

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

Contributors

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HOUSE OF LORDS

SESSION 1992-93

MINUTES OF EVIDENCE
TAKEN BEFORE THE
SELECT COMMITTEE ON
MEDICAL ETHICS

Tuesday 4 May 1993

BRITISH MEDICAL ASSOCIATION

Dr S Horner, Dr F Fisher and Ms A Somerville

SIR DOUGLAS BLACK

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McFarlane of Llandaff, B.	

Memorandum by the British Medical Association

The British Medical Association submits herewith the following documents:

1. A brief paper addressing the nine issues raised by the Select Committee
2. BMA statement on advance Directives
3. Joint BMA/RCN statement on do-not-resuscitate decisions
4. BMA proposal for decision making procedures on behalf of mentally incapacitated adults
5. BMA discussion paper on treatment of patients in the persistent vegetative state
6. Draft BMA guidelines on treatment of patients in the persistent vegetative state.

Prepared by the Medical Ethics Committee of the British Medical Association, 1993
Chairman Dr J S Horner

PREAMBLE

The British Medical Association (BMA) has given a great deal of consideration to the ethical, legal and clinical implications of giving or withholding medical treatment at the end of life. Appended to this submission are several documents which explain our deliberations and the BMA's current policies.

Relevant to this discussion, there are several points which the BMA considers to be of fundamental importance. The first is that, although much of our response concerns the rights of patients to accept or refuse treatments, we also think it vital to consider the practical scope of their options. In our view, decisions about treatment at the end of life are inextricably linked with the availability of high standards of nursing care, including appropriate rehabilitative and palliative care. Empowering patients to make decisions requires a commitment from society to provide genuinely caring alternatives. The BMA believes that some people are attracted by the concept of euthanasia because they fear the alternatives, seeing these as necessarily involving pain, neglect or indignity. To some it may appear that the only realistic choice is between euthanasia, invasive medical interventions which they fear they may not be able to direct or marginalisation which amounts to the "warehousing" of incapacitated patients.

Part of the BMA's message is that relatively uncomplicated procedures such as good nutrition, caring attention and a willingness to listen, effective communication, stimulation and adequate pain relief will often make the difference between an acceptable and unacceptable life for the person concerned.

Our second general point flows from the first. The BMA emphasises the difference it perceives between medical treatment and medical care. In our view, medical treatment is dependent upon the prior agreement of the patient (unless the patient is unable to give an opinion about it). Medical treatment is also dependent upon the prospect of some anticipated benefit for the patient. Doctors have a duty to consider the clinical appropriateness of any treatment they recommend and discuss this with the patient. Medical treatment cannot ethically be given if it is not clinically appropriate or if the competent and informed patient refuses it (either currently or through an anticipatory decision). Medical care, however, is an expression of the doctor's long recognised duty to respond with compassion to the sick and needy. Even when medical treatment has been refused or is clinically inappropriate, the continuing availability of care and comfort is indispensable. Ceasing treatment can never imply an abandonment of the patient.

int is that the BMA can only hope to reflect the views of doctors but we hope that

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decision-making will involve a number of people in addition to the patient and doctor. Good standards of treatment at the end of life rely on the commitment of the health care team and people close to the patient to see that the patient's wishes and needs are recognised and met.

BMA EVIDENCE

The Select Committee has drawn our attention to nine issues in particular.

1. *The respective weight to be attached to the sometimes conflicting moral principles of the sanctity of life and the right to personal autonomy*

Some people argue that medical ethics is excessively dominated by the issue of personal autonomy, and the individual's competency to exercise it, to the virtual exclusion of other values such as care and commitment. In the BMA's view, respect for each of these values should blend together in a manner appropriate to the circumstances of each case. Doctors are more conscious than most of the enrichment brought to society by people who experience disability or suffering. We believe that the way in which we respond to those who are suffering is a measure of our society's civilisation. The sincerity of our commitment to the concept of sanctity of life can be seen in the efforts and resources we are prepared to devote to helping individuals achieve a life which despite limitations is satisfying to them. In the BMA's view, life should be cherished and no individual should be seen as any less valuable because of physical or mental impairment.

Doctors must endeavour to do the best for each individual but sometimes "the best" is hard to define. It involves a subjective judgment. Most people can make this for themselves and hopefully their decisions are made on the basis of a dialogue with the health professionals who look after them. Doctors are opposed to the idea of forcing people to undergo treatment they do not want or clearly would have rejected if able to do so. We must hesitate, however, to carry out what some patients consider best for themselves if to comply would infringe the rights of others. (We have discussed this further in point 7). When individuals are unable to express a choice, we generally do not consider it in their interests to subject them to treatments unless these bring them some benefit and are what that patient is likely to have wanted.

The BMA sees that there is a very strong public interest in preserving the life and health of all citizens but that ultimately the individual's right to self determination decides whether or not treatment can be given. When competent adults refuse life-prolonging treatment, all health professionals find it profoundly disturbing to stand back and offer only counselling and comforting. The BMA, however, advises that the decisions of a competent patient regarding non-treatment must be respected and considers that patients whose competence is temporarily impaired can only be treated until they have regained the rational ability to decide. We are in accord with the widely accepted view that prolonging life is not always in the patient's best interest.¹ We believe that assessment of what is best for an individual entails respecting that person's autonomy and also having regard to the contribution which medical treatment can make to the patient's improvement.

Autonomy, however, is not the sole ethical imperative. Automatic acquiescence to the concept of patient autonomy also carries risks. Some cases come to our attention of patients whose apparent refusal of life-saving treatment in an emergency situation is respected although later it can be seen that this may not have been a true choice but a manifestation of their illness. Even apparently clear patient requests for cessation of treatment sometimes stem from ambivalence or may be affected by an undiagnosed depressive illness which, if successfully treated, might affect the patient's attitude. The Law Commission's recent consultation documents² touch briefly upon the issue of determining a true choice and, in our view, doctors have an obligation to combine respect for autonomy with professional judgment and thorough clinical investigation. We emphasise patient autonomy as part of a genuine striving for partnership in decision-making between patient and doctor but it would be wrong to assume that this is easy to achieve.

Some of the hardest decisions concern people who cannot choose for themselves and have never had that capacity. Doctors question whether incompetent patients who cannot understand the potential benefits of painful or distressing life-prolonging treatments, such as chemotherapy, can be said to benefit from them. Unlike competent patients they cannot weigh the drawbacks and side-effects against an anticipated potential gain. Such cases have to be judged on an individual basis with regard to the burdens of treatment and potential gains in each case. We have also considered whether any benefit can be said to derive from the continuation of purely vegetative reflexes as in the case of patients in persistent vegetative state. We feel it is difficult to justify continuing any treatment when it becomes evident that the patient does not benefit from it. We recognise, however, that the definition of "benefit" is itself complex and can be assessed in all manner of ways. We see also that many people feel concern about the prolongation of treatment which results in the sort of existence which few of us would be prepared to accept for ourselves. Thus, while recognising and sharing some of the anxieties that many people feel about withdrawing treatment in such cases, the BMA has supported the House of Lords judgment on this issue.³

¹Re J (1991) Fam 33, 52 per Balcombe L J; *Airedale NHS Trust v. Bland* (1993) 2 WLR 316, 371 per Lord Goff.

²Consultation paper 128, paragraphs 3.27-3.35 and paper 129, paragraphs 2.18-2.19.

³*Airedale NHS Trust v. Bland*.

In summary, we do not believe that either autonomy or sanctity of life is ultimately determinative but we accept that a doctor should not intervene to preserve life against the clearly expressed wishes of a competent patient. Our view is that life should be preserved when its continuation brings benefit to the individual. "Benefit" is usually best assessed by the person living that life whose views might be conveyed through an advance directive. The BMA does not support the notion of the absolute sanctity of life or that purely organic functions must be prolonged indefinitely. It recognises circumstances in which it is appropriate that medical treatment should cease. Efforts to prolong life might be regarded as intrusive in circumstances where the patient's capacity to experience life and to relate to others is very severely impaired or non-existent. The Association feels that health professionals have a particular responsibility in these matters but that decisions of such importance to the whole of society should not be left for them to struggle with alone. We very much welcome informed public debate on all of these matters. The Association is committed to assisting as much as possible the Law Commission's current discussions on decision-making for the incapacitated.

2. *The extent of a doctor's duty of care to a patient*

Although doctors owe a duty of care to all their patients, competent individuals are entitled in law to refuse any treatment. In such cases, doctors must make sure that they give patients all the information that the patient needs to make a valid choice. The BMA also advises that doctors cannot simply abandon patients who refuse treatment but that they have a moral duty to offer whatever degree of support the patient finds acceptable and is practical in the circumstances. That is to say we see "care" as a continuing function whereas treatment is not. If the patient is incompetent, doctors have an ethical duty to act in the patient's best interests. They can and should cease medical treatment which is not in the patient's interest although, as we have said previously, the patient's interest is sometimes very difficult to define. The help of the courts may be needed to ascertain this and the views of the whole clinical team, including any relevant carers must have been taken into account. Doctors would not wish to continue treatment if the rest of the team and/or carers believed this to be against the patient's wishes. Doctors who cease treatment at the patient's request or in his best interest, as defined by the means mentioned above, are not in breach of their duty of care even if this results in the patient's death.

In trying to help doctors analyse the morally relevant factors in individual cases, the BMA has agreed with the guidance from the courts. In the case of baby J,¹ for example, it was held that burdensome life-prolonging treatment need not be given to the patient, even though he was neither on the point of death nor dying. This judgment makes clear that there are recognised limits on the doctor's duty to treat and that when considering giving life-prolonging treatment to people who cannot speak for themselves, the benefits of treatment must be weighed against the burdens of it.

The BMA does not, however, sanction positive steps to terminate life and wholly supports the General Medical Council in emphasising that treatment whose only purpose is to shorten the patient's life is wholly outside the doctor's professional duty to a patient. We believe that such actions by doctors fall short of the high standards which the medical profession must uphold. Some of the reasons for our view are discussed in point 3.

3. *The distinction between the withholding or withdrawal of medical treatment and deliberate intervention to end life*

This question is not amenable to any easy answer despite having been extensively debated by many who are expert in moral reasoning. Philosophers tell us that there is no moral distinction between withdrawing treatment and killing. A distinction exists in law and we see this as a proper safeguard against the possibility of abuse. The BMA argues that some boundaries may appear arbitrary but that this is not necessarily an argument for removing them altogether. A recent example² given in another context concerned the limits on driving speed. The choice of 30 mph as the legal limit rather than 31 mph may be hard to defend on rational grounds but all acknowledge the necessity of having recognised limits which apply to everyone in society.

Some argue that a lethal injection may be a kinder option for some patients than a protracted dying process. Our response is to acknowledge this as a possibility. Nevertheless, cases where the patient's distress cannot be fully relieved are exceptional and arguably should not be the basis for changing rules which affect (and protect) all members of society. (This is discussed further in point 7.) We believe that our aim must be to relieve suffering in its broadest sense—both physical and mental anguish—by caring support as well as appropriate medication.

On the matter of deliberate interventions to end life, the BMA has a long established policy, drawn up by its members who comprise the majority of British doctors and who oppose euthanasia. Their objection is based on the premise that the fundamental objects of medical practice are the relief of suffering and

¹*Re J* (a minor) (wardship: medical treatment) (1990) 3 All ER, 930.

²This was part of an argument for establishing clear boundaries in ethical matters put forward by Professor Jonathan Glover at a BMA conference.

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preservation of life.¹ We acknowledge that in both withdrawal of treatment and deliberate killing the patient's death will be the foreseen consequence of a medical action or omission. Nevertheless, despite the difficulties of defending their position with strictly logical arguments, almost all doctors and most other health professionals feel there is a gulf between the two.

The doctor's role has always been to provide treatment in order to bring about improvement in the patient's condition. One might argue that for some people death represents an improvement but we believe medicine is not intended for such ends. Treatment will be withdrawn if it cannot achieve its purpose of amelioration. If doctors are authorised to kill or help kill, however carefully circumscribed the situation, they acquire an additional role, alien to the traditional one of healer. Their relationship with all their patients is perceived as changed and as a result, some may come to fear the doctor's visit. There are, for example, studies which appear to indicate that changes in euthanasia practice in Holland have led to fears among some elderly people that their human rights may be threatened.²

On the other hand, there are a number of ethically valid reasons why a treatment which might prolong life is not given. It may be that the patient refuses the treatment. If the patient is incompetent, doctors may believe that the side effects and burdens of the treatment outweigh any benefits an extension of life would bring. Doctors may consider the treatment would be futile, in the sense that it would not achieve the desired effect for this particular patient. Scarce resources might be a factor in a decision whether to treat or not (although the BMA does not endorse the view that resource considerations alone can be determinative). We do not feel that these factors undermine the trust that patients have in the medical profession.

The BMA maintains that the deliberate killing of patients would radically alter how the public sees doctors and how doctors see their own role. (This is discussed further in our response to question 7.)

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

In our view, this question has three parts rather than two. Patients who are competent and who have been properly counselled about the benefits and drawbacks of treatment options can accept or decline any of those options. They cannot ask doctors to kill them because this is not an option on offer but they are free to choose within the scope of what is available. (As stated above, we do not consider that active killing should be an option because although it might benefit some people, it might bring harm to others.) Their decisions can be based on good reasons, bad reasons or no reasons at all.

People who are incapacitated either because they are babies or unconscious or suffer from a permanent mental disorder clearly cannot express any view. Decisions for them must be based on their best interests. Assessing best interests is often immensely difficult and will require prolonged discussion between doctors and other members of the health team, the people who care for the patient and other sensible and independent members of the public. The BMA has drawn up one framework for decision-making on behalf of the mentally incapacitated.³ Some decisions are so sensitive or important that they should only be made in consultation with the courts or some other independent review system.⁴ Such procedures include sterilisation of incompetent people or any proposal that an incompetent person donate non-regenerative tissue to someone else or that artificial nutrition be withdrawn from an incompetent person. Where there is a difference of view within the care team (including voluntary carers) referral to the courts or review system should be automatic.

A third category of people are those who are now incapacitated but have previously been able to express opinions about how they would wish to be treated. They may have formally made an advance Directive or appointed someone to speak for them.⁵ The BMA believes that these views should be accorded respect but the Association has argued that advance Directives should not be legally binding upon doctors for reasons detailed below. We draw attention to the BMA's statement on advance Directives which is appended.

5. *The role of advance Directives and proxy decision-makers*

All things being equal, the person best placed to assess what is being gained from life is the person living that life. Individuals facing deterioration of mental or physical health may want to assess the potential quality of their own lives in certain circumstances. It is very clear that many people fear (we believe unnecessarily) that their lives will be prolonged beyond what is acceptable by doctors anxious to use to the full the technological advances in medicine.

¹This policy was established at the BMA's annual meeting in 1969.

²Segers J H. Elderly persons on the subject of euthanasia, *Issues Law Medical*, 1988; 3: 429-37.

³This framework was submitted to the Law Commission and is reflected in the 1991 Law Commission Consultation Paper 119, *Mentally incapacitated adults and decision-making: an overview*.

⁴We note that the Law Commission is proposing various systems.

⁵We have called such an appointed person a proxy decision maker. The Law Commission sees proxies as court appointed agents and calls those nominated by parents attorneys.

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In the past, it was thought that patients, if asked in advance, would find it too distressing to contemplate non-treatment or non-resuscitation in their own case. The profession's views about this have changed. The BMA receives ever increasing indications of interest in advance Directives from the public and our general policy statement is appended.

In the BMA's view, part of the importance of advance Directives lies in educating the public that they have choices and that these should be a subject of continuing discussion with their doctor while the patient remains competent. They will need to know, for example, whether a proposed treatment is likely to affect cognition or longevity, improve quality of survival over a limited time or impose burdensome side effects. Patients' informed assessment of such factors may lead them to decline certain life-prolonging treatments. Such dialogue will help doctors understand what the individual would have wanted in the particular circumstances which arise. Selection of a proxy decision-maker could also be helpful in ascertaining what the patient is likely to have wanted in a particular situation.

While recognising that an anticipatory decision which is clearly established and applicable to the circumstances is likely to be as ethically and legally¹ binding on doctors as any current decision made by a competent patient, the BMA considers that specific legislation on advance Directives is unnecessary and could be unhelpful. We believe that medical adherence to the patient's wishes is achievable and actually preferable by encouraging frank dialogue between patients and their doctors at all stages.² Noting some of the problems which have arisen in the United States with advance Directive legislation, we are worried that specific legislation in this country might create as many difficulties as it solved.

