship. I think if patients get to know that doctors execute them, and it is all right because the particular patient may very well have asked for it, but it will have an effect on all patients.

391. Could I just ask a more general question as a follow-up. In your opening statement you mentioned a couple of times that people of your generation (your expression again) saw the natural history issues relating to medical behaviour as one way and people of a different generation might see them differently. Could you expand on that a little?

A. I have been involved in teaching doctors and students, again the whole time, and I certainly have noticed a major change in what is available and what medical treatment and surgical treatment can be done. It is quite extraordinary what can be done. At the same time, over the same period, there have

been other developments related to society. This topic is very, very polarised. There are a lot of pro-life people, not so many anti-life. I think a lot of the younger doctors are acutely aware that if they do not intervene, in other words they don't do as I do, which is withholding treatment or withdrawing it, that they may be assailed in some way. That is why I think they tend to keep going longer than I do.

Chairman

392. You suggested that the main purpose in rendering such a patient, as you describe, unconscious, was to relieve massive pain, distress or suffering, and you made the point that if that had the secondary effect of terminating life you would regard that as being acceptable?

A. Yes. I think what I said in terms of unconscious was related to a lady in the situation of the Cox case—

393. Or motor neurone disease?

A. —because of the pain. There was just no way in which this pain could be controlled (having listened to it in great detail and asked a lot of questions) without rendering the patient unconscious, and Hoffenberg also felt the same. What I said about what I think is a worst case, namely motor neurone disease, I would not render them unconscious, I would sedate them which is quite a long way from unconsciousness; but in sedating, their reflexes become less acute so that, for instance, you can inhale saliva during sedation without actually being unconscious.

Lord Colwyn

394. Do you mean you, or would you bring in an anaesthetist to do this?

A. Do you mean in terms of unconsciousness?

395. I am someone who does sedation every day of my life as a dentist and I am very aware of the fact that reflexes have to be protected. If you sedate somebody or anaesthetise them to the extent their airway is not protected then they will very quickly die.

A. There are so many instances. Another problem, if you were trying to produce a form of words to allow a change, is the difficulty of making sure that it would cope with all situations. If I can give you an example of what I mean. If you are going to give morphine or heroin to relieve pain that produces some depression of reflexes. Not much, in a therapeutic dose, but some; for instance the cough reflex virtually disappears. If you use a normal dose of morphine in someone with marked respiratory insufficiency—emphysema for instance—even a normal dose of morphine may render them into an acute problem of respiratory depression. It is so related to the individual circumstances.

Lord McColl of Dulwich

396. As usual, I find what you said very helpful indeed and crystal clear and I have no problem with what you said at all. Could I take you back to the question of protecting the public? I am concerned,

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Sir ROBERT KILPATRICK

[Continued

[Lord McColl of Dulwich *Contd*]

as we all are of course, with the most vulnerable in society, people growing old and ill, who feel a burden on their relatives and I am worried that if there is a change in the law from murder to mercy killing, it will make it easier and therefore the pressure will be on these vulnerable people to take the easy way out and that is why I am (along with a number of other people) unhappy about the change in law. What do you feel about that in terms of protecting these vulnerable folks, often elderly, often very ill, who do feel that they are putting a burden on society?

A. I think I agree. I think however, how I would put it is that one of the great problems is always to work out the implications of a change, because they may be much more far reaching than one can see at the time it is done. The easiest example is of course the abortion law. Certainly the implication of that was not thought out, in my view, because the number of abortions was expected to be no more than what—2,000 or 3,000 and now it is nearly 200,000. I think that pressure inevitably would be there. I think it is there in Holland actually, as I hear it from individuals that I have spoken to.

Lord McColl of Dulwich

397. Going on with the abortion side, what I found very distressing indeed was the enormous pressure put on those and there were two Professors and university employees here in the Health Service, one in Birmingham and one in Aberdeen, who decided to stick to the law as it was laid down in 1967 and therefore would not agree to abortion on demand and they were pilloried in the press and in all sorts of ways, because they insisted on keeping within the letter of the law and I was particularly concerned that they, as university professors, were subjected to such enormous pressure, because of the law.

A. I think it was much wider than university professors, Lord McColl. I think it applied to a very large number of individuals and a *modus vivendi* had to be found.

Baroness Llewelyn-Davies of Hastoe

398. I have a question about the young doctors. I was very interested in what you said at the very beginning of your talk and that you referred to it again and I wondered myself whether you were going to talk about moral implications for the young and in that case which way did they go? When you clarified it later you said that the young doctor was more likely to let it go on?

A. Yes, I think that is right.

399. Is that a callous decision because youth is slightly more callous than older people, or is it just the technicality of the situation?

A. I think it is largely protective, because they are so aware of litigation complaints etcetera.

400. I see, yes. The old must be as aware of that?

A. I suppose they are more able to withstand it. I certainly have a lot of experience of doing that.

Archbishop of York

401. I think I heard you saying that in your insistence that you should not actively give substances

which will terminate a patient's life, the bottom line for you ethically is the relationship between doctors and patients?

A. Yes.

402. The trust on which this depends? Is this correct, or would you see the ultimate prohibition of this in more general ethical terms than that? That is very much a doctor's point of view.

A. Mine is?

403. Yours is, yes

A. Yes, it is, but I think it is held by a very large number. I am only here as a practising physician, expressing views that I think many of them do hold. I think many of them will have a religious view as well, but I kept my remarks in relationship to natural history, in other words natural order. I do not know whether—I was fearful that I might be given a rigorous examination of ethics and morals and I cannot do it.

Archbishop of York] We are a very gentle Committee.

Chairman

404. Thank you. I think we ought to end at that stage, but we have not taken up with you all the issues which we had hoped to cover, such as the treatment of patients who do not have the capacity to participate in the decision-making process, nor have we taken up with you the issue of advance directives and whether they should be enshrined in law. If you do have comments to make on those, we would be grateful.

A. Could I say on advance directives, because I wanted to get this point in, it is very important in discussing euthanasia in the narrow definition, which I gave at the beginning. You see there is a major difference between acute medical problems and chronic and I would see advance directives being helpful or a helpful factor, much more in terms of chronic than I would in terms of acute medicine. It could be for instance—it is very much within your area Chairman—that someone gives an advance directive and a year later has a massive stroke, probably from a thrombosed vessel and not a haemorrhage. In that year, there may very well have been developments that can reduce the effects of ischaemia in the brain and I would have no hesitation in giving such therapy, because the individual would not have been aware of it at that time. That is one of the problems and it is seen best in terms of acute medicine. It is much less likely in terms of chronic.

Lord Hampton

405. The scheme for advance directives seems to be based on the belief that unless we sign one, we may be (as the quotation puts it) kept "officially" alive. I feel there is an adverse or a negative effect and that unless an advance directive has been signed, may not the doctor be afraid to do what he believes best and allow a patient to die, since he would live in a society that would go so easily to litigation.

A. I am inclined to agree.

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Sir ROBERT KILPATRICK

[Continued]

[Lord Hampton *Contd*]

406. That is the problem we have to face.

A. I think so much depends on how advance directives are framed. I think they could be a factor, but only a factor in relationship to a decision about withholding or withdrawing therapy and I think it would depend on the individual clinical circumstances, which are so numerous. Virtually no patient replicates another.

Chairman

407. On the very last word, before we say "thank you", would you agree with the many medical organisations whom we have seen, who favour the principle of advance directives, but say they must not be legally binding upon the doctor?

A. Yes, I am sure that is right. I have got a quotation and I expect it is awful to bring it up in this House but there was an attempt in 1969 by Lord Raglan, to introduce a Bill which gave patients a right to request euthanasia through an advance directive. As I am sure you know, and I was very struck by the quotation which was attributed to him afterwards (and I have no reason to doubt that it is anything but correct) because that Bill failed. He said, "All attempts that I have seen of drawing up a declaration have too many weaknesses for my liking and have too many holes picked in them".

Chairman] Thank you for that ending, Sir Robert. Thank you very much indeed for coming along to talk to us.

Memorandum by the United Kingdom Central Council for Nursing, Midwifery and Health Visiting

INTRODUCTION

1. In the aftermath of the consideration by the House of Lords of the application to terminate the feeding by nasogastric tube of Mr Anthony Bland, and also of the hearing at Winchester Crown Court of charges against Dr Nigel Cox culminating in his conviction for attempted murder, the Council welcomes the decision of the House of Lords to establish a Select Committee on Medical Ethics.

2. In expressing that welcome, the Council also expresses its regret that the committee is named as it is, bearing in mind that its terms of reference are very wide, being concerned with the giving or withholding of life-prolonging treatment, consent or the inability to give consent, and the broad subject of a person's best interests or what are perceived by others to be his best interests.

3. These are all matters in which members of the professions regulated by this Council and named in its title have a deep and abiding interest. These issues concern the practice of nursing and, in the case of the newborn, the practice of midwifery.

4. The Council recognises that the two cases referred to in paragraph 1 have sharply focused attention on the inconsistency in the existing law. Anyone who wilfully assists another person to die will be liable to be regarded by the courts as having acted unlawfully. Despite this, nurses see the same end result achieved throughout the country day after day by deliberate decisions not to prescribe treatment for infections and by the prescription of very large doses of potent analgesic drugs. They will also, however from time to time observe (and even be party to) the resuscitation, against his will, of a terminally ill patient who has attempted suicide. On other occasions they observe the inappropriately aggressive resuscitation of terminally ill people who have not sought to end their own lives. Practitioners cannot but be forgiven if they find the present state of the law in this field both confused and confusing.

5. At the heart of this confusion is the "killing or letting die" distinction. At times this distinction can appear nothing short of hypocritical. Superimposed upon it comes the "intentional killing/alleviating pain" equation. It seems to many nurses, and to this Council, that to prohibit euthanasia as a passive or active measure, yet permit the use of narcotics to alleviate pain, even at doses which will dramatically shorten life or even bring it to a close within a very short period, is no longer a sustainable position. Statements within the House of Lords judgements in the Anthony Bland case re-inforce this conclusion.

6. It is imperative, therefore, that the Select Committee address these issues and arrive at conclusions which will allow professional practitioners, after all appropriate consultations between themselves and more widely, to exercise their judgements in the future against a background of honest and open appraisal of all the facts and to allow them to serve the interests of patients without fear of criminal proceedings being brought against them.

THE BASIS OF THE COUNCIL'S POSITION

7. The Council's position on the issues which feature in the Select Committee's terms of reference derives from the central elements of its "Code of Professional Conduct for the Nurse, Midwife and Health Visitor".⁽¹⁾

8. The principal theme of the Code, found in explicit terms in the introductory paragraph and the first two clauses, and implicitly throughout the document, is that of respecting and serving the primacy of the interests of patients and clients. It is, therefore, concerned with the public interest in general terms, but

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more specifically with the interests of those members of the public who, when at their most anxious, vulnerable and dependent, have no option but to place themselves in the hands of the health professions.

9. It is important to note, however, that the Code also states, in the second element of its introductory paragraph, the Council's expectation that each individual practitioner will act in such a manner as to "... serve the interests of society". These words can be seen as significant in the context of the important issues being considered by the Select Committee, since a decision made in respect of one individual patient which appears to be appropriate for him or her in the particular circumstances that apply, might contribute to establishing a precedent which might be inappropriately applied in other cases. The wider societal interests should not, therefore, be ignored when decisions are being made about individual cases, even though the individual case should be considered on its particular merits and within the context of the law and professional ethical principles.

10. The Council's Code of Professional Conduct also promotes respect for the autonomy of the individual patient or client. This principle is particularly evident in clauses 5, 7 and 9, all of which complete the statement in the important stem sentence.

THE SELECT COMMITTEE'S TERMS OF REFERENCE: GIVING OR WITHHOLDING CONSENT

11. The first paragraph of the terms of reference states that the Select Committee is appointed:

"to consider the ethical, legal and clinical implications of a person's right to withhold consent to life-prolonging treatment, and the position of persons who are no longer able to give or withhold consent".

12. In respect of the first element—a person's right to withhold consent to life-prolonging treatment—it is the Council's position that the autonomy of the individual must be respected. Therefore, any decision made by such a person, on the basis of comprehensive information and when they are both legally and mentally competent, to refuse treatment, should be respected, even though the inevitable outcome will be the death of that person sooner than would otherwise have been the case.

13. This does, of course, emphasise the importance of the information on which the individual can make an informed and carefully considered judgement either to receive or refuse treatment. This Council's position on this important aspect of professional practice is set out in the section headed "Consent and Truth" in its publication "Exercising Accountability".⁽²⁾

14. The Council regards it as important that professional paternalism or a failure to face up to a difficult task should not obstruct the flow of information to an individual which would equip him or her to arrive at a decision to give or withhold consent. Any decision by a professional practitioner to withhold essential information from a person or to present it in dilute or distorted form must be able to be justified by that practitioner as serving the patient's best interests and not the interests of the relatives or the views (for example, on sanctity of life) of the practitioner.

15. The issue is much more complex in respect of persons who are no longer able to give or withhold consent because, for whatever reason, they are no longer competent to receive, weigh and respond to information about their condition.

16. It is noted that Lord Browne-Wilkinson, in his judgement in the case of Anthony Bland, pointed out that the court "... even if it thought fit, has no power on Anthony Bland's behalf either to consent or refuse consent to the continuation of the invasive procedures involved in artificial feeding."⁽³⁾ It is further noted that he added:

"Faced with this lacuna in law, this House in *In re F* developed and laid down a principle, based on concepts of necessity, under which a doctor can lawfully treat a patient who cannot consent to such treatment if it is in the best interests of the patient to receive such treatment."

The judgement goes on to apply that principle to the withholding or withdrawing of treatment which was the issue before their Lordships.

17. This aspect of the judgement therefore raises, in a sharply focused way, the question of who is to be regarded as the arbiter of the best interests of the patient. The five Judges in the House of Lords were clearly deeply sympathetic towards Mr Bland's parents and mindful of their support for the application to withdraw and withhold treatment. They were also aware, however, that, in the current state of the law, the wishes of those distressed parents gave no legal authority for the action they wished to take place in order that their son could be allowed to die.

18. The Council is of the view, therefore, that it would be appropriate and helpful for the Select Committee to explore the possible inclusion in United Kingdom law of the "substituted judgement" test as a possibly preferred alternative to the "best interests" test. The principle of substituted judgement, as an alternative to the "best interests" test, is helpfully explored by Kennedy and Grubb in "Medical Law: Text and Materials".⁽⁴⁾

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19. The authors quote an official report from The Institute of Law Research and Reform of Alberta as stating that:

"the 'substituted judgement' test has been employed by some American Courts in recent years as an alternative to the best interests test. Under the substituted judgement test the decision is to be the one that would be made by the mentally incompetent person if she were mentally competent. The test requires the application of the subjective values of the individual insofar as they can be known. To apply it, an attempt must be made to ascertain the mentally incompetent person's actual preference for or against such matters as sterilisation, other means of contraception and parenthood.

The substituted judgement test was developed in terminal illness cases involving decisions about the use or removal of life support systems. The Supreme Judicial Court of Massachusetts used it as the basis for a sterilisation decision in the case of 'Re Moe'. This court found that the substituted judgement test protects the mentally incompetent person by recognising the dignity, worth and integrity of the person and affording him the same personal rights and choices that are afforded to persons in the mainstream of society."

Although the issue was the sterilisation of minors and mentally incompetent adults, the principle seems applicable to many situations and certainly to those to be considered by the Committee.

20. It would be the Council's expectation that, were the principle of substituted judgement to find a place in United Kingdom law, the law would be constructed in such a manner as to give the maximum possible weight to the views of the person or persons closest to the individual who was the subject of consideration, even in the absence of familial or marital ties.

21. It is not suggested that the "substituted judgement" test should necessarily replace the "best interests" test. Each may have its place in particular cases. They could, therefore, co-exist and complement each other in providing a means to allow consent or the withholding of consent on behalf of an incompetent person. (See also paragraphs 38 and 39 on "Advance Directives".)

THE SELECT COMMITTEE'S TERMS OF REFERENCE: TERMINATING OR SHORTENING LIFE

22. The second paragraph of the terms of reference states that the Select Committee is appointed:

"to consider whether and in what circumstances actions that have as their intention or a likely consequence the shortening of another person's life may be justified on the grounds that they accord with that person's wishes or with that person's best interests."

23. Before addressing the important issues on which attention is focused by that paragraph, the Council places on record its unequivocal view that it must only be the person's wishes or best interests that lead to the decision. That is to say that the Council is opposed to decisions being led on the grounds of cost and economics. It must always be the patient's best interests and not the financial position of a purchasing authority or agent that is the determining factor.

24. The Council is also anxious to ensure that necessary debate and consideration of these important issues should not be allowed to distract the health professions from considering the implications for them which emerge from the two cases named in paragraph 1 of this paper. These certainly include the need:

24.1 to overcome the relative neglect of research in the area of care of the terminally ill;

24.2 to examine anew the knowledge and skills required in respect of pain control and of attitudes to patients and their pain and

24.3 to re-assess their attitudes to preventing suffering and supporting dignified death.

The health professions must continue to address these issues and do so in greater depth and with greater candour than ever before.

25. It is apparent that the matters covered by this paragraph were a cause of concern to their Lordships in arriving at the House of Lords judgement in the case of Anthony Bland. Indeed, Lord Browne-Wilkinson, in the final paragraph of his judgement, appears to reflect the confusion felt by many members of society when he said:

"Finally the conclusion I have reached will appear to some to be almost irrational. How can it be lawful to allow a patient to die slowly, though painlessly, over a period of weeks from lack of food but unlawful to produce his immediate death by a lethal injection, thereby saving his family from another ordeal to add to the tragedy that had already struck them. I find it difficult to find a moral answer to that question."

26. The Select Committee's terms of reference refer to "... actions that have as their intention or a likely consequence the shortening of another person's life ...". Although the phrase "termination of life" is not mentioned, it is this and the word "Euthanasia", whether with the prefix passive or active, that must be regarded as the issue to be addressed.

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27. Those who openly support euthanasia typically argue that it is morally wrong to allow people to suffer unnecessarily. Their arguments appear to cluster into four main categories as follows:

Individual Autonomy and the Right to Choose

27.1 Proponents of voluntary euthanasia argue that the right to choose includes the right to choose to die. Given the right to die means that, in some instances, others have a positive duty to assist achievement of the desired outcome.

Loss of Dignity and the Right to Maintenance of Dignity

27.2 Proponents of euthanasia recognise that advances in medical technology have increased medicine's capacity to prolong a person's life. Its effects, however, are not always seen as humane, since they can create circumstances which seriously erode a person's concept of self, character, self-worth and self-esteem. Such individuals are often aware of their own deterioration and of the burden they have become to others. Some argue that, in either excessive pain states or chronic conditions, euthanasia is the most dignified option.

Reduction of suffering

27.3 It is argued that, in cases where suffering is intense, protracted, intractable and seemingly unendurable, it is cruel to deny the suffering individuals the choice of death as a means of release from suffering.

Justice and the Demand to be Treated Fairly

27.4 It is argued that to deny patients (and particularly those who are suffering) the right to die in a manner and at a time of their choosing is to unfairly impose on them the values of others and that this is a denial of their autonomy.

28. Nurses, being the professional practitioners who spend large amounts of time with patients, are able to recognise and identify with those who, from their own harsh experience, argue on the basis of any or all of those points. They are not stereotypes and must be taken into account in the Select Committee's considerations.

29. Set against them are a battery of arguments in rebuttal. These include arguments concerning:

29.1 the sanctity of life;

29.2 misdiagnosis and possible recovery;

29.3 risk of abuse;

29.4 the absence of necessity;

29.5 discrimination (ie that which implies or suggests that some lives are not worthy to be lived);

29.6 irrational, mistaken or imprudent choice and

29.7 the slippery slope concept.

30. Again, nurses can identify with many of these arguments. Those who have given the subject serious attention recognise that none of the arguments (for or against euthanasia) are uncontroversial. All must therefore be placed in the scales if this issue is to be given the serious attention it must surely now receive.

31. Both the Council and the practitioners on its register are aware of the fact, however, that, in the past and still now, the need for debate and serious consideration of these issues has been stifled and obstructed by concealment and a lack of candour. The Council's conviction on this matter has been illustrated in the introductory section of this submission. (See paragraphs 4 to 6 inclusive).

32. The Council therefore seeks a sensitive law which allows professional practitioners the opportunity to identify and serve the best interests of their patients. There are others who are better equipped than the Council to advise the Select Committee as to the changes in the law that are necessary to achieve the outcome described above. Such new law should give credence to the professional practitioner's overriding duty of care to patients.

THE SELECT COMMITTEE'S TERMS OF REFERENCE: CHANGES IN THE LAW

33. The third and last paragraph in the Select Committee's terms of reference states:

"in all the foregoing circumstances to pay regard to the likely effects of changes in law or medical practice on society as a whole".

34. It is significant that both Lord Browne-Wilkinson and Lord Mustill, in their respective judgements in the Anthony Bland case, have indicated their belief that Parliament must review the law, or the Courts

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will soon be faced with cases which are not as clear-cut as that on which they have now passed judgement. Lord Mustill in particular has stated that:

"The whole matter cries out for exploration in depth by Parliament and then for the establishment by legislation not only of a new set of ethically and intellectually consistent rules, distinct from criminal law, but also of a sound procedural framework within which the rules can be applied to individual cases."

The Council is sympathetic to this view, but questions the place of rigid rules in resolving issues of such a delicate and sensitive nature as the Anthony Bland case brought to the attention of the courts. The Council, for its part, would prefer to see the development in law of a sound framework of principles which establishes the procedures to be followed in considering important issues such as the withdrawing and withholding of treatment. These procedures should require the involvement of relevant professional practitioners from the medical and nursing professions, and other professional practitioners engaged in the direct clinical care of the patient, and should seek to take account of others who are closest to the patient. If no consensus emerges from the team's consideration of a particular case, due regard having been given to the views of the person or persons deemed closest to the patient, such a case might reasonably be referred to the courts.

35. If legislation can be designed in a sufficiently sensitive manner to achieve this it would find the support of this Council. Such an outcome would be consistent with that described in paragraph 6 of this submission.

36. Such an outcome would, it is believed, help to maintain in society a confidence and trust in the members of the health professions on whose judgements and actions they depend at crucial times. There is, however, a reverse side to the coin. Insensitive and rigid legislation might lead to a mistrust of professional practitioners and a belief that their decisions and actions are of a defensive nature and taken only to comply with the law rather than to identify and serve the best interests of their patients. Worse than that still, it might lead some members of society to the view that, in recommending or pursuing a particular course of action, their professional practitioners were adopting a stance, out of some ulterior motive, that was contrary to the best interests of individuals. Legislation that had such an outcome would be very destructive.