Advance Directives cannot help patients who have never been competent or who were unprepared for a deterioration in competency. Other methods of decision-making must be evolved for such individuals. The principal motive for establishing such procedures is to enable treatment rather than authorise its withdrawal but in some instances the latter case may arise. As part of such procedures, the BMA encourages people who are likely to face mental degeneration to think about appointing a health care proxy. The Association believes that in cases where such a person has been nominated by the patient, the criterion to be followed in decision-making would be that of "substituted judgment", with the agent acting as a sympathetic interpreter of the patient's own values, rather than attempting to judge the patient's best interests.

A system of health care proxies (or patient attorney) has the advantages of meeting the circumstances which arise rather than being tied to the particular words of the advance Directive. Decisions made by such an agent have a significant determinative value. It should be possible to challenge, and if necessary displace, a substitute decision-maker whose actions are mischievous. There may also be circumstances where the views of the health care proxy conflict with the patient's written advance Directive. In such cases, the BMA would see the need for a procedure to resolve disputes such as that suggested by its attached paper or those under discussion by the Law Commission. The Association hopes to draw up shortly a detailed response to the Law Commission's proposals.

6. *The role of the courts in interpreting the law in the light of changing medical technology and practice.*

Many decisions concerning treatment and non-treatment are of such importance to society, we believe that they should not be made solely between the individuals concerned but must be subject to various forms of review. This applies most particularly (but not only) to treatments which involve a question of life or death for the particular patient. Decisions about whether incapacitated people should participate in research or donate tissue or be sterilised; which patients or types of treatment have priority with regard to resources (ie treatments which the Law Commission defines as falling within a "special category"); how we govern access to treatments such as reproductive technology and how far it is morally acceptable to try and meet consumer demands with regard to the characteristics of potential children are all issues which require public debate. The BMA supports a variety of monitoring and advisory procedures to deal with such issues, including peer review, institutional ethics committees, multidisciplinary discussion, debate in the media and intervention by the courts.

The courts may be asked to clarify issues both with regard to competent and incompetent patients. If the patient is competent, we believe that it is very important that the courts give a full explanation of the reasoning behind any apparent overruling of the patient's own opinion.³

As is indicated in the attached paper on a decision-making procedure, the BMA considers that incapacitated people will require a wide range of medical decisions to be made for them. Uncontroversial decisions can usually be made satisfactorily by doctors and the people close to the patient. If any dispute arises

¹Following the dicta in *Re T* and *Airedale NHS Trust v. Bland*.

²A new handbook of ethical guidance shortly to be issued by the BMA takes as central tenets the concepts of partnership in decision-making and continuing dialogue between doctors and patients.

³Many doctors have been left confused, for example, by the recent decision to overrule a pregnant woman's refusal of treatment. *Re S*, 1992.

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between these parties or if there is any doubt about the benefit of the treatment, another independent opinion must be sought. We are suggesting that this might be from some sort of specially appointed ethics committee, representing the viewpoint of the reasonable person. For dilemmas that are too difficult or carry too wide-ranging implications, a more expert decision must be sought and we believe this should come from the courts.

The question remains as to whether there might be arrangements for quick and less costly access to lower level courts or other forms of tribunal with special expertise so that seeking such an opinion might be more easily facilitated. This is one of the matters which the BMA hopes to discuss also with the Law Commission during the present consultation process.

Prior to the Bland case, the BMA's opinion was that in general doctors could ethically discontinue a medical treatment which was not seen to benefit a patient. The Association was therefore concerned by some legal opinions prior to the case which indicated that doctors would be legally obliged to provide antibiotics and other treatments despite the fact that the patient would never return to sentience. The BMA greatly appreciated the clarification issued by the courts. It has welcomed the decision that all cases where it is proposed to withdraw nutrition from pvs patients must be subject to judicial review. The BMA makes clear that it does not consider that clinical, ethical and legal decisions made for one patient or one condition can be automatically applied to others which may be superficially similar. That is to say that while welcoming the House of Lords' clarification of the Bland case, the views expressed about appropriate treatment or non-treatment for Mr Bland should not be applied indiscriminately to all those said to be in pvs or to other types of patients such as microcephalic infants or geriatric patients with senile dementia. The arguments in such cases are still to be made.

7. *The case for a change in the existing law and the nature and extent of such a change*

This question does not indicate the specific aspects of law which should be considered. There are several areas which give scope for legislation, including giving or withdrawing life-prolonging treatment when patients are mentally incapacitated, advance Directives, voluntary and involuntary euthanasia.

Following the case of *Re F*,¹ doctors felt a great need for general clarification about decision-making on behalf of people who are incapacitated. The BMA issued interim guidance on these general treatment decisions and separate advice in relation to pvs patients while this matter was considered by the Law Commissions in England and Scotland. The Association is still considering a number of issues raised by the English Law Commission's latest paper on medical treatment and research with regard to mentally incapacitated adults. We look forward very much to participating in the continuing discussions regarding medical treatment of the mentally incapacitated and protection of them from abuse or neglect.

The BMA does not support any change in legislation prohibiting murder or manslaughter. The Association is opposed to active euthanasia. It recognises that there is a body of opinion within the public for change. The BMA recognises that denial of a right to euthanasia runs counter to the concept of autonomy and self determination to which we accord great respect. Nevertheless, in our view, personal autonomy has limits and granting the desires of some entails an unacceptable cost for others and therefore is contrary to other ethical imperatives such as the concept of justice.

The BMA recognises that for a very small minority of patients, terminal pain and distress may be resistant to complete control. Even hospices, which can confidently claim to control suffering in most cases, recognise a small margin of cases which elude the domination of modern palliative care. Clearly, the profession must soon hope to arrive at the situation where all pain can be controlled by skilled management and this is where we think effort should be focused. Until that time, however, there will be exceptional cases where death is inevitable but slow and the doctor can neither abandon the patient nor fully relieve pain. It is essential that doctors master the techniques to control pain and distressing symptoms. Doctors who have patients with apparently intractable pain should ensure that they promptly seek expert advice from specialists in symptom control. In addition to the technical skills required, the BMA also believes that the health care team needs to be able to develop a relationship with the patient. Dying people show a wide range of emotions to which health care professionals must be able to respond appropriately. In this sphere, the educative influence of experienced hospice staff cannot be over-valued.

In some such cases and when the dying patient and doctor "stand in a special relationship", some argue that a caring doctor may take exceptional action and also be excepted from the legal rules and moral principles to which all other doctors and members of society are subject.² While the general prohibition on killing would remain, "a special defence" might be defined which could be claimed by doctors in certain specified situations, as long as the doctor first conformed with a number of requirements. Experience in the Netherlands, however, has shown that even where such a framework of requirements has been

¹*F v. West Berkshire Health Authority and Another (Mental Health Act Commission intervening)*, 1989.

²This is discussed, for example, in Jecker N, Giving Death a Hand: When the Dying and the Doctor Stand in a Special Relationship, *Journal of the American Geriatrics Society*, 1991; 39: 831-5.

established, euthanasia is practised outside the scope of the rules¹ without being detected unless the doctor reveals it.

Thus, even for such very exceptional cases, the BMA would not wish to see any change in the law. Its view is based on the principle that any moral stance founded on the permissibility of active termination of life in some circumstances may lead to a climate of opinion where euthanasia becomes not just permissible but desirable. Once active termination of life is a matter of choice for competent people, the grounds for excluding non-competent people from such treatment become harder to defend. We feel there is a real danger of a slippery slope from voluntary to non-voluntary (eg because they are incompetent) and possibly even involuntary euthanasia.

Many British doctors fear that even a limited change in the legislation would effect a profound change in attitude. By removing legal barriers to the previously "unthinkable" and permitting people to be killed, society would open up new possibilities of action and bring about a frame of mind such that individuals feel bound to explore fully the extent of those new options. Once a previously prohibited action becomes allowed, it may also come to be seen as desirable—if not for oneself, then as something people might recommend for others, particularly so when an increasingly ageing population is raising the question of imbalance between financial providers and financial dependents. A social environment which recognised a right to die, we believe, would bring about a fundamental shift in social attitudes to death, illness, old age and to disablement. It might encourage us to label people by group and regard some groups as more expendable when they present problems. It would also change the public view of the role of the profession in an irrevocable way and undermine the trust that patients have in doctors.

Thus the BMA fears that, were the law in this country to be relaxed, euthanasia would become an option that everyone must consider. That does not mean that everyone would seek euthanasia but some people might realistically fear that others would choose it for them. Some Dutch studies appear to indicate that some elderly people fear their lives will be ended without their consent² and that, in fact, families in Holland request euthanasia more often than the patient.³ This may be because, as has been shown in many studies, relatives perceive the patient as enduring worse suffering than patients themselves report.

As stated at the beginning of this paper, rather than a change in legislation on the issue of euthanasia, the BMA calls for greater emphasis on high quality care at the end of life. By improving and extending our knowledge about symptom control, some of the fears people have about being neglected or over-treated at the end of life could be dispelled.

8. *The role of the hospice and advances in the care of the terminally ill*

The BMA has attempted to draw the attention of the public and profession to where we believe the true focus of the debate about the end of life should lie—the provision of a high standard of palliative care, communication and support. For many people, death is a taboo subject but often it is not the inevitability of death itself but the manner of their dying that frightens people. We believe that a continuing anxiety among British doctors is how to solve the practical and psychological problems which make patients' lives intolerable rather than hasten their deaths. The hospice movement has made an incalculable contribution to the development of effective symptom control and to medical awareness of how, if handled well, the crisis of impending death can be a time of personal growth and reconciliation for all those close to the dying person. Not all terminally ill patients feel that hospices are right for them but the positive lessons of the hospice movement can be applied successfully in other contexts, including treatment at home, to improve the quality of time remaining for the dying.

In the past, there was sometimes hesitation among doctors and nurses to provide the necessary degree of pain relief due to concern about drug tolerance or fear of shortening the patient's life. It is now emphasised that relief of physical and mental distress must be the first aim of treatment at the end of life. Hospices have demonstrated that in the majority of cases pain can be controlled by analgesics in appropriate doses at regular intervals. Once symptoms are controlled, attention can be given to helping dying people retain their sense of individuality and make the most of their last days. It is of particular concern to the BMA that less attention might be given to effective training in controlling pain and actively helping patients address their fears about death if euthanasia were seen to be an available or acceptable option.

Some patients will choose to tolerate some pain if the quality of life is otherwise good and experience suggests that pain, even when modestly present, is often the least of the issues affecting quality of life. According to the experience of some hospices, many requests for euthanasia are not based on the presence of pain, but on the patient's increasing sense of worthlessness and dependence on others. Only by provision of skilled and compassionate palliative care, can the patient have a restored sense of worthwhile identity. Willingness by society to supply or condone euthanasia will merely confirm the patient's sense of worthlessness, resulting in a society where persons are not deemed valuable unless useful.

¹See for example, Keown J. The Law and Practice of Euthanasia in the Netherlands, *Law Quarterly Review*, January 1992.

²Segers J H. Elderly persons on the subject of euthanasia, *Issues Law Medical*, 1988; 3: 429–37.

³Fenigsen R. Mercy, murder and morality: perspectives on euthanasia. A case against Dutch euthanasia. *Hastings Center Report* 1989; 19(1)(suppl): 22–30.

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9. *The experience of other countries in particular Western Europe and the USA*

At present, Holland is the only model, where we might hope to see whether or not an acceptance of euthanasia does bring about changes in society's attitudes. Many find the evidence there difficult to assess in any meaningful way. A great many statistics from the Rummelink¹ report have been issued but the interpretations drawn from these appear variable and somewhat difficult to compare, partly due to different definitions as to what constitutes "euthanasia".

The BMA has noted claims that the medical decisions and patterns of treatment prior to patient deaths in Holland are similar in many cases to those generally considered acceptable in this country. One extrapolation from the Rummelink report indicates that in every 100 deaths, 38 result from some action or inaction by a doctor. In 35 of these 38 deaths, however, BMA policy and current English law and practice would support the doctor's action. Such deaths might, for example, involve a decision to cease futile treatment or not to resuscitate a person with a poor prognosis. Only in three is there active killing of the patient (as we would define it in this country) and in this group one third of deaths fall outside the recommended procedure. That is to say that 1 per cent of deaths in the Netherlands do not meet the strict criteria laid down and are technically illegal. This indicates that the practice of euthanasia is being informally extended.²

All seem to agree that the so-called rules of careful conduct (official guidelines for euthanasia) are disregarded in some cases. Breaches of rules range from the practice of involuntary euthanasia to failure to consult another practitioner before carrying out euthanasia and to certifying the cause of death as natural. Some would see this as lending credence to the view that even careful circumscription of the practice cannot guarantee observance of the rules.

Comparisons are often drawn between medical practice in Britain and that in the United States. In our view, however, many aspects of professional practice are not comparable because of differences in how health care is organised in the two countries. It is often said that American doctors feel obliged to over-treat patients who have a poor prognosis for fear of litigation if any procedure is omitted. Also American health insurance schemes will sometimes finance treatments that would be unlikely to be contemplated in the British context unless the patient could expect a reasonable quality of life to ensue.³ The development of advance Directives in the United States can be seen partly as an expression of patient fears that doctors will "assert their right to preserve a life that someone else must live or, more accurately endure⁴ when there can be no hope of improvement or recovery for that patient.

The BMA feels that the British context and focus is different. We believe that there is a willingness on the part of doctors to talk frankly with patients and respect their opinions about the acceptability of the various treatments likely to be considered appropriate.

The BMA supports wide public debate on the issues. Such debate is both necessary and inevitable. We stress the importance of informed public debate which takes full account of the needs of people who are not able to speak for themselves. It would be unhelpful to resort to emotive arguments (which portray the end of life as "necessarily painful" or "undignified") or to try and introduce measures here on the grounds that they satisfy the Dutch. The unique contribution of the hospice movement in this country has shown what can be achieved and has established a quite different arena within which our debate will be conducted.

BMA Statement on Advance Directives

Introduction

The BMA is publishing this statement in response to a request from its members at the 1991 Annual Representative Meeting to clarify the Association's views on advance directives. The Association has also been involved in consultations carried out by the Law Commission, with a view to amending the law in relation to decision-making for mentally incapacitated adults. As part of this process, in addition to this statement, the BMA has drawn up proposals for a decision-making procedure.⁵ These proposals are under consideration by the Law Commission.

The Association has concluded that there are significant benefits to advance directives within the framework of continuing doctor-patient dialogue. It recognises that such documents will not solve all the questions

¹Medische Beslissingen Rond Het Levensende. I.—Rapport van de Commissie Onderzoek Medische Praktijk inzake Euthanasie. II.—Onderszoek voor de Commissie Medische Praktijk inzake Euthanasie (Medical Decisions about the End of Life. I.—Report of the Committee to Study the Medical Practice Concerning Euthanasia. II.—The Study of the Committee of Medical Practice Concerning Euthanasia. The Hague: 1991).

²Potts S G. Euthanasia and other medical decisions about the end of life. *Lancet*; 338: 952-3.

³One example is seen in a much debated American case of a woman of 87 years of age, hospitalised in 1990 when comatose with severe anoxic encephalopathy. Doctors and nurses did not consider continued treatment to be medically appropriate but she remained in an acute care facility for over a year receiving a number of treatments. Her family refused to consider any curtailment of treatment or transfer to a nursing home.

⁴*Bouvia v. Superior Court of the State of California*, 1986; 225.

⁵Proposals for the Establishment of a Decision-making Procedure on Behalf of the Mentally Incapable.

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which arise concerning treatment for mentally incapacitated patients who have previously been competent but believes that intractable dilemmas which might arise in connection with advance directives could be resolved by means of the decision-making procedure previously espoused by the Association.

Before finalising its statement, the BMA held discussions with a number of bodies including representatives of the hospice movement, and organisations such as the Alzheimers Association and the Terrence Higgins Trust. Note was taken of the position in the United States where such documents are legally binding upon health professionals. All of the bodies consulted saw value in advance directives. For some the principal value lay in the opportunity for patients to open a continuing dialogue with their doctor concerning aspects of their impending death; for others the value resided in the comfort brought to patients by positively asserting their will over the final stages of a disease process. A further advantageous aspect was seen in the relief offered to relatives when patients had made informed treatment decisions themselves.

The Association perceives a significant ethical and legal difference between the concept of an advance directive and the issue of euthanasia. In supporting advance directives, the BMA confirms its commitment to the fundamental and legitimate right of patients to accept or reject, by particular means, treatment options offered to them. This is in contrast with euthanasia, where the primary purpose is to cause or hasten death. Euthanasia is illegal and the Association's conclusions should not be seen as supporting it.

Definition of the Role of an Advance Directive

An advance directive is a mechanism whereby a competent person gives instructions about what he wishes to be done if he should subsequently lose the capacity to decide for himself. It may cover any matter upon which the individual has decided views but is most often quoted in connection with decisions about medical treatment, particularly the treatment which might be provided as the patient approaches death. The "living will" has a similar aim but whereas an advance directive can give instructions about any decision and can request as well as refuse specific treatments, the living will is essentially a formal declaration by a competent adult conveying his wish for any life-prolonging measures to be withheld in circumstances where there is no prospect of recovery. The object is to rebut any presumption that the patient has consented to treatment which may be administered on the grounds of necessity. The scope of the "living will" is therefore more limited than the advance directive and since many have shown that the term "living will" is a misnomer and gives rise to confusion about the document's legal status in comparison with other types of will, the BMA has preferred to use the term "advance directive".

The fundamental aim of the advance directive is to provide a means for the patient to continue to exercise his autonomy and shape the end of his life by pre-selecting or refusing treatments which are likely to be proposed for him. The principle is not new. Patients who are aware of approaching death have often discussed with their doctors how they wish to be treated. The advance directive registers these views in a more formal way and can be seen as part of a broader willingness to discuss death openly and to deal with the anxieties patients have about what might happen to them if they become mentally incapacitated.

It is clear that advance directives will be especially sought by those who have some form of advance warning by age or illness of approaching death or of impending mental incapacity. Commentators have envisaged that the most common condition for which an advance directive would be appropriate would be senile dementia of the Alzheimer type or dementia related to arterial disease. The later stages of dementia always lead to mental incompetence but by means of an advance directive, the individual would be able to control the provision of treatment as far as this could be foreseen.

Outside such categories of patients who have forewarning of irreversible mental decline, other people are no more likely to make a "living will" than an ordinary will and many die intestate despite the urgings of solicitors. Therefore the BMA has concluded that the spectre of a mass of people who sign a document decades in advance of their final illness and forget to update it is unrealistic. Until there is some harbinger of severe illness, most healthy people are unlikely to consider the subject.

Other Relevant Decision-Making Mechanisms

There are other methods by which patients can make their views known, such as by appointing, in advance, another person to act as a proxy and make decisions for the patient in the particular circumstances which arise. The precise role, powers and title of a proxy decision-maker are not defined by either custom or law. The English Law Commission is considering a range of options which include establishing enduring powers of attorney for health care, or a legal mechanism for formally appointing a professional carer to act as guardian or for that role to be taken informally by a decision-maker nominated by the person concerned (health care proxy). The BMA sees advantages to this latter idea and notes that various other bodies, including the joint Working Party of Age Concern and Kings College Centre for Medical Law and Ethics and the Terrence Higgins Trust have seen value in the patient nominating an agent to express the patient's views later. Pending clarification in law, the BMA believes that in cases where such a person has been nominated by the patient, the criterion to be followed in decision making would be that of "substituted judgment", with the agent acting as a sympathetic interpreter of the patient's own values, rather than attempting to judge the patient's best interests.

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The proposed system of health care proxies has the advantages of meeting the circumstances which arise rather than being tied to the particular words of the advance directive and reflecting the patient's true wish, so respecting patient autonomy. Decisions made by such an agent have a significant determinative value. It should also be possible, however, to challenge, and if necessary displace, a substitute decision-maker whose actions are mischievous.

The health care proxy and the advance directive are quite separate measures. Patients can choose either measure or combine the two. In some cases where the patient has opted to express his views through an advance directive, this may need to be interpreted in the light of the circumstances. Again some have suggested that this interpretative role might be carried out in a formal legal context by a guardian, tribunal or court and there may need to be recourse to such procedures where no person has been nominated by the patient to speak for him. Clearly, there is greater likelihood of the individual patient's views and values being reflected by the patient's own nominated health care proxy, familiar with the patient's opinions.

The Need for Dialogue Between Doctors and Patients

The most obvious disadvantage of drafting an advance directive is that the patient may fail to foresee the particular circumstances of his own case and this may give rise to confusion about his wishes. The likelihood of this eventuality is diminished when patients have gained particular insight into the phases of their disease and the likely treatment options. For this reason, the BMA has very strongly recommended that any patients who wish to draft advance directives should ensure that they are well informed and do so with the benefit of medical advice. It is also recommended that this initiative should become part of a continuing dialogue between doctor and patient so that both are fully apprised of the other's opinion. As part of this exercise, it is advised that doctors should notify patients of the risks as well as the advantages of such a document.

The possibility of a patient inadvertently misdirecting his doctor by an inadequate appreciation of the circumstances or of the evolution of new treatments led the Association to recommend strongly that advance directives should not be legally binding upon doctors. Opinions expressed in recent legal cases, however, indicate that anticipatory decisions which are clearly established and applicable to the patient's current situation would be legally binding on doctors. The BMA believes that mutual respect and a common accord is better achieved without further specific legislation. Furthermore, not only does the mechanism of an advance directive permit the patient to refuse the treatment offered but it may be used by patients who wish to request every possible life-prolonging treatment, including those which are clinically inappropriate or which might distort resource allocation. Some patients may request illegal procedures such as active euthanasia or may have informally indicated a change of view to that recorded in the directive. Although the Association has concluded that it would be impractical for advance directives to have obligatory status, it stresses that, all matters being equal, they should be regarded as a valid expression or refusal of patient consent to particular procedures.

Recognising Patient Autonomy

Great emphasis is placed on the need to provide patients with sufficient information to allow them to exercise their autonomy in choosing treatments. The emphasis on information and dialogue is even greater when patients wish to make decisions in advance of an anticipated loss of competence. The upsurge of public interest in advance directives may be seen as part of an increasing desire by individuals to manage all aspects of their lives insofar as this is possible. Medical technology has assisted this process but must be matched by a willingness on the part of health professionals to respect the decision of patients who do not wish to undergo further treatments.

Such treatment decisions are relatively uncomplicated when the patient is competent and can express an opinion although doctors are sometimes criticised for apparently seeming overly inclined to question the patient's competence when he declines their advice. A 1988 report by Age Concern and the Centre for Medical Law and Ethics, for example, predicted that doctors would have problems in recognising the validity of patients' refusal of life-saving treatment:

"Doctors have found it difficult to accept this as a patient's right. Much of the doctor's difficulty relates to the question of the patient's competence to make a decision. It is relatively easy to diminish a person's claim to be competent either by asserting that the complexities of the medical considerations are beyond the ability of the person to comprehend, or by arguing that there is a psychiatric disorder such as depression which could distort the person's interpretation of the facts."¹

On the other hand, most people agree that it is vital and proper to take steps to verify that the patient is competent when he chooses options which appear to be clearly contrary to his interests and survival. It is hoped that advance directives will reduce such questions. If drafted against a background of informed discussion between the doctor and patient, it should be evident that the latter is competent at the time

¹"The Living Will", 1988. Joint report by Age Concern Institute of Gerontology and Kings College Centre for Medical Law and Ethics, p. 44.

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of drafting. Also, it is anticipated that most people who wish to make advance directives will do so, having in mind circumstances in which not only will their mental faculties have deteriorated but their quality of life will be seriously compromised. It is assumed that the non-implementation of futile treatments, which most people will want to reject, will often coincide with good mental practice. In many cases, the patient will only be asking the doctor to do what would probably be done in any case. Nevertheless, mechanisms will have to be devised for the cases where the directive conflicts with widespread medical opinion. The previously mentioned BMA proposal, submitted to the Law Commission, envisages a mechanism for resolving conflicts in decision making for mentally incapacitated people. Until such a mechanism is in place, when confronted with difficult cases where the law may be unclear doctors are advised to consult the views of colleagues, their professional body and the defence societies as well as any person nominated to speak for the patient.

The BMA believes that written advance directives are not in the same category as oral remarks a patient might make impulsively or when despondent. The latter are unlikely to be indicative of a considered view, whereas an advance directive, in the absence of contrary evidence, should be regarded as representing a stable opinion and therefore worthy of respect.

Sharing Information

Some people criticise the emphasis placed on patient autonomy, seeing this as a rather empty concept which, although currently in vogue, fails to recognise the practical limitations on patients' options and the undoubted fact that doctors do influence patients, even inadvertently, by the way in which they present information. In the BMA's view, the stress on patient autonomy represents a genuine striving for partnership in decision making between doctor and patient. This can only be done on the basis of shared information about diagnoses, prognoses, realistic treatment options and the patient's view of these.

Doctors know more than patients about treatment realities and some fear that patients making advance directives will fail to imagine concretely the outcome of what they request. In some ways, this has been seen as a self-fulfilling prophecy since there has been a widespread reluctance within the profession and society at large to discuss frankly aspects of death and dying. Considerable pressure has often been put on health professionals to convey an overly-optimistic rather than a frank approach to the patient's death with subsequent reduction of information upon which patients can express preferences at the time when the patient is competent to do so.

The BMA has noted the apparent support for curtailment of treatment arising from opinion polls taken by bodies such as the Voluntary Euthanasia Society but has not based any of its views on such assessments of public opinion. It accepts that it is generally easier to understand the concept of death than it is of sustained mental disability for individuals who have no contact with either. Anecdotes abound of patients who expressed in advance an abhorrence of treatment in the event of a specific illness, such as severe stroke, but whose views changed when they developed the disorder. If doctors are to give advance directives the respect envisaged, then patients must have information about what they personally want and receive counselling. Such counselling could explore treatment options and their consequences, including the implications of requesting withdrawal of hydration and nutrition, which is a component of some draft directives. It is highly recommended, therefore, that patients discuss the specific terms of an advance declaration in depth with a doctor and that this be part of a continuing dialogue. Equally important is continuous dialogue with any nominated proxy decision maker.

The articulate and expanding group of HIV-positive patients has made efforts to acquire knowledge about treatment options. Some of these patients have witnessed the decline of a partner and know that similar options may arise in their own case. Such patients often require little medical information in order to draft an advance directive since they may have already seen the very situation which awaits them. Nevertheless, dialogue, counselling and support should be available.

Responsibilities of Patients

The Association recognises that there are risks involved in taking advance directives seriously and patients should be aware of the need for very careful thought in drafting. As discussed above, patients will require assistance to make choices appropriate for them. Ideally, such discussion should not be a single event but a continuing process. It is important that patients who make advance directives take steps to ensure such dialogue.

The onus for ensuring that the advance directive is appropriately drafted and available for those to whom it is addressed lies with the patient. The BMA suggests that patients who have drafted an advance directive carry a card indicating that fact as well as lodging a copy with their doctor.

While any coherent statement drafted by a competent person is worthy of consideration, patients must be aware that a poorly drafted document may complicate rather than clarify the situation and is more likely to be regarded as irrelevant. In cases where treatments option cannot be predicted, a simple statement of the patient's views may be more helpful than a complicated document which tries to cover all possibilities.

The Association recommends that any person making an advance directive updates it at regular intervals.

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Five years is suggested as an appropriate interval for patients to review their decisions. The possible nomination of a health care proxy has been raised above and may represent a safeguard for patients in the event of an advance directive being made many years prior to illness and unchanged despite changing circumstances. Such cases of unrevised directives will exist but are unlikely to present a profound dilemma for doctors, unless binding legislation on advance directives is introduced, since instructions written so previously can clearly only give the most general of indications, if that, of the patient's ultimate views.

Doctors' Freedom of Conscience

It may be that in some circumstances involving terminally ill patients there may be conflicting moral duties for health professionals. The Association has noted, for example, an American case where treatment she had declined was carried out on a pregnant terminally ill woman¹ in order to allow her foetus the best chance of survival. Such cases are likely to be exceptional.

The most obvious limits on patient autonomy, however, arise from the rights of doctors, who cannot be obliged to act contrary to conscience or the law. In raising the issue of conscientious objection, the BMA hopes to reduce the arbitrariness of medical response to which patients are now subject, with some doctors refusing to consider the subject, others insisting on retaining ultimate judgment of what is best and only some being prepared to commit themselves to respecting a competent advance directive.

A 1988 report² by Age Concern and the Centre for Medical Law and Ethics identified the existence of several different approaches to advance directives. One is that "the concept of advance directives is morally wrong because in no circumstances has any person the right to refuse measures which will prolong life". Indisputably, individual doctors adhering to the absolute "sanctity of life" principle will perceive patient choice for anything less than the maximum in life prolonging treatments as representing a personal test of principle, even though other doctors would not see competent refusal of treatment in such terms. The Association advises its members to consider their own views and inform patients at the outset of any absolute objection the doctor has to the principle of an advance directive. The patient then has the opportunity to consider consulting another practitioner or re-considering the importance he attaches to the advance directive. The Association believes it is not ethically acceptable for a doctor simply to put an advance directive on file, without discussion and with the expectation of claiming conscientious objection when the time comes for its potential implementation.

Possible Legal Liability

In Canada like Britain there is no specific legislation governing advance directives but a court has held that a doctor was liable in battery for ignoring the wishes expressed by an incompetent patient prior to the onset of incompetence.³ In this country the law is, as yet, untested but an eminent legal expert has held that:

"if the patient has foreseen the circumstances which have since arisen and there is no reason to believe that he would have changed his mind if still capable of doing so, the doctor should only be justified in proceeding to the same extent as he could if the patient were still capable of consenting".⁴

Some have questioned the liability which might arise for a doctor who complies with an advance directive instruction to curtail treatment. Given that a patient can validly refuse consent to treatment when capable of expressing such consent, a doctor can hardly be accused of negligence by reason of giving effect to wishes expressed before the onset of incompetence and which he has no reason to suppose have been altered subsequently.

Problem Areas

The BMA considers it inappropriate to draft definitive guidelines for the resolution of difficult cases which give rise to ethical conflicts. These would require the type of debate at various levels envisaged by the BMA in its proposals for a decision-making mechanism. Nevertheless, it may be helpful to doctors to identify some of the problematic areas.

Questions often arise about the ethical status of discontinuing a course of treatment, which has been initiated but it is now thought it should not have been embarked upon. Such cases might arise when treatment has been initiated prior to the doctor's knowledge of an advance directive. The BMA considers that late discovery of an advance directive after life-prolonging treatment has been initiated is not sufficient grounds *per se* of ignoring its provisions. If practicable, treatment should be discontinued in accordance with the directive once it is known. If the patient nominated a proxy decision-maker, his views should also be sought with a view to confirming the patient's likely view.

Patients in persistent vegetative state (pvs) are often young people who have had no forewarning of

¹Re AC 1988, 533, A 2d 611.

²"The Living Will". Age Concern, Kings College Centre of Medical Law and Ethics, p. 2.

³Malette v. Schulman (1990), 72 O R (2d) 417 (1991), 2 Med L R 162 (Ontario Court of Appeal).

⁴Skegg P D G. Law, Ethics and Medicine, 1984.

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disease. They are therefore unlikely to have drawn up an advance directive. Even when such patients have drawn up a directive, questions may be raised about whether it should be observed, given that the provisions of an advance directive usually come into play when the patient is nearing the end of life. Pvs patients are not in this situation in the sense that they may continue for decades in an insentient state without hope of recovery. If, however, an advance directive has been drafted the BMA believes it should be accorded the same weight as any other valid expression of a competent patient's opinion. Ethically and legally, if specified in the advance directive, all medical treatments can be withdrawn from the pvs patient.

As a separate issue, the Medical Ethics Committee of the Association has discussed the diagnostic difficulties and general aspects of the provision of treatment to patients who have remained in the persistent vegetative state for longer than one year. A discussion paper, summarising the dilemmas for doctors treating patients in a persistent vegetative state who have made no advance directive or formally appointed a health care proxy is available from the Medical Ethics Committee secretariat.

One of the possible provisions of an advance directive concerns the withholding of nutrition. It is not a necessary part of the advance directive and is an issue upon which much discussion may be required between patient and doctor. Many commentators have drawn attention to the apparent arbitrariness of the profession's recognition of patient's right to refuse artificial ventilation, chemotherapy or dialysis but not naso-gastric feeding or hydration despite the fact that patients die just as assuredly from discontinuation of any of these options. The BMA believes that artificial feeding is a medical treatment which cannot be implemented contrary to the wishes of a patient who refuses consent. Such refusal can be expressed through a competent advance directive.