37. It is noted that Lord Mustill, in his judgement in the Anthony Bland case, referred to the present situation as creating "... a legal and ethical maze" in a case of that kind. That it certainly is. Unless there is reasonable certainty that legislation can be devised which can win the confidence of a significant majority of members of the public, while respecting the views of the remainder, doubt must continue about the wisdom of taking this route.

ADVANCE DIRECTIVES

38. The list of issues in respect of which the Committee has indicated an interest in receiving evidence includes "Advance Directives". Given its general position of respect for the autonomy of the individual and its belief that the decisions of a person made when legally and mentally competent must be respected, it is logical that the Council takes a generally favourable view of the concept of advance Directives.

39. The Council's view, however, that the associated facility to designate, when competent, a person to act as one's proxy when one is no longer capable of making informed decisions, would need to be encompassed within the sensitive new law referred to earlier in this submission. This would be seen as beneficial, in that it would give to the identified person a role which, under current law, does not exist. This would assist the professional practitioners to make crucial and difficult decisions with enhanced confidence. (See also paragraphs 18 to 21 on "substituted judgement".)

CONCLUSION

40. The Council offers this submission in the hope that it will assist the Select Committee in its difficult task. If it would prove of assistance to the Committee, arrangements can be made for representatives of the Council to attend to respond to any supplementary questions.

REFERENCES

- (1) Code of Professional Conduct for the Nurse, Midwife and Health Visitor, Third Edition, June 1992, UKCC;
- (2) Exercising Accountability, A UKCC Advisory Document, March 1989, UKCC;
- (3) House of Lords Judgement in the case of Anthony Bland and
- (4) Medical Law: Text and Materials, Ian Kennedy and Andrew Grubb, published by Butterworths.

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Memorandum by Professor Sheila A M McLean, International Bar Association Professor of Law and Ethics in Medicine

DECISIONS ABOUT DEATH AND DYING

For long, society, individuals, professional health care workers and the law have struggled with the problems of decisions about death and dying. As a multi-cultural society, the long used concept of sanctity of life no longer defines or delineates the totality of concerns of this, and other, communities. Changes in laws regarding suicide, abortion and the increasingly common use of the principle of double effect have consistently—and fundamentally—reflected changes in our attitudes. The success of wrongful birth actions, and the attempts to raise actions for wrongful life, point towards a community which no longer holds all life to be preferable to none. It is against this backdrop that those involved in issues of life and death—be they individuals, health care workers or judges—must, in my view, now firmly grasp the nettle of formulating an approach which embodies a number of important values. These values can loosely be described as follows:

- (1) Formal justice and certainty of outcome;
- (2) Respect for individuals;
- (3) Certainty for decision-makers, eg doctors and nurses;
- (4) Accountability of decision-makers;
- (5) Transparency of decision-making;
- (6) Procedural accuracy and regularity;
- (7) Community involvement;
- (8) Disinterested decision-making;
- (9) Accessibility.

There are doubtless many others also, but I would submit that if all the situations in which decisions are made about death and the terminally or hopelessly ill are to achieve these values, it is essential that legislation is put in place which once and for all sets up appropriate procedures, and clarifies both the civil and the criminal consequences for families and health care workers who can no longer be expected to carry the burden of uncertainty in a situation, or set of circumstances, which arises all too frequently. Given the relative unlikelihood of many opportunities arising for such to be done, I would also respectfully submit that this opportunity might also be taken to deal with a matter which is tangentially related and that is the availability of cadaver organs. The relationship may be somewhat tenuous at first sight, but many of the problems of shortfall in donations can be traced to community uncertainty about the point at which death actually occurs—indeed, evidence suggests that clinicians themselves are not immune from concerns about this. For this reason, I would propose that in addition to the weighty considerations already under scrutiny, the Human Tissue Act 1961 be amended to incorporate a legal, but not unnecessarily rigid, definition of death.

In respect of decisions about the end of life, the discussion paper which I have enclosed demonstrates my own view that too often the "right" decision is reached by the only available mechanisms, which are themselves inherently flawed, and—even when they are not so—they reflect different standards in respect of what is ultimately the same issue and certainly seeks the same outcome. Although some of the issues addressed below are considered in more depth in the discussion paper, there are some points which I believe are worth highlighting briefly here. Critical to my view is my firmly held opinion that the medical or professional model is the wrong position from which to start. The tendency to endorse "reasonable medical practice", whilst intelligible, also fails to address the fundamental issues at stake. Moreover, it leaves decision-makers in the field (ie doctors and nurses) to carry a burden from which I believe they should be relieved, and which it is inappropriate for them to carry. Obviously, therefore, what follows takes a particular view of the role of law, and one which is not, of course, shared by everyone. Nonetheless, it is my conclusion that only legislation, of a permissive rather than directive nature, can meet the values outlined above whilst at the same time generating a sense of security in those members of the community currently or in the future affected by its terms. For example, that there is some evidence from the United States that the incidence of suicide in the elderly is on the increase because people fear the unwanted prolongation of life-prolonging technology is a matter of great concern which might be eased by the knowledge that the individual and not the doctors—who may act defensively where the law is equivocal—will have charge of the final decisions. Of course, equally, a population in which the elderly are on the increase must also be reassured that technology or other treatment will not inappropriately be withheld. Handing the decision to the individual in a clear and unequivocal manner may achieve both outcomes.

The Sane Adult

It is, I believe, incontrovertible that we believe the individual to have the right to make decisions about what shall or shall not be done to his/her own body. The individual who refuses health care, and who is

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sane and adult, is respected by our common law in that decision even if the decision seems manifestly "wrong" to others and even if its inevitable outcome is the death of that individual. Yet, whilst on the one hand recognising that choice, and no longer criminalising suicide, we tolerate only those decisions which the individual can physically influence. The individual with the same competence (legally speaking), the same desires and the same reasons who is not physically or psychologically capable of taking the step of self-destruction is denied the protection of a caring community's respect. In other words, despite the same moral values being involved, the need for the involvement of a third party is sufficient to refuse to that individual the right to make the same decision and reach the same (personally) satisfactory conclusion. Obviously, this has a certain internal logic given that the criminal law does not recognise consent as a defence to a charge of murder, but we do not in any event routinely apply criminal concepts to the clinical setting and any exception made within that setting would not have the inevitable consequence of cheapening life nor of opening any floodgates. For example, over the years, courts in this and many other jurisdictions have moved away from conceptualising an inadequately informed "consent" to surgical intervention as an assault, preferring language which is less laden with criminal connotations, at least in part because of a recognition that, although surgery would otherwise be criminally capable of categorisation as a serious assault, or attempted murder, the motivation is benign. This would also carry forward into recognition that for a physician to assist a patient in ending a life which for that patient was intolerable, and only within very clear guidelines, was in itself not a criminal act.

The distinction between act and omission, so often used to justify the difference between killing and letting die, is one which has long been widely regarded as philosophically disingenuous, and should in my opinion be so treated. For the competent adult, then, the real unresolved question is whether or not to legalise voluntary euthanasia.

The consequences here are two-fold. First, that this is our opportunity to give formal legal endorsement to the rights of individuals to control their own destiny, and second that the removal of the acts/omissions doctrine can safeguard the position of the doctor in a case such as that recently prosecuted against Dr Nigel Cox, with whose behaviour many were in agreement and whose trial was seen by many as bringing the law into disrepute. This is not to suggest simplistically that because the majority of people polled agree with something it should inevitably be endorsed by law, but rather is adduced only as one small piece of the puzzle which makes up the reality of current practice and increasing demands.

For the reasons given above and elucidated elsewhere, it is my view that—and given opinion poll evidence which suggests the concurrence of the majority of the community—this opportunity should be taken to de-criminalise physician-assisted suicide. The way in which this might be achieved will be discussed under "Proposals" below, but for the moment it is necessary here to say that any such provision would, of course, require a carefully formulated conscience clause, requiring that conscientious objection should also trigger referral on to another physician who does not share these doubts (as is now the practice with abortion).

Handicapped Neonates

The main discussion of these cases is contained in the accompanying paper, but again—where the infant is not terminally-ill—courts seem to struggle with a variety of tests, such as "best interests" which—unless clearly defined can lead to inconsistency and leave a margin for error sufficiently wide to be of considerable concern. The one apparent attempt to use a "substituted judgement" test is manifestly difficult to justify rationally, although as a test in other circumstances it may have more validity (see attachment). One further consideration raised in a recent case was the problem of resource allocation. In my view, this is a consideration which should never be used as a predictor of life or death, even although the reality of resource-based decisions is ever present.

Persistent Vegetative State

Again, the major discussion is contained in the attached paper, but there are one or two points which merit mention here. If we are to make decisions about terminating the existence of those in pvs, we must be able to reassure ourselves and the public of the accuracy of the diagnosis. This requires the adoption of stringent clinical guidelines, as it is sometimes said that doctors may not be sophisticated enough in their predictions or diagnosis of this condition. In addition, with the memory of the "Panorama" programme in mind, it must follow on a campaign of public education in order to allay potential community concern.

To a large extent this may be achieved by requiring that each case is scrutinised by a court, but to insist on this is to defeat a number of the values outlined above, and to add the further problem of accessibility—financially, emotionally and in terms of time.

Proposals

Clearly, any amendment of the law in this area is likely to generate considerable debate and may even cause some people deep concern for their future safety. A number of opportunities exist to avoid this. Given the principles outlined above, the aim must be to reassure the public, to enhance individual rights, to relieve doctors and nurses of the fear of prosecution and of the perceived need to continue inappropriate treatment, to treat everyone equally and to offer some sense of certainty to those in, or contemplating,

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such situations. This, in my submission, requires a legislative statement. However, it also requires a move away from the tendency in United Kingdom courts to adopt a professional standard when considering such matters. Issues of life and death are not ultimately referable to current, reasonable or even responsible medical practice at any given time and the temptation to use such considerations is to be resisted. It is for the law and not the clinician to reach such conclusions and it is for the community and not the physician or nurse to face and shoulder the moral burden of such decisions.

Not least, and given that patients' rights are increasingly perceived as of paramount significance, this review provides the opportunity to offer legal backing to the provisions of advance health care Directives and proxy Directives. Once it is accepted that we do not always value all life over everything else, concerns about the individual's disposition in terms of their health care becomes less acute. Proxy decision makers should be expected to act on the understood and clear wishes of the incompetent person. A test will need to be devised which the proxy must satisfy, and I would suggest that this test must be stringent. In the US case of Nancy Cruzan, and in the absence of a "living will" the court required "clear and compelling evidence" of Nancy's wishes before endorsing the termination of life-prolonging treatment. This test might well be usable in the situation where no advance Directive exists, but might also be appropriate where such a Directive does exist in a slightly modified form—that is, that the proxy should be able to show that there is no such evidence that the individual had in fact changed his or her mind. In any event, in the consideration by the House of Lords of the Tony Bland case, it was suggested that acting on previously expressed wishes of the individual was no more than a reflection of the fact that—had the person been currently competent—they would legally have been able to make such a decision. Perhaps the United Kingdom might also consider the US practice of informing everyone on admission to hospital should be told of the opportunity of making such a Directive. Unlike what I understand to be the position of the BMA, I should also submit that the terms of such a will should be binding on the health care workers and should relieve them of any liability civil or criminal should they follow its terms. This again reflects my view that this is not primarily a medical matter and my antipathy to the absolute position that the law neither should nor could force clinicians into treatment which they object to giving (or presumably withholding)—see attached paper.