Summary of Points

1. The BMA strongly supports the principle of an advance directive which represents the patient's settled wish regarding treatment choices when the patient may be no longer able to competently express a view. Through advance directives, patients have a right to decline any treatment, including life-prolonging treatment, in the absence of any evidence of a subsequent change of view. The patient's refusal of specific treatments should be respected but does not imply or justify abandonment of the patient. Doctors and health care institutions should offer such medical care and pain relief as would appear acceptable to the patient and appropriate to the circumstances.
2. The BMA is not in favour of legislation on advance directives. An individual patient's rights do not supersede the rights of other parties; doctors cannot be obliged to act contrary to conscience or the law and, for some patients, such as pregnant women, requests to discontinue treatment may have to be weighed against a moral duty to another human being. Patients cannot insist on the provision of treatments which clinical experience indicates to be futile for their condition or which divert resources from other patients.
3. The BMA considers that a written advance directive, in the absence of contrary evidence, must be regarded as representing the patient's settled opinion. Drafting an advance directive is the patient's responsibility. It is recommended that this be done with medical advice and counselling. Discussion between patients and doctors of the specific terms of an advance declaration should be a continuing dialogue.
4. It is the responsibility of the patient to ensure that the existence of an advance directive is known to those who may be asked to comply with its provisions. It is recommended that individuals who have made an advance directive consider indicating that fact by carrying a card, identifying the location of the document. Doctors, having been notified that an advance directive exists, should make all reasonable efforts to acquaint themselves with its contents. In cases of emergency, however, necessary treatment should not be delayed in anticipation of a document which is not readily available.
5. As yet no person has a legal right to accept or decline treatment on behalf of another adult. Nevertheless, in addition to advance directives, the BMA recognises that the nomination of a health care proxy by the patient may be another helpful development in communicating the patient's views when the individual is no longer capable of expressing these. Nominated proxy decision makers can reflect the patient's other known views, supplementary to his wishes recorded in an advance directive but, in the absence of legislation, the opinions of proxies are not legally binding upon clinicians. Advance directives and health care proxies are not inextricably linked and patients may select either or both to represent their settled wish.
6. It is strongly recommended that patients review their advance directives at regular intervals (at least once every five years). Also strongly recommended is that patients destroy rather than amend the advance directive if they feel dubious about any previously expressed choices. Any new directive should be thoroughly discussed with health professionals (and health care proxy if one has been nominated). Equally important is the maintenance of a continuous dialogue with any nominated proxy decision maker.
7. The BMA believes that an advance directive can be overridden by clinical judgment in exceptional circumstances. Nevertheless, if, in an advance directive, the patient has expressed a clear opinion about non-treatment or discontinuing treatment, having taken medical advice and having in mind the precise clinical circumstances which now pertain, doctors should regard the patient's wish as determinative. Patients should note that a poorly drafted document may complicate rather than clarify the situation and is more

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likely to be regarded as irrelevant. The BMA recommends that a mechanism (such as that devised by the Medical Ethics Committee and Mental Health Committee to facilitate treatment decisions for mentally incapacitated people) be established as a means of arbitration for ethical conflicts arising from advance directives.

8. The BMA urges its members to consider their own views and inform patients at the outset of any absolute objection the doctor has to the principle of an advance directive. Doctors with a conscientious objection to curtailing treatment in any circumstance are not obliged to comply with an advance directive but should advise the patient of their views and offer to step aside, transferring management of the patient's care to another practitioner.

9. The Association encourages doctors to raise the subject in a sensitive manner with patients who may be thought likely to have an interest in the matter or who are anxious about the possible administration of unwanted treatments at a later stage.

10. Late discovery of an advance directive after life-prolonging treatment has been initiated is not sufficient grounds for ignoring it.

April 1992

Decisions Relating to Cardiopulmonary Resuscitation

A STATEMENT FROM THE BMA AND RCN IN ASSOCIATION WITH THE RESUSCITATION COUNCIL (UK)

Introduction

Cardiopulmonary Resuscitation (CPR) can be attempted on any individual in whom cardiac or respiratory function ceases. Such events are inevitable as part of dying and thus CPR can theoretically be used on every individual prior to death. It is therefore essential to identify patients for whom cardiopulmonary arrest represents a terminal event in their illness and in whom CPR is inappropriate.

Background

"Do-not-resuscitate" (DNR) orders may be a potent source of misunderstanding and dissent amongst doctors, nurses and others involved in care of patients. Many of the problems in this difficult area would be avoided if communication and explanation of the decision were improved.

A letter from the Chief Medical Officer (PL/CMO (91) 22) following a case brought to the attention of the Health Service Commissioner has clarified where responsibility lies. The Chief Medical Officer makes it clear that the responsibility for resuscitation policy lies with the consultant concerned and that each consultant should ensure that this policy is understood by all staff who may be involved and in particular junior medical staff. Unfortunately, in many cases discussion and consultation about the resuscitation of a patient is carried out by staff least experienced or equipped to undertake such sensitive tasks.

In a recent survey, the Royal College of Nursing found that most Health Authorities and Health Boards have taken steps to ensure that appropriate health workers are proficient in CPR. The problem of who should be resuscitated has not been addressed and several authorities stated they would welcome guidance. The factors surrounding a decision whether or not to initiate CPR involve complex clinical considerations and emotional issues. The decision arrived at in the care of one patient may be inappropriate in a superficially similar case.

These guidelines therefore should be viewed as a framework providing basic principles within which decisions regarding local policies on CPR may be formulated. Further assistance for doctors and nurses where individual problems arise, can be obtained from their respective professional organisations.

Guidelines

1. It is appropriate to consider a do-not-resuscitate (DNR) decision in the following circumstances:
 - (a) Where the patient's condition indicates that effective Cardiopulmonary Resuscitation (CPR) is unlikely to be successful.
 - (b) Where CPR is not in accord with the recorded, sustained wishes of the patient who is mentally competent.
 - (c) Where successful CPR is likely to be followed by a length and quality of life which would not be acceptable to the patient.
2. Where a DNR order has not been made and the express wishes of the patient are unknown, resuscitation should be initiated if cardiac or pulmonary arrest occurs. Anyone initiating CPR in such circumstances should be supported by their senior medical and nursing colleagues.
3. The overall responsibility for a DNR decision rests with the consultant in charge of the patient's care.

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This should be made after appropriate consultation and consideration of all aspects of the patient's condition. The perspectives of other members of the medical and nursing team, the patient, and with due regard to patient confidentiality, the patient's relatives or close friends, may all be valuable in forming the consultant's decision.

4. Discussion of cardiopulmonary resuscitation with all patients would be inappropriate. However, there are circumstances in which sensitive exploration of the patient's wishes should be undertaken, ideally by the consultant concerned, for example, with patients who are at risk of cardiac or respiratory failure or who have a terminal illness. Such discussions should be documented in the patient's record.

5. Although responsibility for CPR policy rests with the consultant, he or she should be prepared always to discuss the decision for an individual patient with other health professionals involved in the patient's care.

6. Proper understanding of the DNR order is impossible without knowing the rationale behind it. The entry in the medical records of the decision and reasons for it should be made by the most senior member of the medical team available who should ensure that the decision is effectively communicated to other members of staff.

7. Recording in the nursing notes should be made by the primary nurse or the most senior member of the nursing team whose responsibility it is to inform other members of the nursing team.

8. The decision reached following admission of the patient should be reviewed by the consultant in charge at the soonest available opportunity. Such decisions will, of necessity, need to be reviewed regularly in the light of changes in the patient's condition.

9. When the basis for a DNR order is the absence of any likely medical benefit, discussion with the patient, or others close to the patient, should aim at securing an understanding and acceptance of the clinical decision that has been reached. If a DNR decision is based on quality of life considerations, the views of the patient where these can be ascertained are particularly important. If the patient cannot express a view, the opinion of family or others close to the patient may be sought regarding the patient's best interests.

10. Discussions of the advisability or otherwise of CPR will be highly sensitive and complex and should be undertaken by senior and experienced members of the medical team supported by senior nursing colleagues. A DNR order applies solely to CPR. It should be made clear that all other treatment and care which are appropriate for the patient are not precluded and should not be influenced by a DNR order.

11. Experience with DNR orders is an appropriate subject for clinical audit.

March 1993

Proposals for the Establishment of a Decision-Making Procedure on Behalf of the Mentally Incapable

Consent

When a doctor is confronted with a decision relating to diagnosis or treatment of any patient it is good practice to involve that patient in the decision-making process. The patient is then able to consent to what is to be done knowing the consequences of that decision and any alternatives that are available. This enables the doctor to respect the patient's autonomy and protects him from legal liability should the patient later dislike the effect of what has been done. This ideal practice works when the patient is able to comprehend the explanation of what is to be done and what the alternatives are. When through mental illness or handicap the patient is incapable of that degree of understanding then any consent becomes invalid. If that patient is an adult then there needs to be a mechanism to obtain a valid consent for treatment.

Proposed Mechanism

It is proposed that in each health district a new committee should be established to provide such a mechanism. This committee will have the legal authority to act on behalf of any mentally incapable adult seeking diagnosis or treatment or being brought for investigation or treatment in that area. This committee should have at least four members. The presence of four members would be necessary for a quorum and deputies should be named to ensure the committee's work can proceed. They will be appointed by the Secretary of State for Health on the advice of the Mental Health Act Commission. As with magistrates they should be volunteers but have their expenses paid. Their appointment should be for a fixed term of five years but they should be eligible for reappointment. The composition of the committee should be as evenly balanced as possible. The sexes should be evenly represented and one at least of the members should be chosen from an organisation representing the patients. An office with a full-time secretary/assistant will be needed and the funds for this should be centrally provided.

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First Level Decisions

If every medical therapeutic decision relating to the mentally incapable were referred to this committee, the committee would be overwhelmed. There are many decisions that do not require such formality. It is probably easiest to think of the decisions which have to be made in three tiers or ranks of significance. At the first level there are simple treatment or diagnostic options such as the taking of samples for anaemia or lithium levels or the provision of a mild analgesic for a headache, dressings to a bruise or abrasion or antibiotics for a urinary tract infection in an otherwise fit person. There would be no controversy about the decision and it is unlikely that any formal consent need be sought. This level of decision can be left to the medical attendant, the patient and the people providing the patient's environment whether that be the patient's relatives or the staff of a residential home. Within this level of decision making there would be a spectrum of decisions ranging from the totally trivial to those approaching the next tier. The more serious the decision the more consultation the medical attendant should take and it is reasonable to involve caring relatives or attendants. All decisions, investigations and treatment given should be recorded, dated and signed. Should anyone question such decisions at this level then the matter could be referred immediately to the local committee or to a member of the committee for a more formal consent.

Second Level Decisions

The next tier of significance relates to decisions which are not so simple or straightforward. In this group are decisions relating to elective surgery of a simple nature, significant medical decisions relating to long-term medication or the use of drugs with major side-effects. Although not controversial such decisions are the sort that would usually involve a competent patient in making a rational decision whether or not to accept the diagnostic procedure or the treatment. It would be reasonable to involve here a member of the committee to act on the patient's behalf. That member of the committee would be expected to ask the sort of questions that the patient would have asked had he or she been able. The decision could then be made by that individual on the nature of the treatment and the explanations received and consent be given or withheld. This decision would be recorded and then should be reported back to the full committee at its next regular meeting. If anyone involved with the patient was not happy with the decision then it could be deferred and taken to the main committee for a full discussion and decision. Where necessary the involved committee member would be legally entitled and expected to formally authorise in writing that procedure or that surgical or medical treatment.¹

Third Level Decisions

When the treatment or diagnostic procedure proposed was not simple or straightforward or if there were significant side effects then any decision would be expected to be made by the full committee. Included in this level of significance would be any diagnostic procedure such as aortography or HIV testing or treatment relating to fertility or pregnancy, major surgical procedures with risk to life, treatment options in patients with terminal illness or any research procedures. The full committee would also review regularly decisions made by its individual members acting independently and adjudicate when there was dispute about decisions at lower levels of significance. When the committee was deliberating on a decision it would be expected to take into account the views and wishes of relatives and carers and the social and cultural background of the patient. If there was a question of the appropriateness of the medical advice then the committee would expect to be provided with a second opinion from another practitioner in the same field of practice in order to help make the decision. If, after taking further opinions and if necessary interviewing the patient and the doctor concerned, the committee cannot make a decision then the committee will refer the case directly to the Family Division of the High Court.² If someone involved in the care of the patient disagrees with a decision of the committee then an appeal can be made to the same quarter.

At all three levels of decision making, the views of interested relatives should be sought, considered and given due weight.

Delegation of Decision Making

The full committee should be empowered to delegate some decisions to an appropriate interested party in individual cases. Such arrangements to delegate decision making should be subject to periodic review. It is suggested that when a mentally incapacitated person approaches the age of 18 years, the carer(s) might request the committee to consider the delegation of decision making within defined limits to carer(s).

The High Court (or in Scotland, the Court of Session) might also consider delegating some decisions to the full committee in appropriate cases.

Supervision and Accountability

The committee may at times wish to have guidance and support from above, and there should be some form of supervision of the committee. This overview guidance and support should be provided by the Mental

¹The legislation introducing this procedure should make clear that the committee member authorising treatment will have only general liability in law for decisions made.

²In Scotland, such cases would be referred to the Court of Session.

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Health Act Commissioners. Each committee should produce an annual report which should be available to the public and the Commissioners. These reports should not identify any individual patients whose confidentiality would be protected although the Commissioners would be able to investigate any case they felt warranted it. The members of the committee would be expected to agree to abide by the same rules of confidentiality that bind doctors and breach of those rules should be grounds for dismissal and possible legal action.

October 1990

Discussion Paper on Treatment of Patients in Persistent Vegetative State

The principal concerns of this discussion paper are to attempt to define the persistent vegetative state; to examine the practical and ethical problems associated with the condition, including the current uncertainties regarding diagnosis and how these might be addressed; to consider briefly the principal treatment options and some attitudes to them; to draw attention to the vital need for early rehabilitative measures; to note resource considerations; to review the legal position in the United Kingdom insofar as it can be clarified; to consider briefly the position of those close to the patient, including their need for support. (The patient's own views if previously expressed, are considered in a separate BMA paper on advance Directives.)

1. INTRODUCTION

This paper is issued as an aid to debate in response to enquiries as to the Association's views about appropriate treatment for patients in the persistent vegetative state (pvs). It has been drawn up by the BMA's Medical Ethics Committee, whose attention was directed to the need for guidelines on treatment options. The Committee did not feel the elaboration of guidance to be an appropriate task for it to undertake but recognised that there is confusion regarding the condition itself, the extent of the clinician's ethical duties and the legal status of some suggested options. The Committee also considered there to be a vital need to draw the attention of the profession to the urgent need for rehabilitation and stimulation of suspected pvs patients as soon as is practicable after the patient's condition has stabilised. Committee members have been particularly struck by accounts¹ of improvements achieved in some patients by relatively simple methods, including improved nutrition, treatment of pressure sores and specialised seating to maintain muscle tone and encourage eye contact. While recognising that not all patients improve under such regimes, the Committee expressed strong support for all pvs patients to be offered the opportunity of such programmes. The Committee also considered that there would be a value in exploring all of these issues with the aim of supporting the efforts of clinicians working in this area to bring the issues to public attention.

The Medical Ethics Committee recognises that pvs is an issue which polarises opinion because it borders on the discussion of euthanasia and involves definition of life itself. It also raises fundamental questions of the appropriate use of limited resources. The debate is complicated by the availability of many learned contradictory opinions on the subject and some of these are briefly indicated here. Reference is also made to an existing body of BMA policy.

Having taken advice from experts in diagnosis of the condition and those concerned with possibilities of rehabilitation, the Medical Ethics Committee (MEC) puts forward some views for discussion. Although the Committee recognised that it could not answer all of the questions raised, it took a very firm stance on two issues in particular. These centred on the need for good quality care, including provision of coma arousal programmes in the early stages and a clear conviction that questions of possible organ donation by pvs patients should not be considered. Other facets of the subject clearly require wider airing. In such debate, the complexity of the clinical, moral and legal questions must be recognised.

A major problem of this discussion lies in the fact that the arguments and terminology are emotionally weighted and have already been extensively analysed. There is little advantage in reiterating stale debate and since the MEC's aim is to address the practical pre-occupations of doctors, this discussion paper omits some traditional arguments. "Quality of life" arguments are not explored in depth here since they seldom provide practical help, depending as they do upon subjective analyses. Such arguments, however, cannot be ignored and are vitally important in ethical decisions since they are often used as justification for assuming a right to decide on the quality of life of others. While quality of life arguments often lead to more, rather than less confusion, assessments based upon them have formed part of judicial decisions.² Nevertheless, the criteria which courts in the British and American jurisdictions have put forward for assessment of quality of life are vague and subject to wide interpretation. Some would feel the important assessment of quality of life is that made by the patient. (The BMA paper on advance Directives considers this.) Unfortunately,

¹Evidence given to the MEC was later summarised in a published article by Dr K Andrews: Managing the persistent vegetative state, *British Medical Journal*, 305: 486-7.

²See, for example, the case of *Re J* (a minor) (wardship: medical treatment) (1990) 3 All ER, 930, discussed later in this paper.

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there are many vulnerable people at risk of having their quality of life assessed on their behalf, if this is considered an appropriate thing to do.

"Slippery slope" arguments have also been omitted. Increasingly, medical technology empowers doctors to prolong life. Decisions are made every day about whether it is appropriate to do so in specific cases. Such decisions are part of a continuum of care and in practice, it appears inappropriate to classify some decisions as necessarily leading to a degeneration of standards. It can be argued that widely accepted policies on questions such as non-resuscitation or non-treatment already place society on the slope that some would seek to avoid. Nevertheless, the Medical Ethics Committee recognises that it would be a retrograde step if the fact that medical technology empowers doctors to prolong life, were to be equated with giving doctors or others the right to decide when people should die.

2. DEFINING THE CONDITION

Experts agree that pvs is poorly understood. This implies a risk of the term being improperly used and highlights the need for definition. Any lack of rigour or prematurity in arriving at a diagnosis of pvs may carry very serious dangers for the patient, as is shown by the case of *Carrie Coons* discussed later in this paper.

Coined by Jennet and Plum,¹ the term "pvs" designates patients who have lost the function of the cognitive part of the brain. The pathology is usually either neocortical necrosis from lack of oxygen or isolation of the cerebral cortex arising from traumatic damage to the sub-cortical white matter.

Although "persistent" is simply a description of the present state of affairs and does not predict the long term outcome, this loss of cerebral function can be seen retrospectively as permanent in that post mortem examination sometimes confirms the extent of neocortical or white matter damage. Many, however, object to classifying patients as "permanently" vegetative since there are no clinical or laboratory means of confirming this before a post mortem and there is a danger that health professionals will take the attitude that there is no point in treating patients if the diagnosis is of a permanent state. Thus, rehabilitation specialists have pointed to the danger of a self fulfilling prophecy here—since the prognosis is poor, no treatment is given, therefore the prognosis is poor.² While recognising that some patients will be shown retrospectively to be permanently vegetative, the Committee strongly emphasised that this is not a diagnosis that can be made in the early stages of the suspected condition, when all rehabilitative efforts must be made. It is agreed that early, specialised treatment offers the best hope for optimal recovery and there is evidence³ that good standards of nursing care, attention to nutrition, use of appropriate drugs and varying stimulation programmes can be effective in achieving improvements.

Patients in pvs resemble those in coma in that they are unaware and do not react to stimuli. In the literature, comparison of coma and pvs has been undertaken in two ways.⁴ A behavioural approach places coma and pvs as different points on a continuum of arousal with no essential difference between the two other than the lower level of brain response in pvs. Another approach considers coma and pvs to be neuropathologically and prognostically different. This view sees comatose patients as usually suffering from damage to the reticular activating system controlling primitive reflexes, often resulting in breathing difficulties requiring ventilation, and with impaired cough, gag and swallowing reflexes; none of which symptoms categorise pvs patients. Furthermore, supporters of this view claim that the "life span of a truly comatose patient is limited to weeks or months, rarely years"⁵ whereas pvs patients may live for decades. The lack of meaningful consciousness is common to both states but it is sometimes difficult for non-medical observers to recognise this since the pvs patient, in contrast with the comatose, may appear to exhibit a response.⁶

Unlike comatose patients, those in pvs are intermittently wakeful⁷ or in a state of "chronic wakefulness without awareness".⁸ Although often maintaining a cyclical sleep pattern, the body shows no behavioural or cerebral metabolic evidence of any capacity to respond in a learned manner to external events or stimuli. Many types of EEG pattern are found in pvs, from the near normal to the occasionally flat.

¹Jennet B, Plum F. Persistent vegetative state after brain damage: a syndrome looking for a name. *Lancet*, 1972, i: 734-7.

²Andrews K. Managing the persistent vegetative state. *British Medical Journal*, 29 August 1992; 305: 486-7.

³Further details of rehabilitative measures are outlined in Andrews K, Managing the persistent vegetative state, *British Medical Journal*, 305: 486.

⁴Banja J. "Ethical aspects of treatment for coma and the persistent vegetative state". *Physical Medicine and Rehabilitation: State of the Art Reviews*, vol. 4, 3: 579-92.

⁵Cranford R E. The persistent vegetative state: The medical reality (getting the facts straight). *Hastings Center Report*, 1988; 18: 27-32.

⁶Jennett B, Teasdale G. Management of head injuries. Philadelphia: F A Davies, 1981.

⁷Shuttleworth E. Recovery to social and economic independence from prolonged post-anoxic vegetative state. *Neurology*, 1983; 33: 372-3.

⁸American Medical Association Council report. Persistent vegetative state and the decision to withdraw or withhold life support. *JAMA*, 19 January 1990; 263, 3: 426-30.

Although the neocortex may be extensively and irreversibly destroyed in pvs, the brain stem, which connects the cerebral cortex to the spinal cord remains intact and serves such stereotypical vegetative reflexes as breathing, eye movement and digestion. Therefore, not only are the brain stem death criteria (which are related to brain stem function) not fulfilled but to relatives the patient is manifestly alive with open eyes and evidence of respiration. Therefore pvs patients are not typically respirator dependent although some may be ventilated at some stage of treatment. This was the case with Karen Quinlan, who was ventilated from hospitalisation in April 1975 until a New Jersey court decision in 1976 allowed withdrawal of artificial ventilation on the basis of irreversible loss of cognition. Karen Quinlan did not die as expected but continued for many years in a persistent vegetative state. The condition is seen as a new phenomenon resulting from advances in medical technology which prevent natural death after the occurrence of acute brain damage.

3. PRACTICAL AND ETHICAL PROBLEMS

The Causes of PVS

Loss of consciousness is caused by a variety of insults to the brain, arising either from acute injury or possibly from progressive disease. The latter category is more complex, involves other dilemmas to those associated with pvs patients and is not discussed here. Trauma is a significant causation of pvs but resuscitation following profound hypoxia is also a common cause.

Resuscitation following Hypoxia

The paucity of accurate data must be recognised but three broad categories of causation, which might affect outcome can be posited. The condition may occur after the patient has been resuscitated after many minutes without a beating heart.¹ The clinical decision of when it is appropriate to initiate resuscitation is a very difficult one but would be helped by the existence of an agreed policy on resuscitation and clear training for all health personnel. The Law Reform Commission of Canada, for example, concluded that diminished oxygen supply (anoxia) and interruption of blood circulation (global cerebral ischemia) beyond eight to ten minutes resulted in the complete loss of possibility of communication with the outside world "corresponding to a permanent loss of all manifestations of personality".²

When resuscitation has been successful, the length of time prior to further improvement may be significant for the long term outcome. The American Medical Association (AMA) considers that (with the exception of children for whom there is too little data) few, if any, of the group of patients who have suffered cardiac arrest or other asphyxial injury, will recover awareness if no improvement is shown in the first month and asserts that none regain cognition after three months in an unconscious state.

Less severe injury might occur from an anoxic incident such as carbon monoxide poisoning. The AMA believes that patients with lesser anoxic injuries have a better chance of some recovery, but even in this group it is rare after three months. In a third category, the AMA sees slightly more optimism for cognitive recovery in patients, under 40, who have suffered head injury or subarachnoid haemorrhage, but even so it admits that their prognosis is still relatively poor. It does not feel there can be any chance of recovery, even in patients among this group, after 12 months of observed unawareness.

Making a Diagnosis

Fundamental to debate about pvs is the question of whether doctors can confidently diagnose, and if so at what stage, patients in pvs as different from other patients in an apparently indistinguishable condition but from which there may be some degree of recovery. Some commentators, for example, have compared symptoms of pvs with the "locked-in" syndrome; a condition in which a well-defined pontine lesion deprives the patient of all voluntary motor control except for vertical gaze and upper eyelid movements. Paralysis rather than cognitive failure prevents these patients from communicating and awareness may be fully or partially preserved but unless their purposeful eye movements are recognised, these patients may be thought to be in pvs.

To some extent, only time will tell whether patients have any possibility of recovering some degree of cognition. High technology medicine has not yet provided significant help. It is recognised that analysis of neocortical function by electroencephalogram (EEG), for example, has limited accuracy and does not necessarily distinguish between vegetative and "locked-in" patients. Experts are optimistic about the potential for using positron emission tomography (PET) to study the cerebral metabolism of patients who may be in pvs. Experiments at Cornell University have indicated that within weeks of brain trauma, clinical signs are detectable by PET scanning, which may help accurately predict the patient's outcome.³ It appears potentially possible by PET scanning to distinguish between patients in the "locked-in" state, whose cerebral energy metabolism is only moderately reduced compared to the norm, and those who may be in pvs, who

¹Safar P. Resuscitation from clinical death: pathophysiologic limits and therapeutic potentials, *Critical Care Medicine*, 1988; 16: 923-41.

²Law Reform Commission of Canada. Criteria for the Determination of Death. Ottawa: 1979.

³Ray J. The body without a mind: an examination of cognitive brain death, *Humane Medicine*, 1991; vol. 7, 1: 29-34.

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exhibit profound disturbances.¹ This is still early days for such methods and it must be recognised that the availability of PET scanners is very limited.

In the absence of technical measures to confirm diagnosis, concerns remain regarding the reliability of prognoses of permanent unconsciousness. This paper does not engage in a detailed analysis of the clinical steps which may lead to a diagnosis of pvs. In the view of the Committee, however, a pvs diagnosis must be deferred in any case of the slightest doubt because of its connotations for decisions about future care. We have noted some points of general agreement. Experts emphasise the duration of the condition and causation as important interwoven factors. Some also see the age of the patient as relevant, with patients over the age of 40 having a reduced chance of recovering self-awareness after a delay of several months in comparison with younger patients.

All agree that there can be no immediate diagnosis of pvs but some clinicians believe a diagnosis can be made after three months without patient improvement and others put the limit at six months. This approximate time limit is supported by various studies and anecdotal evidence, which show that the recovery of some degree of cognition is possible in some cases between three to six months after the onset of unconsciousness. The AMA, positing that no improvement can be expected after a year, sets a conservative criterion for diagnosis of pvs as 12 months of unawareness. This guideline had been adopted by some other bodies. The Medical Ethics Committee of the BMA considers that diagnosis must be a question for the clinician in the individual circumstances and therefore does not set a recommended time limit on such decisions. Nevertheless, it sees value in the conservative criterion set by the AMA and considers that the 12 month stage would be an appropriate time to review diagnosis and treatment. The MEC recommends that the clinician making a pvs diagnosis should seek the independent concurrence of two other doctors.

Prior to a pvs diagnosis being made, the Committee considers it vital that every effort be made to provide rehabilitative measures in the early stages and exclude all possible factors which might impair cognition. It believes that doctors must insist on intensive efforts being made to stimulate the patient in the first six months and draws attention to the work being done on coma arousal at the Putney Royal Hospital and Home. Sadly, for many patients, this aspect of treatment is often ignored. This is discussed further below with regard to treatment options. Since the pvs diagnosis represents the end of any expectation of that patient's cognitive recovery, clearly all other possibilities must have been first eliminated.

Confidence in the criteria used for establishing a pvs diagnosis is occasionally rattled by accounts of a very small number of patients who have apparently recovered some functions after prolonged periods in a state of coma. What must be examined in such cases is the degree of "recovery" and whether the particular patients might have been misdiagnosed originally. One of the documented cases of recovery, that of Carrie Coons,² demonstrates the dangers of a premature diagnosis of pvs, based upon insufficient data. Mrs Coons, an 86 year old American patient, recovered sentence in April 1989 after four and a half months unconsciousness and six days after a court had ruled that the gastrostomy tube which provided her nutrition could be removed. In this case, although the patient had been diagnosed as being in pvs, she had not been examined by a neurologist. Her gerontologist had considered that Mrs Coons' condition might be attributable to other causes than pvs but his request for further tests to eliminate other factors was opposed by the patient's relatives who obtained authorisation from the New York State Supreme Court to withdraw feeding. After the court ruling, Mrs Coons unexpectedly regained consciousness apparently as a result of aggressive efforts by nurses to stimulate and feed her. Medical assessment of the degree of Carrie Coons' recovery varied. Her doctor made it clear that Mrs Coons was not "up and dancing around" and psychological evaluation found Mrs Coons to be not competent although she was able to communicate. The precise degree of recovery in this case is, perhaps, by the way since the important point is that a diagnosis was made without corroboration of a neurologist and omitting important tests. One can hypothesise that some other reports of recovery from pvs have concerned patients who were similarly diagnosed without full data.

It is clear that the medical evidence given to the court that Carrie Coons' condition was "hopeless and irreversible" was completely wrong. This case might be held to exemplify the very grave risks inherent in cutting corners and making premature diagnosis on the basis of a patient exhibiting some of the classic signs associated with pvs. It also epitomises the vital importance of stimulation to coma patients.

As mentioned previously, professional opinion varies as to the time necessary for confident diagnosis. The AMA, for example, estimated the odds of recovery as less than one in one thousand for patients classified as pvs after a 12 month period. It concluded that:

"the risk of prognostic error from widespread use of the above criterion is so small that a decision that incorporates it as a prognostic conclusion seems fully justifiable".³

¹Levy, *et al.* Differences in cerebral blood flow and glucose utilisation in vegetative versus locked-in patients. *Ann Neurol.* 1987; 22: 673-82.

²See Steinbock B. Recovery from Persistent Vegetative State? The case of Carrie Coons. *Hastings Center Report*, July/Aug 1989: 14-15.

³AMA Council report, as above.

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It has also been suggested that some reports which describe return of cognition after six months¹ may have involved patients who had passed into an unrecognised "locked-in" state upon emerging from a coma.² Clearly, this possibility should be taken into account and reinforces the view that intensive rehabilitative efforts should be made in the initial period to examine whether any outwardly minor change has gone unrecognised.

Defining Death

It is suggested nowadays that in allowing new human states to arise, medical technology raises uncertainty as to whether the occupants of these states are truly alive or dead. We cannot hope to reflect the vast literature available but simply note some of the principal opinions. Some may question whether it is helpful to bring definitions of death into the present debate, but it can be argued that they have relevance to the persistent vegetative state. It must be strongly emphasised, however, that pvs is entirely different from any accepted criteria of death, such as brainstem death.

Traditional criteria for defining death have been based on cessation of heart and lung function but mechanisms which provide artificial respiration or intermittent positive pressure ventilation have made such criteria inappropriate in some cases. In such cases, variations of "brain death" criteria can be applied. The accepted definition in Britain is the formulation offered by the Conference of Royal Colleges and their Faculties based on the permanent functional death of the brain stem.³ This concludes that the identification of brain death means that the patient is dead, whether or not the function of some organs is maintained by artificial means. Without a functioning brainstem, "the body is merely a mass of inert matter in which entropy increases as residual functions decline and organs decay".⁴ In other countries, other criteria are recognised. Lamb draws attention to three distinct but related formulations of "brain death" which have been incorporated into legal definitions of death in different parts of the USA, even though some appear unsatisfactory. (In 1971, for example, Kennedy demonstrated that according to Kansas statute "X at a certain stage of the process of dying may be pronounced dead, whereas Y, having arrived at the same point, is not said to be dead".⁵) It is not our intention here to explore the definitions in depth but simply to note, with Fox and Swazey,⁶ that:

"The introduction of the concept of brain death and its implications has only begun to be explored. But this at once symbolic and organic transposition of the primary site of death from the heart and lungs to the brain has already created new ambiguities about what constitutes life and humanness rather than mere existence."