A definition of death should be incorporated into the Human Tissue Act and a requirement that doctors issue a death certificate before approaching a family for permission to use organs. This might assist the family in coming to terms with their position. The "required request" system used in the US is unnecessarily blunt as an instrument, but education of both doctors and patients may maximise donation, especially where coupled with the issue of the death certificate. In addition, legal standing should be given to the "donor card" system, as an endorsement of the rights of individuals when alive to make decisions about their own bodies—a recognition which is only a logical extension of that which we currently accord to those presently alive.

Voluntary euthanasia should be legalised under strict legal control. The situation in the Netherlands should be avoided since it still leaves the physician uncertain of his or her legal liability until after the event.

In the case of the handicapped neonate who is not in any event terminally ill, decisions should be permitted that life is manifestly more awful than death, but this should be set against a disinterested test and not solely or primarily dependent on clinical judgement.

Legislation can satisfy the values outlined above, but in my submission, only if it is permissive rather than directive. Although we do not adhere so competently to the sanctity of life, we must reinforce the value of all life—handicapped or not. There is an inherent paradox in our laws at the moment which can only serve to confuse and distress. On the one hand our law, using the professionally dominated model, seems to endorse what Jonathan Glover calls non-voluntary euthanasia (in respect of handicapped neonates) whilst simultaneously rejecting euthanasia in its least contentious, voluntary form.

If my basic premise is accepted that we do not always value life over death, and the principles outlined above (doubtless in conjunction with others) are also acceptable, it is for legislation to provide the procedural safeguards which avoid abuse and facilitate disinterested and competent decision-making. A law which restates the value of life, and then—as with the model of the Abortion Act—provides exceptions is, in my submission the way forward.

Paper given to Royal College of Physicians and Surgeons, Glasgow

[For the purpose of clarification it should be noted that the earlier part of this paper related to the suggestion by Dr John Harvard of the British Medical Association that the prosecution in 1981 of Dr Leonard Arthur amounted to a "legal threat to medicine".]

Perhaps more accurately, Dr Harvard might have claimed that the trial represented a legal challenge to what some doctors do. This is a quite different assertion. My first contention is that what doctors do is not necessarily equivalent to medicine, nor is medicine merely the sum of what doctors do. This is an

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important contention, because the way in which the law generally approaches apparent conflict or controversy about what doctors do is generally resolved by reference to their fear about what will happen to medicine if they find the behaviour in question lacking. Doctors, like all of us, are nonetheless subject to the law, and even well-considered and commonly agreed practices may fall outwith what is accepted by that law. In any event, the criminal law watches all of us in what we do, if what we do is illegal, and—despite the somewhat contrary verdict in this case—there is no doubt that the criminal law does prohibit anyone with a pre-existing duty of care from failing, with the intention of causing death, to provide the means whereby life can be sustained. What is interesting about the question posed here is the assumption, implicit (or perhaps more accurately explicit), that everything doctors do is equivalent to medicine, with all of the consequences which flow from that assumption. One important consequence being that what doctors do, based on professional ethics or credos, are medical matters which—more often than not—are most appropriately tested against the ethics and practices of the profession rather than being set against more general ethical principles. This is a very significant elision of professional judgement and common morality which has tended over the years to result in the behaviour of doctors being judged very much by that of their professional colleagues rather than as against some underlying set of legal or ethical principles which might be of more universal application.

Many commentators have noted the power of medicine and the medical model—it is not necessary to restate these comments here beyond noting that the categorisation of things as “medical” has traditionally moved consideration of the relevant ethics or even lawfulness outside of the usually applied tests and into the world of professionalism, and has opened decision-making to the influence of the complexities of professional evidence and the impact of professional practices. As you will doubtless know, seldom has this been more manifest than in allegations of medical negligence in which, arguably, the “Bolam Test” (recently apparently also adopted in Scots Law) seems to have virtually tied the hands of the judiciary to a professionally dominated test.

I raise this because it must be borne in mind that all enterprises, whether or not requiring professional skills, are ultimately subject to the law which may either set or reflect standards acceptable to the community. Indeed, professional and other groups when confronting new challenges will usually bear the law in mind when setting new standards, whilst at the same time they may also legitimately expect the law to take account of their expressed values. But in matters of such significance as life and death decisions, where medicine may prolong life rather than when it cannot, it might be argued that those in the front line may not have the best perspective and that rather the ultimate decision rests elsewhere, albeit with a professional input. There may be values at stake which go far beyond the skills or beliefs of any one professional group and which should be within the jurisdiction of the community as a whole. A failure by the law—which, however imperfect is the main channel for community views—to provide a clear framework, set against accepted or agreed ethical principles has two undesirable consequences: (1) it disenfranchises the community; and (2) it leaves those who are in the position of making the immediate decision (ie the health care worker) vulnerable. In this sense, the law (or the lack of it) may well represent a threat not just to what doctors do but to the good practice of medicine as a whole. Of course, this is entirely the opposite of what Dr Harvard was arguing, but in the kinds of issues which I am discussing tonight in particular, it reinforces my view that he was wrong to demand that only the professionals involved should have the authority to make such decisions. Indeed, I should say that many doctors of my acquaintance would not ideally want to be left to act as the conscience of the community, with the possibility that they may also end up as its whipping boy (or girl). Paradoxically, therefore, what I would suggest is that—at least sometimes—the fight to retain professional autonomy has the undesired consequence of rendering members of the professional group more rather than less liable and more rather than less required to make decisions which for any human being would be extraordinarily difficult. For as long, however, as the law is seen as the enemy rather than the partner, this is likely to continue to be the case.

This is a matter of considerable concern and not simply of academic interest. As I have suggested, once something is included within the exclusive competence and discrete area of decision-making of the medical profession, then its rightness or wrongness (to use very simplistic terms) is tested against criteria which may reflect what is done rather than what ideally should be done. To paraphrase the judge in Dr Arthur's trial when instructing the jury, he enjoined them to think long and hard before concluding that what was standard medical practice amounted to a criminal offence. The role of the criminal law in deterring and punishing acts who go against accepted morality ie deliberately ensuring the death of another in the absence of one of the accepted and limited defences, was subverted to a consideration of whether or not one particular group of people (however highly trained and respected) believed the behaviour to be accepted or acceptable. Indeed, it appears that—unusually—the judge was virtually inviting the jury to apply the “Bolam Test” to the criminal law. It is not generally the case that evidence of accepted practice amounts to a defence in criminal trials, otherwise, presumably, the mafia would never be guilty of a crime!

It must be asked, therefore, to what extent the criminal law in these cases can reasonably be said to represent a threat to medicine. Manifestly, in the case where doctors act in accordance with accepted practice in dealing with handicapped neonates, and perhaps—although not certainly—in other cases, and although the Arthur trial sets no precedent, doctors may assume themselves not to be under any real threat.

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Evidence based on clinical judgement and clinical practice will apparently be sufficient to convince, at least in those cases where quality of life judgements may also play a part. The civil law position will be considered in more detail later. On the other hand, although those in Dr Cox's situation may well find themselves sanctioned by the criminal law, is this in fact (and however much one sympathises with his motivation) a threat to medicine? I would submit that it is, rather, a threat to the assumption by any one individual with the necessary access to drugs and the skills to use them of the power of life and death, outside of those circumstances which are currently permitted by the law. Of course, the public and professional response to this trial might suggest that the law is out of step with common morality, but this still does not represent a threat to medicine. It may, however—as I shall discuss later—suggest that the law needs to look to itself with the possibility of reform in mind.

The Civil Law

Sticking with issues of life and death, does the operation of the civil law constitute any threat to medicine? In the cases considered by our courts, it seems that a pattern is emerging which points towards an answer to this question.

More often than addressing the potential criminal liability of doctors, courts have been invited to conclude on whether or not there is civil liability following decisions about whether or not, and in what circumstances, treatment can be withdrawn or withheld. Most commonly, and pre-dating the Tony Bland case, these questions were raised in respect of the handicapped neonate. In exploring what courts have actually said, I hope to identify whether or not there are principles which can be elucidated from this and how satisfactory these principles might be in terms of a disinterested morality.

First, then, I would like to look at the cases involving infants in order to see what, if any, principles can be extracted from them, and then I will seek to apply these principles to the Tony Bland situation.

Several distinct strands emerge on analysis. The first is that the courts (for example in *Re J* and in *Re R*) concluded that there is no inherent power to force doctors to treat against their will. In *Re R* the court said "The decision whether to treat is dependent on an exercise of ... clinical judgement ...". In *Re J*, the court stated that to compel a doctor to act to provide treatment which, in his or her "bona fide clinical judgement" was "contra-indicated", would be an abuse of power. Indeed, the court went further and, for once sidestepping the "Bolam Test", indicated that this would be true even if other doctors were prepared to offer the treatment.

Second, the court in *Re J* unashamedly addressed itself to the impact of treatment provision on others. It was said, for example, that it would be undesirable should the court embark on "making an order which may have the effect of compelling a doctor or health authority to make available scarce resources (both human and material) to a particular child, without knowing whether or not there are other patients to whom those resources might more advantageously be devoted".

Third, and perhaps most importantly, the babies in these cases were doomed to die. The imposition of treatment might only prolong an uncomfortable existence and might, indeed, add to the discomfort. It was, therefore, not "in the best interests of the child" that treatment should be continued or resumed.

My conclusion here, therefore, is that in the case of the handicapped neonate, the courts have striven to identify principles in addition to what good or accepted medical practice actually is, albeit they have been very dependent on the testimony of doctors as to this practice. Although dependence on professional rather than strictly ethical considerations is sometimes a worry to the lay public, there seems to be—at least in these cases—an acceptable interaction between the professional and the other ethical standards which evidence some attempt—however unsatisfactory—to seek a universally applicable set of standards. Certainly, the courts seem to have accepted that death is not always the worst option, at least in those cases where dying would only be prolonged rather than life with quality being saved. However, the way in which these cases are resolved leaves a certain unease. The classification of nutrition and hydration as "medical" is one source of concern, and also goes back to my original point about whether or not medical merely means what doctors do. And the reason for raising this point now is that—if we are to provide formal justice and the concomitant certainty of outcome, then it is necessary that we have a set of criteria which have universal application—at least for as long as these cases are decided by courts. My second contention is that—even given what I have just said—our courts are not facing the situation fair and square. The decisions which have concerned those infants who are not terminally ill are elided into those where they are, thus setting apart the moral dilemmas from those which relate to the futility of treatment. The courts, therefore, are required—in reaching the conclusions which they wish to reach—to engage in sophistry of a type which I believe to be unacceptable and which legal reform (of which more later) could eliminate.

It seems, therefore, that in these cases the courts are willing to adopt the position that accepting medical diagnosis, prognosis and treatment plans is the best available option bearing in mind the best interests of the infant. Although our courts will declare themselves as beginning from a presumption in favour of life, they may in certain limited circumstances hold that death looms so large and treatment would be so against the best interests of the patient, that doctors may be permitted to reduce life expectancy provided this is done in a humane manner.