The accepted British medical definitions of death—irreversible cessation of cardio-respiratory function or permanent functional death of the brainstem—cannot be applied to patients in pvs although some of the reasoning behind brain death definitions appears relevant, as is indicated by the way in which the BMA⁷ has viewed brainstem death:

"The diagnosis criteria of brain death are well-known but it is valuable to understand the justification for this standard. For some the criterion is justified because it is a sure prognostic sign that cardio-respiratory death is imminent. But it also seems that by accepting brain death as a criterion for the end of life we have indicated that it is the distinct functions provided by the human brain that make human life of unique ethical importance. Where an individual can no longer have the experiences of a human being and never will have again we think that the functions that remain are of no further value to that individual. This is why controversy over whether the brainstem is completely and in every part dead and whether the whole brain can be said to be not functioning just on the basis of the accepted battery of tests, are beside the point."

Furthermore, the World Medical Association, in its Declaration of Sydney,⁸ reminds us that death is a process and that "clinical interest lies not in the state of preservation of isolated cells but in the fate of a person". Taking up this point, it is clear that the persistent vegetative condition stimulates debate of how to define terms such as "person" or "human life". A common argument, which would appear to flow from the WMA statement, is that personal existence is founded on psychologic and not merely biologic traits.⁹ Human individuals are differentiated from each other and from other species by non-physical personal characteristics—personality, psyche, cognitive functioning and emotion. For those who consider the value of human life resides in self awareness and the continued existence of such characteristics, or

¹For example, Arts W, et al. Unexpected improvement after prolonged post-traumatic vegetative state, *Journal Neurol Neurosurgery Psychiatry*, 1985; 48: 1300-03.

²Snyder, et al. Delayed recovery from post-anoxic pvs, *Ann Neurol*, 1983; 14: 152.

³Memorandum issued by the Honorary Secretary of the Conference of Medical Royal Colleges and their Faculties in the United Kingdom on 15 January 1979.

⁴Lamb D. Death, Brain Death and Ethics, 20-32. Croom Helm: 1985.

⁵Kennedy I (1971). The Kansas Statute on Death: An Appraisal, *New England Journal of Medicine*, 285: 946-50.

⁶Fox R F, Swazey J P (1974). *The Courage to Fail*. University of Chicago Press.

⁷BMA Euthanasia report, 1988; p. 9.

⁸The WMA formulated a Statement on Death in 1968 known as the Declaration of Sydney. It was amended by the 35th World Medical Assembly in Venice in 1983.

⁹Green & Wikler. Brain Death and Personal Identity, *Phil Public Affairs*, 1980; 9: 104-33.

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the potential for achieving such awareness and expression, permanent loss of sentience equates death. It is therefore argued by some that since the qualities which make up the identity of the person are permanently and irreversibly lost, the cessation of cognitive functions in pvs, regardless of how this is medically assessed, should be regarded as death of the whole person, with all the concomitant implications. It is argued that it is "loss of upper brain function which marks the person's death. Death of the brainstem is no more constitutive of *death simpliciter* than death of the kidneys or other vital organs."¹ Green and Wikler argue that residual life has little significance if psychological life has ceased and propose a brain-death statute, which would give grounds for suspending any treatment of pvs patients. Objections by some that this could lead to similar measures for patients who are mentally ill or suffer from senile dementia are countered by the authors' proposal to limit the licensing of "letting die by brain death statute" to the "permanently comatose and no one else".²

There are obvious, and unacceptable, risks in arguing that diagnosis of death can be dependent upon loss of certain psychological attributes. Personal identity theories of death are not widely accepted and were firmly rejected in the United States by the President's Commission³ on the grounds that:

- Many questions relating to personal identity remain unsolved and the abstract terminology of such theories render them less useful for public policy than biologically based concepts.
- If accepted, the practical application of such theories would be difficult and give rise to many borderline problems. Senile or mentally handicapped people might fail to meet criteria for personhood but any argument which attempted to classify them as dead would be rejected.
- Patients with substantial damage to the neocortex and subcortical areas continue to breathe independently but the implications of the personal-identity argument would be that pvs patients are on a par with the traditionally "dead".
- Diagnosis of lost personal identity is vague and fraught with difficulty. "It is not known which portions of the brain are responsible for cognition and consciousness; what little is known points to substantial interconnections among the brainstem, subcortical structures and the neocortex. Thus the 'higher brain' may well exist only as a metaphorical concept, not in reality. Even when the sites of certain aspects of consciousness can be found, their cessation often cannot be assessed with the certainty that would be required in applying a statutory definition."

Nevertheless, there is an ambivalence in attitudes shown to pvs patients. The BMA Working Party which produced the Euthanasia report took evidence from the wife of a pvs patient who eloquently summarised the confusion felt about whether the "person" has gone or not and the implicit mixed message which appears to come from the health care team.

"There is permanent conflict. You are told and you know, that there is no personality, nothing going on in there, no feelings or intentions or knowledge. But it is standard medical practice and your natural inclination to talk to him. You stroke him and talk and sometimes you think from his reaction you are giving comfort, but you know in your heart you are not. When he has pneumonia the doctors say 'we don't think he will last the day', and then the nurses come in saying 'we are just going to do this for you, Alan, or that for you, Alan'. It is surreal."

The Working Party advised:

"We believe that a medical decision not to prolong life should be made as and when the relatives and the care team can concur with the conclusion that the patient is, in a very important sense, no longer there. The conclusion that the patient is 'gone' from us should, however, be based on firm evidence of widespread and irreversible structural damage sufficient to preclude recovery, not merely on clinical assessment."

The Medical Ethics Committee confirmed the vital importance of establishing the irreversibility of the condition in each individual case before discussion of withholding treatment is initiated.

Many think that proposals for redefining death dodge the main issue and are tactics to divert the controversy away from that main point, which concerns the implications of that medical decision not to prolong life. The BMA's Medical Ethics Committee has certainly not seen redefining death as the way forward but has taken the view that the ethical problems arising in connection with treatment of pvs patients cannot be resolved by a surreptitious moving back to the moment of death.

The question, however, remains as to whether the life of a persistently comatose person is so poor or so meaningless that it should be ended. This question is discussed below. In noting, however, the BMA's view of the situation of pvs patients, attention is drawn to an important corollary:

¹Green & Wikler, above.

²As above.

³President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research (1981). *Defining Death*, July 1981.

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"At present we cannot move from brain death to neocortical death because there is no way to establish that irreversible and complete loss of neocortical function has occurred. Therefore, we need a humane and definitive policy to those who are condemned to persisting in this state. Of course, any conclusions reached about patients in pvs would have absolutely no implications for the termination of life of a sentient person. There is a vast clinical and philosophical distinction between the two because in the case of voluntary euthanasia it is a living and sentient being who makes the choice to have his life ended."¹

Doctors' Moral Duties

Doctors are ethically bound to ensure that diagnosis and medical decision making are based upon thorough evaluation of the data. Current tests for pvs cannot be regarded as infallible even when carefully performed and interpreted. Good management, however, can eliminate some factors which impair functioning. It can be argued, therefore, that in the absence of totally reliable measures of testing, doctors should do all in their power to ensure that good standards of nursing care and aggressive stimulation are available in the early stages of suspected pvs.

Despite the lack of confirmatory laboratory tests, most neurologists are confident about their ability to diagnose pvs in the course of time. Few people would then argue that doctors are duty bound to prolong human existence in any form and in all circumstances but where boundaries can be confidently drawn remains a question for debate. While few support rigid "outer boundaries" (all life-prolonging treatments in all circumstances), there is similarly little or no evidence of support for rigid "inner boundaries" (which would espouse compulsory withdrawal of treatment for some categories of patient). It is clear then, that in discussing the doctor's duties we are in the realm of ill-defined boundaries which depend upon a number of factors which will be individual to the case.

The 1988 BMA report, which represents Association policy, states:

"To be a human life of the type that we all regard as being of special ethical importance we require that there be a persisting capacity for sentience. Where we know that any such capacity has been irreversibly lost we conclude that there is no ethical reason to prolong the biological functions that remain."

The BMA also sees an important role for patients through advance Declarations or nominated proxy decision-makers and has issued a statement on this subject.

The "Best Interests" Debate

Attempting to define what might possibly be in the "best interests" of a patient in pvs entails similar hazards as those which attend discussion of "quality of life". Some writers have concentrated on the distress to the family, appearing to imply that what is in the relatives' interests must be best for the patient, but the weakness of this argument is evident. Others have questioned whether a person in pvs, lacking awareness or capacity to experience discomfort, can be said to have interests at all. They maintain that it is misleading to attribute interests, in the sense in which the word is commonly understood, to the permanently unconscious.

"We do not have positive obligations to use scarce human and natural resources to promote the 'interests' of beings whose good can never matter to them. The best interest principle, however, is a principle that expresses a *positive obligation*, a duty to do what best promotes someone's interests or is most conducive to his or her good. As such, the best interests principle does not apply to beings who permanently lack the capacity for consciousness and whose good can never matter to them, and this includes human beings who are in a permanent vegetative state."²

The authors go on to qualify this statement, recognising as interests those stable values and wishes which might have been expressed prior to the patient falling into this state. The American case of *Brophy* contributed to this discussion. Mr Brophy lapsed into a persistent vegetative state after an operation in 1984 and his wife requested the courts to authorise removal of a feeding tube in 1986 and it was understood that this would have been his wish. The guardian *ad litem* challenged this request on the grounds that it was contrary to Mr Brophy's interest "to be starved to death". Again Buchanan and Brock³ have raised three points:

"It was in his interest not to be maintained (in pvs), if avoiding a prolongation of irreversibly unconscious life was extremely important to him when he was conscious. Second, since he derived no benefits from the bare preservation of his vegetative functions—being permanently unconscious—there was no current interest in gaining such benefits that could outweigh his previously expressed interest in avoiding a prolongation of permanently unconscious life. Third, the unstated implication that being 'starved to death' would entail suffering was incorrect for a permanently unconscious patient. So the guardian *ad litem*'s conclusion that it cannot be in the patient's interest to die of malnutrition is simply false".

¹BMA Euthanasia report, 1988; p. 10.

²Buchanan A, Brock D. Deciding for others: the ethics of surrogate decision making, 126-9. Cambridge University Press: 1989.

³As above.

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They go on to say that, assuming the testimony of his family was correct and Mr Brophy when conscious opposed the idea of such prolongation of life, then the appropriate principle for resolution of his case was one of substituted judgment and not best interests. In other cases, where the permanently unconscious patient was not known to have previously expressed a preference, such as the *Quinlan* case, the guiding principle might be said to be "best interests" with all the reservations expressed about the use of the term.

Although some find this argument unpalatable, the conclusions reached by Buchanan and Brock are not substantially different to those reached by many other authors. They are that, contrary to what one might intuitively presume, the best interest principle does not require that the unconscious patient be sustained indefinitely but does require that they be maintained long enough to make reliable prognosis. They suggest that the proper question regarding treatment for such patients is not "Would withdrawal of life support best serve the patient's interest?" but rather "Would continued support provide any benefit?".

4. TREATMENT OPTIONS AND AIMS

The aims and options regarding treatment can be divided into two stages. In the early months, the aim must be to stabilise the patient and investigate all measures which might stimulate improvement. Since definitive diagnosis cannot be reached at this stage, there may be a temptation to make minimal efforts and simply keep patients "ticking over" until their condition is reviewed. This, however, may be detrimental to the patient's long-term prognosis. The BMA's Medical Ethics Committee emphasises that this should be a time of varied effort to stimulate the patient and reduction or withdrawal of treatment should not be contemplated whilst there is any doubt about the patient's ability to progress. Once diagnosis of pvs has been made, the aims and options may be entirely different. If the patient is truly in pvs, there can no longer be expectation of improvement and the option of withdrawing all treatments may be posited.

Prior to Diagnosis

If we begin by defining the minimum which must be provided, it is clear that all unconscious patients are entitled to a high standard of nursing care, even though completely insensible as to what is done for them. The importance of high quality care, particularly in the early months prior to definitive diagnosis, cannot be over-emphasised. In the case of patients who are suspected pvs, lack of attention to minor conditions may further impair cognitive recovery and thus deprive the patient of proper assessment. The Committee regrets that efforts to provide stimulation are not consistently made or only initiated at a late stage, even though studies have shown that regular and varied programmes of stimulation, bring about improvement in some cases.¹ Doctors who attempt to provide rehabilitation report that some patients have not been taken out of bed, have sores, infections and other conditions which could have been treated earlier. Nutrition, also, is often neglected, partly because of the nursing time consumed by maintaining nutrition by nasogastric tube and it has been shown that upon admission to rehabilitation programmes, brain damaged patients are usually under their ideal weight.² Endoscopically placed percutaneous gastrostomy tubes represent an advantageous way of managing nutrition for such patients.³

After Diagnosis

At the stage when clinicians can feel confident about diagnosing pvs, the aims of treatment come up for review. These aims have also been discussed by Buchanan and Brock:⁴

"The chief goals of medical care are these: the promotion or restoration of opportunity through the prevention or treatment of disability; the prevention or palliation of discomfort, pain and suffering; the extension of life or the prevention of unwanted death; and the provision of valuable information about one's health status. For the permanently unconscious patient the first goal cannot be achieved since disability is total and opportunity is irretrievably lost. Prevention or palliation of discomfort, pain or suffering, is irrelevant because the patient is permanently bereft of all sentience and awareness."

After diagnosis of pvs has been reached, the fact of a patient being unaware must not imply any sense of his being abandoned. It is suggested below that treatment be reviewed after one year and as part of that review, withdrawal of medical treatment might be discussed with those close to the patient. This should not be seen as withdrawal of care and doctors must also be aware of the legal implications of this action. In such circumstances, there should normally be no question of the patient being discharged from hospital (on the grounds that the patient was no longer receiving treatment), unless families specifically request it.

Treatment/Non-Treatment

PVS patients are vulnerable to infection and either may or may not be treated with antibiotics. It is significant that there appears to be no controversy about doctors, nurses and families deciding not to give

¹Andrews K. Managing the persistent vegetative state, *British Medical Journal*, 305: 486-7.

²Brooke M, Barbour P C. Assessment of nutritional status during rehabilitation after brain injury, *Arch Physical Medical Rehabilitation*, 1986; 67: 634.

³Forgacs I, et al. Percutaneous endoscopic gastrostomy, *British Medical Journal*, 1992; 304: 1395-6.

⁴Buchanan A, Brock D, as above.

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antibiotics in the event of the patient developing an infection, although it is evident that the intention behind such a decision is that a patient, who is not otherwise terminally ill, should die. This is usually seen as "allowing nature to take its course". Although it may appear harsh when taken out of context, for many doctors and families the main problem is seen as lying in the fact that "these opportunities to withdraw treatment may not arise for many years".¹

In relation to pvs patients, the BMA recognises that "most patients' relatives and doctors feel that medical intervention is no longer warranted because it can be of no benefit to the individual concerned once this 'hopeless' state has come about".² The Association gives further guidance:

"Where medical intervention cannot benefit a patient in any appreciable way we do not consider it to be justified. But because in some sense there is a human being still present we feel that care and comfort should not be withdrawn and recognise that what are regarded as reasonable measures to secure care and comfort will vary from patient to patient."

Those close to the patient are likely to worry that stopping treatment may cause suffering to the patient but, by definition, in pvs the patient's capacity to perceive stimuli and the neocortical function required to generate affective response to stimuli are both destroyed.

Hydration and Nutrition

Many point out the common apparent arbitrariness of condoning the discontinuation of artificial ventilation, chemotherapy or dialysis but not nasogastric or gastrostomy feeding or hydration when patients die just as assuredly from removal of any of these.³ The difference in view may be partly due to the way in which provision of food and water is seen as an elementary expression of care and partly due to the fact that by discontinuing nutrition, doctors are making explicit the intention that the patient should die. Withdrawal of other treatments may lack the same explicitness of intention. Removal of a ventilator, for example, may result in the patient breathing unaided, as did Karen Quinlan. When treatments such as chemotherapy have failed to arrest the disease, their discontinuation allows the disease process to take its natural course. Some view removal of a ventilator or feeding tube as on a par since both will result in the patient's dying from respiratory failure or nutritional insufficiency caused by the patient's inability to breathe or swallow unaided. For others, discontinuation of nutrition is in a different category and viewed as active killing in a way that withdrawal of other treatments are not. It must be noted that there appears to be a divergence of legal views on this.

In Britain some legal experts consider that "artificial feeding inevitably requires some medical expertise and is, therefore, rightly considered part of selective medical treatment".⁴ American authorities have also seen distinction between different methods of feeding. In the Supreme Court of New Jersey, Justice Schreiber held that:

"artificial feeding by means of a nasogastric tube ... can be seen as equivalent to artificial breathing by means of a respirator. Both prolong life through mechanical means when the body is no longer able to perform a vital bodily function on its own".⁵

The BMA's Euthanasia Report gives clear guidance on the definition of artificial feeding as a medical treatment. The Association considers that:

"feeding/gastrostomy tubes for nutrition and hydration are medical treatments and are warranted only when they make possible a decent life in which the patient can reasonably be thought to have a continued interest".⁶

Other British bodies which have considered the matter include the Institute of Medical Ethics, which in 1991, published its majority view that "it can be morally justified to withdraw artificial nutrition and hydration from patients in persistent vegetative state".

The BMA report also elaborates a view about the treatment of the pvs patient:

"The need to offer care and comfort to someone in this state is important even though he may not be aware of any benefit. There is no justification for continuing medical intervention in such a state and the working party feels that the individual concerned is most appropriately treated as an incompetent patient with a terminal condition."

and quotes a Roman Catholic opinion about artificial feeding regimes:

¹Jennett B. Decisions to limit the use of technologies that save or sustain life, *Proceedings of the Royal College of Physicians*, Edinburgh, 1990; 20: 407-15.

²BMA Euthanasia report, 1988; p. 10.

³Heintz L L. Legislative hazard: keeping patients living against their wills, *Journal of Medical Ethics*, 1988; 14: 82-6. Banja J D. "Ethical aspects of treatment for coma and the persistent vegetative state". *Physical Medicine and Rehabilitation: State of the Art Reviews*, vol. 4, 3. Philadelphia: October 1990.

⁴Mason & McCall Smith. *Law and Medical Ethics*, 3rd edition: 343. Butterworths: 1991.

⁵Re *Claire C Conroy*, 464 A 2d 303 (NJ 1983), 486 A 2d 1209 (NJ 1985).

⁶BMA Euthanasia report, 1988; p. 23.

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"To persist in indiscriminately using such gestures can convey stupidity and cruelty, not compassion and love."¹

A doctor who became closely involved in a controversial case in 1992 and who discussed the issues with individuals from a range of religious persuasions reported to the Committee that representatives of the Catholic and Anglican Churches appeared to accept the concept of withdrawing medical treatment from patients firmly diagnosed as in pvs.²

In line with the BMA's 1988 report, the Medical Ethics Committee has concluded that in pvs cases where the clinician judges there can be no realistic chance of improvement and two other doctors independently concur with that view, it would be reasonable to remove all forms of invasive treatment, including nutrition and hydration. The Association rejects active measures to hasten death. Not only are such measures very clearly illegal but may be considered as a reflection of the needs of carers rather than those of the pvs patient, who by definition does not experience suffering.

5. THE LEGAL POSITION

The law can be invoked in several ways into the discussion of treatment options. It can address the provision or discontinuation of treatment in terms of legal permissibility, tortious liability or apportionment of damages in litigation. Only the first of these is considered here.

United States

In areas where British law may be unclear, it is sometimes thought helpful to note developments in the various states of the United States. A number of decisions in criminal and civil cases in the United States relate to withdrawal of all medical treatments, including artificial feeding, from both competent and incompetent patients.

The position of competent patients has been clearly established. The Massachusetts Supreme Court, for example, stated that:

"the constitutional right to privacy is an expression of the sanctity of individual free choice and self-determination as fundamental constituents of life. The value of life as so perceived is lessened not by a decision to refuse treatment, but by the failure to allow a competent human being the right of choice".³

Some have argued that pvs or other incompetent patients have no "right to privacy" and therefore no right to reject medical intervention can be exercised⁴ but this was rejected in 1984, by the Florida Supreme Court which put forward the opinion that "an incompetent person has the same right to refuse medical treatment as a competent person";⁵ a view later confirmed in the cases of *Conroy* and *Cruzan*.

In a criminal case in the early 1980s, two Californian doctors⁶ were charged with murder after withdrawing treatment including nutrition from a pvs patient. The Superior Court of Los Angeles eventually determined that the doctors' action was justified since treatment was shown to be ineffective and also determined that artificial feeding was medical treatment and therefore subject to the same tests as to whether it was legally obligatory.

Legal experts have seen indications in American cases, such as *Conroy*, of how English law might develop. In this case, it was recognised that not only could treatment be withdrawn from permanently comatose patients but also that the prior wishes of incompetent people could be determinative as to withdrawal of treatment, including artificial feeding and hydration. In the absence of any evidence of the patient's prior wishes, however, the court believed that treatment should only be withheld if that action would "clearly and markedly outweigh the benefits the patient derives from life" and in cases of doubt "it is best to err in favour of preserving life".⁷

More recently, the debate was renewed in the widely publicised case of Nancy *Cruzan*. When the *Cruzan* case went to the US Supreme Court in June 1990, 14 other American state courts had already approved ending life-sustaining treatments for incompetent patients, drawing no distinction between artificial feeding and other medical procedures such as ventilation. Each court had held that competent people can refuse treatment and for incompetent patients, that decision can be made by a proxy decision maker reflecting the patient's known views. In the *Cruzan* case, the Missouri Supreme Court initially held that, although proxies can express the views of the incompetent patient, they cannot presume to guess what the patient's view would have been if the patient had not specifically expressed a view. It held that if the patient's wishes

¹Paris & McCormick. The Catholic tradition on the use of nutrition and fluids, 356-61. America (1987): May.

²Personal communication to the Committee.

³In *re Eichner*, NY App Div 2nd Dept, 27 March 1980.

⁴Kamizar Y: Right to die, or licence to kill?, *Legal Times*, 13 November 1989; 26-7.

⁵*John F Kennedy Memorial Hospital Inc v. Bludworth*.

⁶*Barber and Nejd v. Superior Court of Los Angeles County and the People*, 147 Cal. App. 3d 1006 (1983).

⁷*Re Conroy* 486 A 2d (1985), cited in "The Living Will" by joint Age Concern, Centre for Medical Law and Ethics Working Party, pp. 35-6.

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are unknown, life-sustaining treatments once in place cannot be terminated. The majority (5-4) of the American Supreme Court upheld the initial Missouri decision, stating that even if a right to refuse treatment exists, a State is entitled to demand a high standard of proof, ie that any expression of view be established by clear and convincing evidence.

The dissenters in the US Supreme Court, however, considered that Missouri had set too high a standard of what evidence could be considered indicative of the patient's wish. The Missouri court then withdrew its opposition to withdrawal of treatment in December 1990 when further testimony was made available regarding Nancy Cruzan's previous views. She was allowed to die.

Several important conclusions were drawn from the *Cruzan* case. Firstly, the majority view of the US Supreme Court appeared to uphold a right to refuse life-sustaining treatment, including nutrition. It rejected the distinction between a feeding tube and other forms of life support and, in the words of Cruzan's lawyer, the decision "effectively ended any debate about the nature of gastrostomy tubes and other artificial feeding devices—they are medical treatments".¹ Secondly, it gave rise to the view that "states are more likely to expand their law to allow families to speak for incompetent patients, rather than limiting the exercise to those who have clearly spoken for themselves".² It must be noted, however, that not all commentators agree with this opinion. Undoubtedly, it heightened American awareness of the issues and drew public attention to the need to make known one's wishes regarding prolongation of treatment.

Furthermore, some American courts have addressed the issue of the specific cause of death when life-support systems are withdrawn. In the case of *Brophy*, whose family sought to have a gastrostomy tube removed, the Massachusetts Court ruled in 1986 that withdrawing this form of medical treatment allows a disease to take its natural course. In *Greenspan*, the Florida Court decided that if a "death-delaying feeding tube is withdrawn in scrupulous accordance with law, the ultimate agent of death is the illness and not the withdrawal".³

Thus American courts are prepared to uphold withdrawal of artificial feeding at the patient's request or where it can be demonstrated this is what the patient would have wished.⁴

United Kingdom

In the United Kingdom, the law has not been put to the test in the same way as in the USA. In law, patients must consent to treatment if they are capable of so doing and no one can consent on behalf of an adult if he is not competent. Thus, legally the views of relatives carry no weight. The principle value seen in consulting relatives is that contact might throw light on whether the patient has made an anticipatory choice about treatment or it might reveal information about the choice the patient might have made if he was in a position to choose.⁵ In practice, decisions for the incompetent are made according to "best interests" criteria and the Law Commission is examining procedures for deciding treatment options for incompetent adults. An advance Directive in which a competent person refuses treatment which may be offered when he is incompetent has recently been considered, obiter, by the Court of Appeal in *Re T*.⁶ The view expressed was that an anticipatory choice has the same legal effect as any other refusal of treatment if it is clear that the person making the decision was competent, gave his mind clearly to the issues and expressed an unequivocal view which is applicable in the circumstances.

Difficulties arise for doctors because of the ill-defined boundaries around what may be legitimately termed "medical" decisions and how far they may go in judging "best interests". It is clearly unlawful to give treatment with the deliberate intention of causing death. This is usually termed "euthanasia" or "active euthanasia". (In its 1988 report on the subject, the BMA considered that qualifying terms such as "active" and "passive" do not lead to precision but may confuse and therefore preferred the phrase "an active intervention by a doctor to end life".⁷) The law regards such interventions as murder. The doctor's motive is irrelevant to the law. His intention is determinative and if the doctor intends to kill, he is liable to prosecution. Clearly, an unconscious patient represents an extreme of vulnerability and is entitled in law to be cared for in an appropriate manner. The deliberate killing of such a patient would raise a question of homicide. Neglect resulting in the patient's death would occasion a charge of manslaughter or murder.

It is argued, however, that assessment of appropriate medical treatments or withdrawal of those treatments in individual cases is a discrete area and should be considered a matter for the medical profession. Some term such decisions "passive euthanasia" but, as mentioned above, the BMA has not felt this to be a useful description and maintains that "a decision not to prolong life" or "a non-treatment decision" are more appropriate phrases. Some maintain that since the patient's death is an inevitable and predictable

¹Coly W H. Missouri stands alone, Hastings Center Report, 1990; 20: 5-6.

²Rouse F. The Cruzan case, *Lancet*, 12 January 1991, vol. 337: 105-6.

³United States Law Week, 59 LW 2049, 24 July 1990.

⁴Mason & McCall Smith give examples of seven such American cases between 1980 and 1986.

⁵See comments expressed by Lord Donaldson in the case of *Re T* (1992).

⁶*Re T*, reported in *The Times*, 24.7.1992. The case is being appealed to the House of Lords at time of writing.

⁷BMA Euthanasia report, p. 3.

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result of withdrawing treatment, it is hard to see how the doctor can be considered as having any other intention.

The law, however, acknowledges that in many cases, provision (and by implication, withdrawal) of treatments will impact directly on the timing of the patient's death. In such cases:

"(N)o people of common sense would say "oh the doctor caused her death". They would say the cause of her death was the illness or injury, or whatever it was, which brought her into hospital."¹

The same judgment, however, clearly states:

"it remains the law, that no doctor, nor any man, no more in the case of the dying than of the healthy, has the right deliberately to cut the thread of life."

The law then does not distinguish between killing for a good motive and for an evil one, as has been shown by the courts' unwillingness to sanction any active interventions by doctors to end the lives of patients even when patients request this. Furthermore, some appear to believe that withdrawing a treatment and an active intervention designed to kill are the same in law. In 1991, for example, the Home Office, when asked for clarification about the law on withdrawal of medical treatment and nutrition from a pvs patient, gave no advice specific to treatment withdrawal but simply said that the Government had no plans to change the law and that "under present law, killing another, even to relieve suffering, is murder or manslaughter. Similarly, assisting someone to commit suicide is an offence under the Suicide Act 1961. An attempt to commit a criminal offence is also an offence in itself, whether the act was successful or not".² Nevertheless, a number of legal experts firmly maintain that there is a difference and the withdrawal of a treatment which cannot ameliorate the patient's condition is entirely lawful even though the patient's death is the predictable result.

Legally and ethically speaking a doctor has a duty of care to his patient. A patient who has been receiving hospital treatment is clearly owed a *prima facie* duty of care. In law, a question of criminal liability arises when within the terms of such a relationship, a person owing a duty of care fails to prevent avoidable harm being suffered by the person who is the object of care. This might be thought to beg the question of how we define "harm" and some have seen the possibility of harm accruing from the prolongation of treatment which cannot benefit the individual and may be contrary to what he would have wished. It is unclear whether such an argument would be persuasive in law, given society's fundamental interest in preserving life. It must be noted, however, that the case of *Re J* (1990) discussed below, suggests that the law condones non-treatment or withdrawal of treatment if the patient's prognosis is extremely poor.

One solution is seen in the stance of the American courts in distinguishing between different methods of nutrition. In this view, as has been mentioned in the discussion of nutrition and hydration, feeding by gastrostomy or nasogastric tube is an artificial process akin to ventilation. Such techniques, it is argued, amount to medical treatment and can be withdrawn on the same grounds as those upon which doctors discontinue other treatments. It is further argued that "this can be done without abandoning the notion that there is still an obligation to provide basic care".³ This is the view taken by the Medical Ethics Committee, which would firmly assert that "care" must continue beyond the withdrawal of specific treatments. The Committee does not see such a decision to withdraw artificial nutrition as in breach of the duty of care. It maintains that such decisions should have the independent support of colleagues.

In recent years, some have seen an indication of future developments in a series of cases. For example, in the 1990 case of *Re J*,⁴ a handicapped baby, who was not terminally ill and whose requirement for life-prolonging treatment was considered by the Court of Appeal. In this case, it was not the intention of the Appeal Court to rule on hydration and nutrition but to consider whether to support medical opinion advising against the provision of ventilation to keep the child alive. The Court confirmed that, in appropriate circumstances, life-prolonging treatment could be withheld from an individual incapable of expressing an opinion. It clarified that the law does not oblige doctors to take all necessary measures to keep the patient alive, even when the patient is not terminally ill. Nevertheless, a number of comments by the judges illustrate the law's cautious approach. All of the Appeal judges in *Re J* emphasised a general imperative to preserve life and "a strong presumption in favour of taking all steps capable of preserving (life) save in exceptional circumstances".⁵

In *Re J*, the court ruled that the correct approach was to assess the patient's "quality of life" and decide whether treatment should be given in those circumstances. It emphasised that the courts would require a "high degree of proof" that the patient's quality of life justified non-treatment⁶ but the court did not specify criteria for making such assessment.

Although the law in Scotland is the same as in England, the medical profession and Scottish prosecution

¹(Then) Mr Justice Devlin, *R. v. Adams* (1957) CLR 365.

²Letters of August and December 1991 from the Rt Hon John Patten.

³McCall Smith A. "Ending Life". Doctors, Patients and the Law. Blackwell, 1992, p. 112.

⁴*Re J* (a minor) (wardship: medical treatment) (1990), 3 All ER 930.

⁵Taylor L J at 943.

⁶Taylor L J at 945.

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service find no practical difficulty in dealing with this subject on a case by case basis. No statement has been made by the Crown Office which sees the decision primarily as a clinical matter. There have been no prosecutions in Scotland in cases where doctors have withdrawn nutrition from pvs patients with the agreement of the families.

In brief, the legal position remains to be fully clarified but in cases such as *Re J*, the courts clearly contemplate limits to the doctor's duty.

6. RESOURCE ALLOCATION

It is worth noting that the rulings in the American legal cases have been careful not to allow issues such as "quality of life", priority use of resources or general financial considerations to dictate their decisions but have concentrated on issues of patient autonomy. This has been attributed to a desire not to show any form of prejudice towards the mentally or physically incapacitated.¹ Many would think it entirely correct that treatment decisions should be made without such considerations. Others consider that, in our society where allocation of resources to one group of patients has the likely effect of depriving another, discussion of treatment options for severely brain damaged patients is inconclusive without reference to resource allocation for specialised care and the type of existence in which the patient might be maintained indefinitely. Both questions of resource allocation and "quality of life" are far more complex than can be encompassed in this paper and neither is explored in any depth here.

After brain damage, four categories of survival have been described:² the vegetative state, the severely disabled (conscious but dependent), the moderately disabled (independent but disabled) and good recovery. Judgment of what constitutes an acceptable outcome of treatment depends on the values of the assessor. The current or previously expressed views of the patient establish some criteria for such assessment and will vary with the individual. In this paper, we only give consideration to the first category of survival and note that the overall number of such patients is likely to be low. Each Health Authority will have a small number, if any, pvs patients and some argue that it is impractical to attempt to construct an edifice of care to deal with so few cases. Expertise about the vegetative state is confined to relatively few centres and it is often felt that any positive treatment for severely brain damaged patients should be postponed until sufficient time has passed for diagnosis to be made. This is a view to which the Medical Ethics Committee takes exception.