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So, what can we say so far about the question originally posed? It seems that we can say that the law has an impact on medicine, but does this necessarily constitute a threat? If a threat only means that practices will be modified in order to meet the demands of the law, then clearly this is a threat, but medicine (even if we concede these matters to be solely medical) is in no different position from those others in the community who are constrained by the demands of the criminal or the civil law. However, a threat surely amounts to more than this, and analysis of these cases shows, in my view, that there is no threat posed—rather the law is rightly accepting a role in scrutinising decisions which may lead to the death of an individual, even if it is difficult to identify independent ethical standards in the conclusions reached.

The Bland Case

Never was the need for an underlying set of values more obvious than in the recent and tragic case of Tony Bland. The question of the role which the law should play in such matters was recently before our courts, ultimately reaching the House of Lords—the highest civil court in the United Kingdom.

As you will know, this case involved a young man who was in what has been called a persistent vegetative state. Professor Bryan Jennett, who coined the expression, estimates that there may be at any one time approximately 1,500 people in similar circumstances in the United Kingdom alone. People in this situation have lost higher brain function, and although they may make limited movements and noises, their capacity even to become conscious and aware of pain and pleasure is said to be irrevocably gone. However, they can continue to breathe spontaneously, unlike those who are described as brain stem dead. They are not connected to ventilators and for all intents and purposes they will continue to exist in a permanent coma until they ultimately die. They are not, therefore, dead for legal purposes although many of the recognisable characteristics of life are permanently absent. Given that independent, purposive movement is impossible, it is necessary that they are fed, usually through nasogastric tubes. Without this assisted feeding they will starve to death, although it should be noted that evidence suggests that Tony Bland (and presumably others in this condition) could be fed with a spoon, a point worth bearing in mind when considering what the consequences would be of classifying a nasogastric tube as “medical treatment”. Would the hospital be liable if they did not feed by other means? Is it only the nasogastric tube which makes this “medical treatment”? What if the hospital discharged him because they needed the bed—would his parents be legally liable if they did not feed him by spoon? It is submitted that this shows the folly of describing assisted feeding as medical.

Our courts were, of course, not being petitioned to reach a conclusion about whether or not death should be redefined so as to include those in pvs, but rather to consider what action (or inaction) might be taken by those caring for Tony Bland in order to achieve the apparently desired outcome that he be permitted to die, sooner rather than later. People in this condition have been known to survive for decades and Tony's parents felt that he should be allowed to die with as much dignity as possible. The questions before the court then were as follows:

- (1) When, if ever, can those having a duty to feed an invalid lawfully stop doing so?
- (2) (a) Does withdrawing of food and hydration constitute an omission or an act?
(b) is artificial feeding medical treatment?

I would venture to narrow the field of interest even further by asserting that there is no difference between an act and an omission in these circumstances, and by withdrawing it therefore from consideration for the moment. The major questions centre on whether or not artificial nutrition and hydration amount to medical treatment (and therefore should be judged by the “Bolam Test”) and whether or not it is ever lawful to withdraw feeding in a situation where there is a duty of care.

Although these questions are posed separately in the Official Solicitor's Brief, it seems to me that they are much more closely entwined than this would suggest. In many ways we already know the answer to the first question outside the medical setting, and arguably, unless there is something different about the nature of the enterprise because doctors are involved, the answer seems clear. As I have already said, case law tells us that eg parents will be convicted if they fail to feed their children with whom they are in a relationship which is clearly one incorporating duties of care, so why should doctors not be dealt with in precisely the same way?

The answer to this takes me back to my original comments about the application to all things involving doctors of a different “medical” construct. Now obviously, without technical know-how, patients in this condition could not be fed in this way and the dilemma would not arise. That we can offer artificial nutrition and hydration is the cause of the question being raised in the first place, but the real question is whether the fact that this capacity stems from medical skill, and generally is assumed to require those skills for its completion, makes it medical or part of medical treatment—what if you could train me to do this, would it still be medical treatment? In addition, this question has a heightened focus if the decision to use a nasogastric tube is one made for convenience of management rather than because it is the only option available. Doubtless, nutrition is better maintained in this way, but since the point of the raising of this case is to ensure death (by starvation) the fact that Tony Bland would be less well nourished and doubtless

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die sooner if the nasogastric tube is not used makes the medical aspect seem morally irrelevant since the same result would be achieved.

Given the judgements referred to in respect of infants, it might seem that the answer is obvious. If nutrition and hydration can be encapsulated into medical care in these cases, and can lawfully be withdrawn, then why not also in this situation? Mason and McCall Smith, for example, have long argued that artificial feeding can only logically be seen as medical treatment. The fact that it requires medical skill is sufficient to categorise it as medical. I would, as you will have gathered, dispute (for many reasons) this assertion not least because the elision of matters of life and death into a medical model may serve to obfuscate the issues which are truly at stake. Whether or not the outcome of such a move is the one which we might desire, I will argue later that this is the wrong way to go about achieving it. In addition, and with respect, and despite the fact that the official solicitor's brief relies heavily on the judgements in the cases of infants, there are differences in this situation which require attention.

My brief and somewhat simplistic analysis of the considerations which seemed critical in the case of infants shows that their cases and that of patients in pvs are not on all fours. First, the decisions in respect of children rested on the fact that their life would in any event be short—this is not necessarily the case with patients in pvs. Indeed, if it were the case, this whole matter might not arise at all. Second, the imposition of treatment was thought likely either only to prolong existence in a distressed condition for a short time, or its very imposition might add to the misery of the infant. It would not, therefore, be "in the best interests of the child" for the treatment to be continued. However, these considerations equally do not apply in this case. The tragedy of Tony Bland is that the diagnosis itself means that he had no capacity to express any self-regarding interests (which manifestly at one stage he did have), and therefore decisions which depend on interests are inevitably concerned with the interests of others, except perhaps in the situation where an advance Directive exists, or where courts (as in the United States, for example) are prepared to take account of verbal comments made in the past.

Tony Bland, we are told could feel no pain, and therefore—even if artificial nutrition and hydration are medical treatment—the above justification for its withdrawal (especially when coupled with a potentially long period of existence) does not stand in this case. The courts' overarching interest in the preservation of life is said in cases involving infants to be subject to exceptions which relate to the individual concerned—manifestly this is not applicable to those in pvs. Indeed, of the elements identified from the cases concerning infants, the only one which stands for those in pvs is that which relates to scarcity of resources. This opens up a whole new set of issues which time precludes consideration of today.

What are the Options?

Of course the courts can, and in the Bland case did, require that each decision of this sort was to be scrutinised by the courts, but if the central point is that the decision is "medical" then courts will likely continue to view it as appropriate to apply the "Bolam Test" leaving life and death decisions subject to the professional view of reasonable medical practice. In any event, the Bland case has not clarified the principles underlying the decision to permit him to die. Merely saying that nutrition and hydration are medical only tells us that the desire is to ensure that his existence can be ended. But what are the interests at stake and whose are they? Simply insisting on court scrutiny doesn't advance the cause of identifying the ethical basis for such decisions being taken, even if it provides some symbolic strength. In addition, taking each case to the courts is a cumbersome, time-consuming enterprise which seems to serve the interests of nobody. And, I have already suggested, the use by most of the judges of the "best interests" test is illogical, given Tony Bland's diagnosis.

Despite my dissatisfaction with the way in which this case has been approached, what options did the court actually have? Failure to classify nutrition and hydration in the way the court did would leave the court only with the option of restating that the law has an overriding interest in the preservation of life which can only be modified or deviated from in the face of other compelling considerations. This is effectively what the courts have said in the cases concerning infants, but what are these considerations and are they applicable here? In *Re J*, for example, the court made it clear that the primary consideration would be respect for life. However, it was also conceded that there may be exceptional circumstances where the quality of that life is so bad as to merit this primary commitment being subject to limited exceptions—a position already made clear in the 1981 case of *In Re B*. However, these circumstances were dependent on the suffering of the child, the distress which the lack of quality might cause it and so on. Again, however, this exception did not apply to Tony Bland, and since there equally are no self-regarding interests currently held by someone in pvs there is nothing directly concerning the patient to put in the balance and tip the scales away from the overweening interest in life. A straight translation of this test into the position of Tony Bland would, therefore, arguably have required the courts to hold that nutrition and hydration must be continued.

Or the law could conclude, without indulging in the sophistry associated with a distinction between acts and omissions or what constitutes treatment, that it should not endorse inhumane or futile behaviour, pure and simple. By so doing, they would recognise a further exception to the principle that all life should be respected—an exception based on a moral commitment rather than one which merely coincides with

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accepted medical practice or which is an artefact designed to achieve a desired outcome. Reaching this conclusion would have a number of consequences which would, in my view, be desirable.

First, it would suggest that the proper method of decision-making in cases of this sort is not solely equivalent to accepted clinical practice. Rather it would be viewed as a matter of morality. Evidence suggests that a majority of this, and other, communities would endorse the termination of existence in certain circumstances—this endorsement is one factor which can and should be taken into consideration. However, the courts are not currently in a position to do this, and perhaps for this reason have based their decision on other—less acceptable, or at least more arguable—criteria. It may well be for this reason that two of their Lordships called for legislative intervention to resolve the dilemmas confronting those caring for people in pvs. The logic of suggesting that morality, rather than fine and dubious definitions, should form the basis for decision-making is that it is for Parliament and not courts (or doctors) to decide in what circumstances withholding nutrition and hydration will or will not be legally acceptable. Not only will this be preferable in terms of principle, but it would save the unedifying pursuit through the courts which is currently required. Courts would seldom, if ever, be required to take part in such cases. It is not often in sensitive areas of this sort that legislation seems like a good idea, but in my view this is an example of precisely where it can play a valuable role. A law which classified firmly and unequivocally the defences to allegations of unlawful withdrawal of treatment or hydration and nutrition would not only resolve the problems of civil liability but could also resolve matters of criminal liability. Clarity would also place considerable restraints on the potential for overuse or abuse, and would liberate health care professionals from the fear of legal reprisals.

Second, legislation could address itself to the tests to be applied when such decisions are necessary or thought to be so. As I have said, one difficulty confronting courts at present is that the most commonly used test—that of best interests—is manifestly inappropriate in some cases. As the Canadian court said in the case of *Re Eve*, something which is non-therapeutic can never be said to be in the best interests of the person concerned even assuming them to have self-regarding interests. If the best interests test is not applicable, then it will be necessary to come up with an alternative—perhaps a form of substituted judgement test or perhaps, as in the case of Nancy Cruzan, “clear and compelling evidence of past statements by the individual—against which all decisions are to be measured. In addition, in striving to find an acceptable test, legislators would almost certainly have to address themselves to the validity of so called “living wills” or advance Directives (which interestingly the House of Lords in the Bland case came very close to endorsing). Either of these tests would be sufficiently demanding to ensure that decisions based on morality could be taken without fear that undue influence might be applied.

It would, in my view, also provide Parliament with an opportunity of grasping the nettle of whether or not there is any point in maintaining the artificial distinction between act and omission. If the ultimate good is the termination of an existence from which all hope is gone, then there is no clear moral reason why this should not be done actively rather than passively.

And finally, legislation of this sort has the distinct advantage of recognising precisely what is going on. We cannot pretend that decisions to permit death in such cases are taken exclusively or even primarily in the interests of the individual concerned, nor in my view should we take the easy option of simply saying this is a medical matter, for all of the reasons I have given. In fact what we are doing is to give priority to quality of life and the interests of others—family, carers and perhaps the entire community. Arguably, admitting this in legislation is doing no more than acknowledging what is already the case. It matters not to anyone in pvs whether or not their existence is continued, but it does matter to their families and to those caring for them, and indirectly to all of us. For these reasons, a clear and unequivocal statement based on morality rather than sophistry seems infinitely preferable. Although based inevitably on medical information, the decision is one for all of us.

If the law were to concede that humanity rather than current—and not necessarily unanimous—medical practice should dictate the fate of those in persistent vegetative state, there is nothing which prevents it from authorising the active termination of an existence from which—by virtue of the facts of the condition—all value has gone and in which the individual concerned has no continuing or identifiable self-regarding interests. Indeed, the principle of humaneness might well demand that such a conclusion is reached, since it seems to be considerably preferable that the termination of existence is quick and easy rather than achieved by way of starvation—not in the interests of the individual who, as has been said, lacks the capacity to suffer, but in the interests of the abstract principle of humanity and also those others whose interests are taken into account even if they are not decisive.

Conclusions

There are a number of distinct but entwined strands to what I have tried to say. First, that to define something as solely or predominantly medical has consequences which go much further than mere definition. Absorbing matters which are fundamental to morality within one discrete framework limits the input of society and the law. The repeated dependence on the “Bolam test” in the Tony Bland judgement shows just how pernicious this trend can be, certainly in the United Kingdom Courts.

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Second, that to do so may also have a profound, and I would argue, undesirable, impact on the methods by which decisions based on humanity may be carried out, perhaps even resulting in a humane decision being carried out in a less than humane manner.

Third, that for the law to adopt a role which is independent of the practices or professional morality of a given group, serves as a clear and unequivocal statement of policy. This has benefits both for individuals and for those in the professional group most immediately concerned. It has the value of postulating clear rules and of deterring deviation from those rules, and avoids what, at the moment, seems to be a somewhat disingenuous—and certainly not value free—approach.

Finally, legislation would pre-empt the need for court proceedings which may merely add to the distress of those involved and whose interests we are conceding to have relevance.

I have therefore tried to show two main things: first, that a criticism of what doctors, or some doctors, do should not inevitably be taken as a threat to medicine—it might just as easily be a community based statement of values to which we are all expected to conform; and (2) that although conventional wisdom might see legislation as an inappropriate means of dealing with complex and sensitive matters, it may—at least in some cases—have the potential to provide all interested parties with both a flexible and a sensitive guide both to the morality of their actions and to their legality.

So, to return to the original question—is there a legal threat to medicine? If it is conceded that the perceived need to make decisions of this sort, whilst it may hinge on clinical issues to an extent (for example in diagnosis and prognosis) arises from humanity rather than medicine, then it is clearly not medicine which is under threat when courts or the law speak. The practice of some doctors may be, but medicine itself is not. Thus, whatever decision is reached by courts, or is promulgated by legislators, it is directly or solely about medicine and therefore cannot represent a threat to it.

However, this does not mean that there are not continuing problems. The manifest legal absurdity of the verdict in the Arthur trial, whilst it may satisfy intuitions, did little for the dignity of law. For many, the sight of Dr Cox being convicted of acting in a humane way when, if he had been in a position to, his withdrawal of care, with exactly the same intention and outcome, would not have been the subject of sanction, also does little for the law's majesty. The fact that Dr. Cox escaped serious censure seems to suggest that his conviction brings the law out of step with the ethics of many. The answer, I have suggested, is to remove these fundamental problems from the traditional medical model and to address them as matters of rights and humanity. In this way, the same outcomes may be achieved, but they would be rooted in an ethic which demands the parallel adoption of principles which can result in certainty for the professionals involved and formal justice as well as humanity. Removing the exaggerated and, in my view, erroneous trepidation with which doctors and lawyers often seem to confront each other is a consummation devoutly to be wished. Only then can we move together towards participating—with the rest of the involved community—in the creation of a value system which can supply transparency of decision-making, accountability without threat and humanity.

Examination of witnesses

Professor GEORGE CASTLEDINE, Consultant in Nursing, Head of Nursing and Community Health, University Central England, Professor SHEILA McLEAN, Director, Institute of Law and Ethics in Medicine, University of Glasgow, and Mr REG PYNE, Assistant Registrar for Standards and Ethics, United Kingdom Central Council for Nursing, Midwifery and Health Visiting, called in and examined.

Chairman

408. Thank you very much indeed for coming along and seeing us, Professor Castledine, Professor McLean and Mr Pyne. You, of course, are coming here formally to represent the views of the United Kingdom Central Council for Nursing, Midwifery and Health Visiting. We have of course had your very helpful written evidence, and have all studied that carefully. Do you wish to make an opening statement on behalf of the UKCC to amplify your written evidence, or shall we go straight to the questions?

(Mr Pyne) A brief opening statement, if I may, my Lord Chairman, though not to amplify the statement but to put it in perspective. This Committee was established and the Council's views were sought

right at the very moment when we were changing from one Council membership to another. I think it would be important that I say, although we come from the United Kingdom Central Council for Nursing, Midwifery and Health Visiting, it would I think be wrong to say that that Council and all of its members have a single view. The document which I was responsible for compiling represented as best it could the views of the Council membership which ended its term on 31 March. These issues have not been able to be discussed with the new Council membership, very, very much changed, that took office on 1 April. It so happens that Professor Castledine was a Council member both before and continues, and Professor McLean is a new appointed member. I do not think on matters as important as this I would wish to be on record that this was the

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PROFESSOR GEORGE CASTLEDINE, PROFESSOR SHEILA McLEAN
and Mr REG PYNE

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Council's view in terms of pretending that every member of the Council would run in agreement with it, because I know that not to be the case.

409. Thank you, that is a very clear statement. Could I ask you first whether you feel that the expertise of nurses and the intimate knowledge which they have of their patients is given adequate weight in the decision-making process about patients nearing the end of their lives, and whether you would agree with the evidence we have received suggesting that, even with the best palliative care, there are some individuals whose pain, distress and suffering cannot be fully relieved? What do you think might be the proper course of action in such an exceptional case?

(Mr Pyne) Taking the first part of that, as to whether the expertise of nurses and their intimate knowledge of patients is given adequate weight in the process of decision-making, I think our short answer would be, no; but I would immediately have to qualify that by saying that there are settings in which quite the reverse applies, that there is good practice in many situations, true co-operative inter-professional working, and I think in those situations nurses feel that the intimate knowledge they develop, whether that is as a community nurse or within hospital or hospice practice, is paid heed to. We certainly promote the case to our practitioners that they should engage in collaborative and co-operative working to the best of their ability, and seek that that be reciprocated. Indeed, it was interesting to hear the latter part of Sir Robert's evidence, because in his time as President we have been able to form a very co-operative joint liaison committee working with the General Medical Council in the belief that if matters of this kind are to be talked about inter-professionally then it is important we do it one statutory body to another. That, I think, has been a positive development.

(Professor Castledine) With regard to the decisions, I am actually a practising professor as well as an academic professor, and I feel very strongly about this point about decisions because I feel there are many situations nurses are in, particularly in hospitals and out in the community, where they feel very strongly that their decision is not listened to enough by the doctors and by all the members of the team. I think it is also because, nowadays, we are stressing to nurses to develop that close relationship with their patients, and it is part of our teaching to them. They feel very strongly that they have a different sort of relationship perhaps from what Sir Robert was referring to. There is a lot in the nurse-patient relationship and I think that often gets glossed over very quickly by medical practitioners. The nurse is often there all the time and is often visiting and is more sensitive to picking up the patient's wishes. I think nurses often feel frustrated that their decision is not listened to or is not encouraged in those team conferences.

410. Do you think the position has improved in recent years? Is it still improving? If not, what action could best be taken to improve it?

(Professor Castledine) Particularly in palliative

care and care of the elderly and in many of those situations there has been quite a good improvement. I would not say it is ideal, but there certainly has been a marked improvement in those areas, and they have been showing other areas of nursing that decisions in palliative care and care of the elderly that doctors and nurses can certainly work together. What I think worries us, certainly in the other more technical and medical areas of care, particularly in intensive care units and acute medical and surgical situations, often nurses feel that they are not allowed to express the opinions which they would like to.

(Mr Pyne) May I interject another point. Pain or distress cannot be fully relieved. I think it is important to try and tease out those two words—"pain" and "distress", because I think it often seems to members of the profession, of which I am pleased to be a part, that some of that pain and much of that distress is, at least in part, the product of the fear and the loneliness of people suffering terminal illness and approaching death. I think one cannot look at the major issues that you are faced with without remembering as well the need for people in this condition to have a supportive presence. Certainly sometimes that is difficult to achieve because of resource problems. Nursing the terminally ill is not about performing tasks; it needs a great deal of continuity of care, and a deal of understanding. The distress and the pain that people sometimes feel is, I think, exacerbated by the absence of the ability to receive good care in continuity.

411. May I take you to one or two points which we did not have an opportunity of discussing with Sir Robert. Firstly, your comments upon advance directives; secondly, upon what you refer to in your document as the "substituted judgment" test, which in some respects is comparable to a proxy appointment; and, thirdly, upon the issue which has been suggested somewhat differently by the BMA, on the one hand, and the Law Commission, on the other, that instead of having to refer every case such as Tony Bland to the High Court there might be some kind of local tribunal mechanism established, which could be set up to handle such cases, leaving only the ones where there was a major dispute to be resolved in the High Court?

(Professor McLean) It occurred to me, looking through the provisional questions that we were sent, that many of the answers would actually hinge on how we answered the question about the lawfulness or legislation to give force to advance directives and I think one of the things that we were discussing is the extent to which in many, many aspects of our legal process, we have already taken account of the notion that people who had pre-existing rights, should not have those rights denied to them when they come into a situation where they are no longer competent to exercise them—and I am thinking of the mentally handicapped and dealing with handicapped infants and so on, who admittedly had no pre-existing rights or decisions. One possible way of viewing advance directives would be as a logical continuation of the process of expressing a right in advance of becoming incompetent and whilst I

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accept the concern that people might have that these would be difficult to frame adequately, we at least do have the evidence and examples of other jurisdictions to rely on to improve upon, were we to go towards a situation where legislation would give force to these directives. The second part of the provisional question actually suggests—and Sir Robert addressed this before he left—the extent to which professional judgment would or should override such directives. I would suggest the critical question here is the extent to which the advance directive is reflecting some kind of on-going concept of people's fundamental rights, or whether it is dependent on the clinical. It seems to me actually both could be written into it, but I think if we were to legislate in favour of advance directives, ideally we would do so with respect to the patient's rights and that being the case, the clinical should not enter, in my view. On the question of substituted judgment, what the paper I think had in mind was a refinement of the very elementary substitute judgment tests which would just be second-guessing what somebody would have wanted, had they been in a position—

412. Yes, quite.

(Professor McLean) I think we did not want to go for something that was quite as simplistic as that, but rather to learn a little again from other jurisdictions, as you know, and try to refine those tests, either to move towards a situation where you have advance directives, or something which can be taken as being at least lawful, or where the substituted judgment test is sufficiently refined that it is first-guessing rather than second-guessing. That might be done by way of looking for clear and convincing evidence, as the Missouri Supreme Court, or something that has been expressed or in writing. Or it might be by permitting those closest to the person, who is no longer able to express their opinion, to perpetuate the rights that person would have had, by making decisions on their behalf. What we were trying to do was to move away from the "best interests" test, at least in respect of those who probably cannot be said to have any ongoing interests.

413. There have been suggestions made that many documents at the moment in hospitals in particular, refer to "next of kin". We have had a good deal of evidence from other sources suggesting that the next of kin may not always be the appropriate proxy to take action on behalf of the individual and that it may be an individual nominated in advance by them, other than a family member. What is your view on this?

(Professor McLean) That is precisely why I used the language of "person who knows the person best" rather than next of kin and I think in a sense that may also resolve some of the problems that were being posed about the extent to which people may feel themselves to be a burden, in that if what we have is the person who knows somebody the best, not only do we thereby include relationships which are not normally part of our idea of kinship or the

standard marital relationship or so on, but we actually permit those who know the person best actually to tell us the truth about a situation, rather than assuming they might feel themselves to be a burden or not, as the case may be. We would certainly want to see there is an extended situation rather than merely relying on traditional relationships.

(Mr Pyne) I think, Chairman, we were not perhaps as clear as we could have been on substituted judgment and Professor McLean has, I hope, clarified our position on that. Certainly I think we were clear in the paper in talking about those closest to the individual, even in the absence of marital or familial ties.

Baroness Llewelyn-Davies of Hastoe]Chairman, there was a witness who brought out rather clearly I think that hospitals tend to automatically say "next of kin" and that can be misleading to patients.

Chairman] Yes, that came out very clearly in the paper from the Terence Higgins Trust.

Baroness Llewelyn-Davies of Hastoe

414. That would coincide with your views?

(Mr Pyne) It would.

Archbishop of York

415. I hope I am not summarising Professor McLean's paper too much by saying I think what you are telling us is that these matters are much too important and complex to be left to doctors and what we have heard in the earlier evidence, which I think you were listening to (on the whole we have heard from the nursing profession) is that we are dealing with a whole set of highly individual cases and close personal relationships. I am wondering how you square with this a sense of what medicine is, the kind of decisions that have to be made, with the notion that you could somehow move over into the field of law, which is inevitably a very blunt instrument and it depends upon the highly disputable interpretations and so on? I am just wondering how you hold this sense that we have, of the large step that has to be taken in individual cases, with your desire to see legislation in this area?

(Professor McLean) I think what I was not trying to say is that this is too complex to be left to doctors. One might be tempted to say it is too complicated to be left to anybody. What I was trying to say though is that I do not see these issues as being predominantly or solely medical issues. There are a number of reasons for that which would have a spin-off on all the health care workers too. What I was trying to say was, I think there are principles underlying this which we should be addressing and that we might want to be consistent. For example, as I pointed out, it seems strange to me that we permit non-voluntary euthanasia but do not seem currently to permit voluntary euthanasia. It is an infelicity in our legal system, which I think perhaps we ought to address. It is not so much really that doctors are not competent to make these decisions which are too complex for doctors, but rather that I do not think we

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should disguise issues of principle by dressing them up and calling them medical, because not only is that failing to address the issue, but it also leaves the clinical health care worker in a situation where both their civil and their criminal liability is really unclear. It is not that I do not think doctors are competent, it is just I am not sure these are simply clinical issues and I suspect that by separating them from clinical context, we also provide some kind of safeguards for the health care workers who have to either watch the inaction taking place, or make the actual act, however we conclude.

Chairman] Thank you. We have had a lot of evidence to suggest that there are decisions in many difficult cases which should be made by the health care team as a whole.

Lord Mishcon

416. In regard to the decisions made by the health care team as a whole, I thought I heard the expression "they are not allowed to" in some cases and I wondered whether it was thought that it was a deliberate decision by doctors not to allow more participation, so far as nursing staff is concerned, or whether it was not deliberate, but due to the fact that hospitals are so terribly busy and the doctors are so often terribly busy, that there is not sufficient time for consultation that would otherwise take place? It is the words "not allowed to" that worry me, because I only wanted to get clarification to see if there was any recommendations that we possibly would want to make, if it was a barrier as against something which unfortunately could not be avoided?

(*Professor Castledine*) Obviously they were my words that they were "not allowed to". I think there are some cases where nurses feel they are not allowed to have a say in what has happened, or what is happening to the patient. I do not know it is altogether always deliberate by doctors. I am sure it is not and your point about them being very busy and rushing about and therefore perhaps overlooking what the nurse's view is, is a very valid one, but I think there are a few cases where perhaps a doctor feels that the nurse really does not have an opinion "because this is a medical matter" and particularly I think if you look at some of the treatments now, you will see that it is their medical decisions to increase the drug or to put down a tube or to put in another line, as it were, in technical jargon. They see that as very much a medical decision and not a nursing decision, so they may feel that the nurse should not be allowed to have an opinion about that aspect. I think what worries some of us is if you start saying that all these things are medical treatments it therefore precludes it from the nurse feeling that she can have a decision to make.

Baroness McFarlane of Llandaff

417. I would like to take you back to the UKCC submission. You talk in paragraph 4 about the inconsistency in the law and then in paragraph 5, "At the heart of this confusion is the 'killing or letting die' distinction ...", which you say is nothing short of

hypocritical. I found myself sitting up and taking notice of that condemnation. "It seems to many nurses that to prohibit euthanasia as a passive or active measure, yet permit the use of narcotics to alleviate pain, is no longer a sustainable position". I wondered if you would expand on that? Why do you think that this distinction is no longer sustainable, because it has been held over many years, has it not?

(*Mr Pyne*) Yes, I think part of the question to which I referred was the focus about: is this an action intended to relieve pain, or is this an action intended to terminate life? I do believe, and I speak from my own experience and I meet many people in my travels around the United Kingdom who could supplement that information, that it is not infrequently the case that the intention is to terminate life. The vehicle chosen is the use in heavy quantity of a drug which has the capacity to relieve pain and therefore brings that intention to terminate life within the law as I believe it is. Whereas if it had been an overt intention by the use of a drug which had no capacity to relieve pain, e.g. Dr Cox, then it falls the other side of the fence. That is really the focus of what I see as somewhat hypocritical.

418. Where does that leave you in terms of your views on active or passive euthanasia?

(*Mr Pyne*) I do not know that in the end we quite get to a conclusion. We search, and I think we search with you as I am sure you are searching considering in various paragraphs of our paper, certainly paragraph 6 is one. I think we say in paragraph 30 that, "The Council therefore seeks a sensitive law which allows professional practitioners the opportunity to identify and serve the best interests of their patients". That should be a new law which gives credence to the professional practitioner's overriding duty of care to patients. It is very, very difficult to know quite how that would be constructed, but I think it would be quite wrong not to accept that there is a significant element of hypocrisy about now. I can assure you the mailbag that the Council received about the lady who, as it were, "blew the whistle" on Nigel Cox would illustrate the extremes of view that there were about that; a very, very strong feeling represented through my mailbag which was of the view that she had acted wrongly because his intentions were good but his path, as it were, was bad. The mailbag was enormous, I can tell you.

Chairman

419. We can understand that but, equally, we are all, I think, fully aware of the fact that the circumstances of that case were in many ways exceptional, and that the act which was carried out by Dr Cox was, within the terms of the law, a criminal act. We are quite clear on that. May I follow up on what Baroness McFarlane has said, that putting it the other way, there is then a danger of a circular argument: if it is clear that the best intention of the doctor, for example, is to relieve pain and suffering but that the drug which was given in order to have that effect secondarily had the effect of shortening life you

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would not regard that as being something which you would oppose?

(Mr Pyne) I agree with that.

420. Similarly, some people do fear dying in pain and indignity, subjected to burdensome medical interventions. How do you feel that such fears can be properly allayed?

(Professor Castledine) I think it is most important that the nurse is involved in communicating very carefully with the patient. What is interesting in the move in nursing today, is to try and bring together this nurse-patient relationship and to communicate better with the patient and to demonstrate to the patient that there are other measures which can be explored so that the patient feels that they are involved in their care. That is an emphasis which we are trying to encourage. I think that is the most important thing. It is part of ethics, really involving the patient in what could be happening to them, and informing them very carefully about what is happening.

421. In a major, overcrowded medical curriculum more and more attention is being paid to teaching doctors about medical ethics and topics of this nature. Indeed, many trainee GPs demand that in their vocational training they should be given specific training, for example, on care of the dying. To what extent would you say that in nursing education this issue is handled?

(Mr Pyne) Could I answer that at several levels. First of all, we are grateful to your Lordships' House and for the help it gave us last year in getting some new legislation through; because we had identified a number of defects in the legislation, one of which did not allow the Council to prescribe (and I do not mean prescribe in exact terms of how many hours) the content of programmes leading to registration. That lacuna was helpfully dealt with for us, and does open the way. Legislation has only become operative from 1 April this year so there is not a great deal of time for usage yet, but I think that opens the way for the Council to be, in the best sense of the word, more prescriptive about programmes of education leading to registration. We do clearly see already, without any compulsion, a significant trend to address these matters in programmes of education leading to registration. I think again we have to be careful not to see that as an issue in isolation. Professor McLean will in a moment address the link that this again has with the advance directive issue. In my response I would have to come back to the fact that we do not just have to address the issue of education in respect of ethics and its application to professional practice, but the need to redirect much of our pre-registration education so that terminal illness and the care of the dying is given as much attention as high technology new frontiers work. I think if that is done then one goes some way to providing a form of care and treatment that makes the indignity factor less of a problem. If there are constant changes and a different nurse coming in every two hours to care for a patient a relationship is not building up and indignity is an issue, which is

not there where there is good continuity of care. Certainly we feel that there are occasions, and I know many nurses would come with me on this, when it does seem that intrusive interventions occur too often, almost as if, at times, any death is a failure. I would personally deplore that attitude. Where does it get you to in the end, having dealt with all those things and having done the best you can in teaching ethical practice, in making terminal illness and the care of the dying something that is good to be involved in and good to do well? I think the ultimate "what if there is still the person with pain" is a problem which is difficult to answer.

(Professor McLean) There are two questions there: one is the question of education and the other is the question about people fearing dying in indignity. One of the pleas I would make is that when people are considering the educational aspect they do not attempt to put things into a vacuum as if there was nursing, then there was ethics and then there was law. In answering the second question I hope to try and show what I mean by that. The question about people being afraid of dying in pain and indignity is a phenomenon we already know is happening in the United States and the evidence suggests that people are committing suicide in increasing numbers because they fear inappropriately being stuck onto technology without having the right to ask for that to be removed, because people are concerned not about the clinical, but about the fear of litigation. So there is obviously a link there. I think that one of the ways in which we can resolve the problems that the health care workers have in perhaps making decisions which are inappropriate is to clarify the position. Another reason why I think perhaps some kind of legislative intervention might make sense, but also this will depend on the extent to which we either render lawful the advance directives and—I keep coming back to that—the extent to which it is given pride of place; we have experience of the Human Tissue Act for example of not actually following through people's wishes in the case of subsequent objections by others and that is, as you know, something that is resisted. I think more important of course is the whole question of truth telling and interestingly many of the issues this raises seem to me to go back to the dialogue between health care workers and patients. One of the things that must confront nurses as much as anyone else in dealing with those who are nearing the end of their life is whether or not they are being told the truth and what standards we impose on people to tell the truth in those circumstances. It is all very complex.

422. I am glad you raised the question of litigation, because I was going to raise that with you. There is no doubt at all that some of the, shall we say, apparently mischievous interventions towards the end of life in the United States, are based upon the fear of doctors concerned that they might be sued if they did not take such action. There is just a hint that this kind of thing is beginning, in certain circumstances, to emerge in the United Kingdom. Is this something of which you are aware in the nursing profession?

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(Mr Pyne) I think perhaps Professor Castledine might have a supplementary view on this. Only in my case, in terms of the increasing anxiety that people seem to feel and communicate to myself and other professional officers of the Council, about interventions that they see as worrying and feel that they are trapped in something of a "catch 22" position as to whether they keep silent, knowing or believing something happened that was inappropriate or colloquially blow the whistle on that issue. I think it is increasingly a dilemma that people have. Another dimension of the same issue is the anxiety that people feel about what they see as inappropriate resuscitative attempts, in respect of individuals who they know have declared a wish not to be resuscitated in certain circumstances. Of course one of the issues we have addressed in our recent document about records and record keeping is our clear belief that where a decision has been made not to resuscitate, it should be clearly recorded and regularly reviewed.

Archbishop of York

423. Can I ask Mr Pyne and Professor McLean whether what you have just said about some inappropriate forms of treatment, is what lies behind what Professor McLean said earlier about involuntary euthanasia? You were justifying voluntary euthanasia on the grounds that involuntary euthanasia already takes place and I was wondering, could you give us an example of what you mean?

(Professor McLean) I was actually referring to what Jonathan Glover called non-voluntary euthanasia, which would be acting in supposedly somebody's best interests in a situation where they do not have the capacity to express a view. So it is not going expressly against someone's wishes, which would be involuntary euthanasia. The examples that I had in mind of that are decisions taken for example in respect of handicapped neonates, in a situation—which has been taken both via criminal and via civil courts—in this situation neonates cannot have expressed a pre-existing wish, so we cannot base it on substituted judgment, if you like, or a refined form of that, and where the "best interests" test is used—in some cases it is very clearly the best interests of the infant, because treatment would be more distressing than failing to treat, but in some cases may reflect the best interests of the carers as well, although the non-voluntary form I was addressing myself to—what I was suggesting was not actually an attempt to justify voluntary euthanasia, it was just to indicate the paradox that there seems to me to be in an approach where arguably the least contentious form of euthanasia would be that in which the individual makes a declared and testable request and yet the law is hesitating to endorse that, whilst at the same time permitting arguably other forms of euthanasia which seem to be slightly more contentious.

424. Can we pursue this further in the case of the neonates, say with massive spina bifida or something like that? The decision presumably would be not to subject that infant to a long series of potentially

distressing operations. It would not be to take any direct action to terminate the infant's life, it would be as it were a withholding of treatment?

(Professor McLean) In all the situations where it has arisen so far, all that has been endorsed has been a withholding or a withdrawal of treatment, yes.

425. You would not see any ethical distinction between that and the delivery termination?

(Professor McLean) I have a problem with the act and omissions distinction, which I think is in fact in many quarters actually rather discredited nowadays as being a distinction which at least at a philosophical level will not stand. I can see why at a personal level, it is vitally important to those involved in the provision of health care, that it may be less distressing to withhold than it is actively to kill, but I think it is a philosophical decision. I have as many problems about it as I do with the principle of the "double effect" issue, which was raised earlier also, in that one cannot actually test intention.

Chairman

426. Yes, in purely moral terms I am sure that what the Arch-bishop said is absolutely right, in that the effect of withholding treatment in such a case would ultimately have exactly the same effect as taking positive action to end life?

(Professor McLean) Yes.

427. I am sorry, I asked you a rather complex question beforehand, which you did not have an opportunity of answering and that was about the Law Commission's suggestion and the BMA's suggestion that there might be a mechanism of establishing local tribunals, in which cases of difficulty like sterilisation of a mentally incompetent person, for example might be referred. Do you have a view on that?

(Professor McLean) Yes, I do. It is again looking at the examples that we have in respect of the United States, for example where they have Committees dealing with handicapped neonates, the experience of Research Ethics Committees and research that has been done into them. It seems to me that one of the very important principles in all of this is also formal justice, which would incorporate consistency of approaches, certainty of outcome. The experience of Ethics Committees in a whole variety of parts of medical practice have been in fact that we do not achieve consistency. It may be you would want to say "Consistency is not the goal here" but how can people feel that the doctor is (a) not an executioner, but (b) will not subject him to unnecessary treatment? One way of doing that is to be able to appeal to the notion of consistency of approach. I think the Ethics Committee approach does not achieve that.

428. I was not thinking of an Ethics Committee. I agree that some of the judgments which such committees have made are somewhat different from place to place, bearing in mind their varying constitution. I think the Law Commissioners suggested something along the lines of a three or four man or woman body, consisting of an independent doctor,

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a lawyer, perhaps another health care professional such as a nurse and a lay person, who would be an independent assessor. That is the sort of tribunal I had in mind.

(Mr Pyne) Certainly I find myself—this is not I hasten to add, an issue that Council has discussed—I certainly find myself attracted to that to some degree at least in theory, because I run very much with the emphasis in certain judgments in the House of Lords in the *Bland* case that takes the view that the courts were not quite the way to deal with issues of that kind and if it is possible to make cases of that kind extreme, but to provide an effective and broadly consistent means of dealing with the other thing, I think we would be willing to look at that with great interest.

429. The House of Lords judgment in that case leaves only three alternatives. One is to allow common-law to develop, which would then inform decisions in subsequent cases; that would be a lengthy process. The second would be to change the law, and that is complicated in itself. The third would be to consider the possibility of some kind of local mechanism as the Law Commission has suggested. There are other alternatives, but those are the principal ones which arise from of it.

(Mr Pyne) Yes.

Lord McColl of Dulwich

430. Could I go back to what Professor McLean said about telling the truth to patients who are dying. Surely in the whole of the hospice movement in our country (and there are, in every district, hospices) the basic principal is that they are not allowed in until it is quite clearly established that they do know they are dying. In the whole of the hospice movement there is no problem. When it comes to outside the hospice movement, one of the things which has always struck me is, having written down what I have said to the patient and I always do this in the notes, it has always surprised me how, later, the patient will deny that they have been told something, and this is one of the facts of life. As far as the fact that they are going to die is concerned, this is particularly the case because people will deny what is happening. This does not worry me because it is a fact of life and the way that many patients cope. When I am told that a doctor or a nurse has not actually told the patient what is going on, I always take that with a pinch of salt. Would you not agree?

(Professor McLean) I was not actually suggesting that people were not told the truth. What I was trying to do was to point to this as one of the difficulties that nursing personnel may have, if there is uncertainty about what the doctors have actually discussed with the patient. I am assuming that part of palliative and other care is being able to talk to the patient and talk around what the patient has or has not perceived. That, I would have thought, very often would be a job for the nurse who is on the ward, and they are there more often than the clinicians. It was not really a comment about doctors not telling patients the truth.

431. I was not applying it to doctors but to everyone.

(Professor McLean) Maybe part of the process is working with the patient so that, having told them the reality of their situation, they are facilitated to coming to terms with it and believing it.

432. Many of them do not want to. They will go on denying it, and why should they not.

(Mr Pyne) Quite clearly this example is a good one, and I wish it were universal; but there are, of course, other situations which we become aware of where nurses are told, "You mustn't tell that patient the truth". There is a view taken that "she won't be able to cope with it", or that "her husband doesn't wish her to know the truth". Whereas I endorse the practice described, examples of the other are still there.

Chairman] It all comes down in the end to the quality of communication between the patient, the doctor and the other health care professionals.

Lord McColl of Dulwich

433. Would you say it is important to define the extent of this problem, because 30 years ago it was the norm that they were not told? It seems to me that one of the problems was that the relatives of the people kept telling us, "You mustn't tell the patient what's going on", but nowadays I would have thought that most doctors and nurses agree that they should be told the truth. Would you not agree with that?

(Mr Pyne) I think the pendulum has swung quite a long way in that direction; it has not reached quite the position I would wish it to achieve.

Chairman

434. I appreciate that yet, at the same time, you know only too well as a nurse, as do people in the medical profession, that when you are told afterwards, after having given even the most detailed explanation to a patient, about what you are alleged to have said, that the actual feedback may be totally contrary to what you actually tried to indicate. It is extremely difficult always to be clear about how this information is handled at times of stress. Communication is one of the hardest problems that we all have.

(Professor Castledine) I think that is a very important point. I think the nurse's role often picks this up. Often when the doctor has told the patient what he thinks is the truth, and tells them in very straight terms, afterwards that patient often comes back to the nurse and says, "What did the doctor say? I'm not quite sure", and then wants the nurse to go through it with them. In fact, part of the nurse's role in palliative care and care of the elderly is actually going through that again and again sometimes.

Lord McColl of Dulwich

435. This business of the distinction between acts of commission and omission you say is discredited, and there is a hypocritical side to this. I do not know whether I understood you correctly. Do you feel that

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that is the majority view in the health care world, or a minority view?

(*Professor McLean*) Where I was suggesting that it is widely discredited was in the philosophical world, as being a distinction without a difference. I am not competent to speak on how the health care workers themselves actually feel.

Baroness McFarlane of Llandaff

436. The UKCC also imply this in paragraph 5, do they not? I wondered how widespread a view that was amongst nurses?

(*Mr Pyne*) I believe it is fairly widespread. As you know, I tread the United Kingdom meeting people in many places, conducting seminars in many places and have indeed rushed back from Belfast for the privilege of attending this hearing, and this is, frankly, reflecting the message that I receive a great deal. There is a feeling that there is this line which made me (and I accept total responsibility for the paper) not hesitate to speak of this hypocrisy.

437. Really what we are calling for is far greater clarity in the underlying ethical and moral principles that we are dealing with, spelling them out in greater detail?

(*Mr Pyne*) I think so.

Chairman

438. Any other questions from members of the Committee? No. Any additional points that our witnesses would like to put?

(*Professor Castledine*) Could I just raise what I think is important, because we are a nursing Council and I realise that we are focusing very much on nursing. I would not like us to give the impression that we are in conflict with the medics but, at the

same time, what I would like to emphasise to you is that there are differences, I feel very strongly, in the nursing model of care from the medical model of care. I think that is sometimes what does cause some of the problems which we have been talking about today. In your first question you asked what difficulties do nurses and other practitioners face as a result of the current state of the law? There are many which we have not had time to talk about. It is not just tube feeding and resuscitation; it relates, when a patient is dying, to caring for them properly and sucking them out and caring for their skin and positioning them, those sorts of activities which I feel are very difficult to actually express in a committee room here, and very difficult to say this is what nursing the dying is all about. I hope in some way we have tried to say that the model of care which nurses follow is in many ways different from what is traditionally seen as a medical approach.

439. We appreciate that point. I am sure that some of us also appreciate it from personal family experiences. There are circumstances where, as you know only too well, particularly with the incontinent elderly person in a state of advanced dementia in a hospital long-stay unit, that the person is often treated by nurses as almost a pet. They can become desperately attached to the care of that individual, giving them the best possible attention; sometimes that may lead them to feel that perhaps antibiotics should be given for the treatment of pneumonia where a doctor would totally disagree. That situation is one which does from time to time arise. If there are examples of this difference of opinion which you feel you would like to amplify in a further document then please do not hesitate to write to us.

(*Mr Pyne*) Thank you, my Lord Chairman.

Chairman] Thank you very much indeed.

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