Having drawn attention above to the difficulties in making a diagnosis of pvs, the time required to do so with confidence and the importance of stimulation in the early stages, the BMA's Medical Committee considers it vital that thought be given to concentrating resources on brain damaged patients in the early months after trauma. If a full range of treatment is provided at this time, some believe that a more informed assessment of the patient's prognosis could be made earlier. To neglect to do so on grounds of limited resources may not only represent a false economy but be ethically unsound in that the limited potential that some patients have for recovery is neglected, they may be erroneously classified as pvs and consigned to a long term minimal level of care, which is nonetheless costly over time.

In 1976, Jennett drew attention to the fact that "in some hospitals, there seems not much middle ground left between intensive care and relative neglect" and recent years have not seen a significant improvement in this situation. He also warned of "the consequences of too readily recommending that many patients should be treated in an elaborate and expensive way on the basis of a clinical impression based on the supposed benefit gained by random cases". The Committee is alive to this risk but nevertheless considers that attention should be given to a form of intensive rehabilitative effort as soon as practicable. It recognises that for some patients this will be wasted effort and lost resources but might contribute to providing answers at an earlier stage regarding the patient's potential for recovery.

At present, a typical pattern of treatment for such patients is that they spend the initial period of two or three months after trauma in an acute unit. After six months, a provisional diagnosis may be made and some will be offered rehabilitation. During this period, some conditions may have developed which, if treated earlier could possibly have improved brain functioning. If rehabilitation is unsuccessful, the patient may be kept alive but unaware for several decades. During this protracted time span, they require careful nursing and take up resources which might benefit other patients.

Allocation of limited resources is often based on the principle of "first come first served". The health care team feel committed to patients who are already under treatment even if their prognosis is poor and it would be difficult to propose that such patients should be discharged to give better attention to newcomers whose possibilities for recovery are greater. That such a proposal should be made is dependent upon alternative care being available. It has not been mooted that treatment be withdrawn solely for resource reasons from pvs patients but some have proposed that, as with any treatment, doctors should be aware

¹Allsopp M. From Quinlan to Cruzan: Pattern in the fabric of US "right to die" case law, *Humane Medicine*, April 1992, vol. 8; 122-31.

²Jennett B, Bond M. Assessment of outcome after severe brain damage: a practical scale, *Lancet*, 1975; 1: 480-4.

³Jennett B. Resource allocation for the severely brain damaged, *Arch Neurol*, 33: 595-7.

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of the measure of benefit to be obtained from treatment and set priorities accordingly. On the other hand, some appear to see a moral imperative to commit resources even while positing the proposition that discontinuing treatment for a permanently unconscious human being may be a more humane act than sustaining it.¹ Banja, for example, considers that the extent to which society is prepared to allocate resources to the irreversibly unconscious reflects its collective conscience. He sees the pvs patient as challenging society's moral choices. Some might feel that society has failed to address that challenge. Needless to say there are many varying views on this issue. We draw no conclusion but note with Jennett that:

"It is inevitable that the attempt to save the lives of badly brain damaged patients will not always be successful; part of the price paid for the good recoveries, of which there are many, is that some others will be left so badly crippled that sensitive observers may judge their survival a greater disaster than if they had died. Both physicians and society need to be aware of this price, and to consider whether it is too high. Acceptance of the principle that survival at any price is no longer an acceptable objective gives a new perspective to the allocation of resources in the realm of medical care for the critically ill. . . . Only when these topics are responsibly discussed in public debate, and perhaps in courts of law, will it become possible for individual physicians to discuss the matter in relation to particular patients about whom decisions have to be made".²

7. THE POSITION OF "RELATIVES"

In this context, "relatives" is used as a shorthand term for those people close to the patient who can be considered to have a strong interest in his wellbeing. The difficulties for relatives arising from the sometimes contradictory messages of the health care team have been noted earlier. This has prompted the Medical Ethics Committee to emphasise the need for frank discussion with relatives about the implications of the condition. It clearly recognises that relatives will require a high degree of support and attention must be given to responding to their distress. Particularly so, if a decision is made to withdraw treatment, which they may view as synonymous with reduced care. It must be made clear to relatives that the patient will be cared for until his death. It is sometimes said that nurses can do most for the patient by caring for the relatives.

The question of whether relatives' views should be determinative of treatment has been debated within the Medical Ethics Committee. The MEC deplored some tendencies to consider rehabilitative treatment primarily for those patients whose relatives bring pressure to bear. It was adamant that, in this respect, relatives' views should not be determinative and that the potential of all patients should be explored in the early stages.

As regards the views of relatives on the withdrawal of treatment, it was recognised that they would need time to assimilate the implications of a pvs diagnosis and that, in any case, such decisions could not be undertaken in the early months when efforts to stimulate the patient would be a priority. It was acknowledged that, in the long term, doctors must balance equitably the use of resources. The Committee has considered it inappropriate for treatments, which have been demonstrated to be clinically ineffective, to be continued indefinitely at the request of the patient or relatives. Thus, a decision may be taken to cease rehabilitative efforts by health professionals if the latter believe that the patient cannot benefit from them and others might. It is recognised that in some cases, relatives may wish to continue rehabilitative efforts themselves.

The issue of withholding life-prolonging treatments, such as artificial feeding is more complex and the MEC expressed divergent opinions upon it. On the one hand, it was felt that decisions of such gravity as the withdrawal of this treatment could only be taken in co-operation with those close to the patient. Members felt that decisions about the potential withdrawal of treatment should be deferred until relatives were ready and that recognition should be given to the difficulty that lay people encounter in disagreeing with doctors. But it was also agreed by most members that the status of the patient cannot depend on the views of relatives since this would be inconsistent with the principle of deciding in the best interests of the patient. Although consensus on this question was not achieved, it was recognised that, in practice, the views of those close to the patient and the opinions of doctors as to the patient's best interests will coincide in many cases. It was felt that, in cases where a decision is reached to continue providing all possible treatment options indefinitely, the resource implications would require public debate.

As a general principle, the BMA considers that the opinions of those close to the patient cannot overrule the patient's own decisions, which may have been expressed formally in an advance Directive. Through such a document, the patient can withdraw consent in advance to specified treatments and although not legally binding, this will assist decision-making. The Committee anticipates that where no such document exists, those close to the patient can be helpful in indicating his known views and that these would be an important part of decision making criteria.

¹Banja J D, as above.

²As above.

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[Continued]

8. SUMMARY

The BMA's Medical Ethics Committee is acutely aware of the dilemmas and uncertainties which face doctors whose patients are in the persistent vegetative state. It believes that the matters touched upon in this paper require further public debate and hopes that its consideration of the issues will assist this process. Matters such as implications for the use of limited resources need to be integrated into the wider debate on resource allocation.

Attention is drawn to some aspects of existing published BMA policy which do not seem to be widely known, including specific views on pvs and general statements such as the opinion that artificial feeding is a medical treatment and that medical treatments can be withdrawn on the basis of a clinical decision. Recognising that some aspects of the legal position remain to be resolved, doctors are advised to seek counsel from their Defence Bodies regarding withdrawal of treatment.

The BMA's Medical Ethics Committee supports the suggestion that clinicians postpone definitive decision-making for patients suspected of being in pvs until after a year has passed, although it recognises that, varying with the circumstances, some clinicians will feel confident of making a pvs diagnosis at an earlier stage. The Committee also considers it vital that every effort be made in this relatively short time to provide rehabilitative measures and exclude all possible factors which might impair cognition.

When treatment decisions are made, respect should be given to the views of the patient expressed in an advance Directive and a separate BMA paper on advance Directives is available. In the absence of an indication of the patient's views, those close to the patient may shed light on the patient's wishes but the patient's status should not be determined by the relatives' views. Relatives should be given support and particularly so, if the decision is to withdraw treatment.

September 1992

Draft BMA Guidelines on Treatment Decisions for Patients in Persistent Vegetative State

BACKGROUND

In early 1992, the BMA's Medical Ethics Committee was asked to produce guidelines for doctors on ethical and legal aspects of treatment for patients in persistent vegetative state (pvs). Over a period of several months, the Committee considered the literature and also took advice from experts but felt unable to draw up guidelines at that stage, partly because of the lack of clarity in law regarding the withdrawal of treatment. Instead, in September 1992, the Committee issued for wide consultation a discussion paper reflecting its considered opinions, recommendations and thoughts on areas where its members failed to achieve consensus. Before drawing up the present summary of advice, the Medical Ethics Committee considered the responses to its discussion document and the implications of a declaratory statement issued by the House of Lords in February 1993.

SUMMARY OF ADVICE

1. Initial Assessment and Treatment

A diagnosis of persistent vegetative state takes time. During the period of initial assessment, it is appropriate to provide aggressive medical treatment. The BMA believes that it is vital that stimulation and rehabilitation should be available for patients suspected of being in a persistent vegetative state as soon as their condition is stabilised. Clinicians should give active consideration to the wide range of specific measures which might effect some improvement in each individual case. While not all patients will improve as a result of being included in coma arousal programmes, this and other appropriate options must be explored at an early stage. It is a matter of clinical judgment as to the most appropriate measures and the length of time they should be pursued.

It is good medical practice to provide artificial nutrition and hydration to sustain any patient whose prognosis is uncertain. Medical treatments, including artificial nutrition and hydration, may be withdrawn at a later stage if it is clear that they offer no hope of recovery but merely suspend the dying process (see below).

2. Diagnosis

Current methods of diagnosing pvs cannot be regarded as infallible. Before a pvs diagnosis is made, all appropriate clinical steps must be taken to eliminate other possibilities. Clinicians must be aware of the dangers of prematurely diagnosing the patient's condition as irreversible.

The BMA recommends that the diagnosis of pvs should not be considered confirmed until the patient has been insentient for 12 months.

From the literature, it appears that two factors influence the point at which a pvs diagnosis can confidently

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be made: the causation of the coma and the age of the patient. For some categories of patient, it is possible to make a diagnosis with a high degree of medical certainty within three months. The BMA, however, recommends that decisions to withdraw treatment should only be considered when the patient has been insentient for 12 months. Positron emission tomography, where available, may provide useful supporting evidence.

The clinician making a pvs diagnosis should seek the independent concurrence of two other doctors, one of whom should be a neurologist. In any case of doubt as to whether the patient's condition is irreversible, decisions about possible withdrawal of medical treatment must be deferred.

3. *Review of Treatment Options*

The BMA recommends that a high standard of nursing care, good nutrition and stimulation should be available to all unconscious patients. Rehabilitative measures should be continued until clinicians consider such measures can no longer benefit the individual patient.

The BMA advises that life-prolonging treatments should continue until the patient has been insentient for at least 12 months even if a pvs diagnosis has been made earlier. If it is apparent at the end of the one-year period that the patient's condition is irreversible, doctors will consider whether it is in the patient's interest to continue with treatment to prolong life. Such a decision will be based on the same principles as other medical decisions. Factors include a careful evaluation of the patient's diagnosis and prognosis, the anticipated benefits or burdens of the treatment, the patient's views if known and the views of people close to the patient. In some cases, doctors may then recommend the withdrawal of all treatment including artificial nutrition and hydration.

4. *The Views of the Patient*

In considering treatment options, doctors should consider the patient's own views and values, if known. These views may have been recorded in an advance Directive.¹ The BMA does not believe that advance Directives should be legally binding although they must be treated with respect. If, for example, an advance Directive instructs that the life of a pvs patient be prolonged indefinitely or curtailed before the one year period recommended by the BMA, doctors should seek specific ethical and legal advice. Treatment decisions for incompetent patients must be based on an assessment of the patient's best interests. The patient's views are an important component but are not the only factor in such an assessment.

5. *The Views of People Close to the Patient*

It is good practice for the doctors to consult the wishes of people close to the patient but their views alone cannot determine the treatment of the pvs patient. People close to the patient may be able to throw light on the wishes of the pvs patient regarding the prolongation of treatment and this is likely to be helpful in decision-making. Treatment decisions, however, must be based upon the doctor's assessment of the patient's best interests.

People close to the patient will need time to accept and understand the patient's prognosis. A decision to withhold life-prolonging treatment, such as artificial feeding, generally requires close co-operation with those close to the patient. The decision will have emotional and symbolic importance for people who love the patient and they will need advice and a high degree of support from the medical team. The BMA believes that in many cases the medical team and the people who are close to the patient will agree about the provision or withdrawal of treatment. All cases of withdrawal of treatment must be subject to court review and the courts are likely to take into account the views of people close to the patient and rule in cases of disagreement.

6. *Doctor's Views*

Decisions to withdraw life-prolonging treatment should be deferred if there is clinical disagreement about the diagnosis or prognosis. If any clinician having care of the pvs patient disagrees with the decision to withhold medical treatment on moral and not clinical grounds, that doctor cannot be obliged to act contrary to his or her conscience. People close to the patient should be involved in the discussion as to whether it would be appropriate to transfer the patient to the care of another doctor in the same hospital or another facility.

7. *Views of the Health Care Team*

Decisions regarding the possibility of withdrawing treatment should be discussed openly by the whole health care team and also with pastoral carers. Consensus on the way forward should be the aim. However, if members of the health care team have a conscientious objection to any proposal which has been authorised by the courts, they should be offered the opportunity of a transfer to other duties.

8. *The Legal Position*

The legal position was clarified by the Lords' hearing of the Bland case in early 1993. This confirmed that it is acceptable in some circumstances for a decision to be made to provide or withdraw treatment

¹The BMA has issued a separate guidance note on advance Directives.

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in the patient's best interest. Doctors following the BMA's guidance are considered to fulfil the legal requirement that they must act in accordance with a responsible body of professional opinion. It was also made clear, however, that the issue of withdrawing artificial nutrition from a pvs patient is one which requires consultation with the courts until such time as a body of experience and practice has built up which will obviate the need for a court application in each case.

9. Organ Donation

In the BMA's view, patients in persistent vegetative state should not at present be considered as potential organ or tissue donors.

10. Pregnant Comatose Patients

The BMA was asked to comment on the treatment of patients suspected of being in a persistent vegetative state and who are also found to be pregnant. Since the Association recommends that no decision to withdraw treatment should be made within the first 12 months, the question of whether it is morally appropriate to keep a pregnant woman alive for the sake of her foetus alone does not arise. In the BMA's view, coma arousal and other rehabilitative procedures should be equally available to pregnant comatose women as to other patients. Treatment decisions should be formulated primarily with the aim of improving if possible the condition or prognosis of the suspected pvs patient. Attention should be given to preserving the life of a viable foetus if this does not seriously compromise the mother's chances of recovery or improvement.

April 1993

Examination of witnesses

Dr STUART HORNER, Director of Public Health in Preston and Chairman of the Medical Ethics Committee, Dr FLEUR FISHER, Head of the Ethics, Science and Information Division and Ms ANN SOMMERVILLE, Secretary to the Medical Ethics Committee, British Medical Association, called in and examined.

Chairman

70. Dr Horner, Dr Fisher, Ms Sommerville, thank you very much for coming to see us and to talk to us. We will be referring, I have no doubt, to the documents you have produced for us and if I may I would like to congratulate you and thank you not only for their quality but for the extent and the range of topics which you have covered.

(Dr Horner) Thank you.

71. Dr Horner, do you wish to make any opening statement in relation to your document or shall we go straight into the questions?

(Dr Horner) Thank you, Lord Walton, and members of the Committee for receiving us. Can I make just two brief comments by way of introduction?

72. Please.

(Dr Horner) The first is to emphasise to the Committee that the British Medical Association, and specifically the Medical Ethics Committee, has been considering these issues now for the last two and a half years. It arose because of the need to revise our handbook which is going to be published in about six weeks' time. During that last two and a half years we have received expert witnesses, like yourselves and we have given these matters a great deal of consideration. So whilst our formal document is a one-off to you it arises from a series of papers that we had worked up in-house. The second point that I would want to underline is the importance that we attach to recognising the autonomy and rights of individual patients, the need for dialogue between doctors and their patients and between patients and their doctors but to do that within a framework of justice within the health care system. Thank you.

73. Thank you very much, Dr Horner. May I take it that the handbook to which you refer is the one which used to be called the BMA Handbook of Medical Ethics and more recently has been published under a different name?

(Dr Horner) Yes, it is going to be called Medical Ethics Today, my Lord.

74. As is clear from your document patients are entitled to decline treatment even where such decisions appear contrary to their best interests. What safeguard is there against such a decision being regarded as a sign of unsoundness of mind and therefore incompetence to decide?

(Dr Horner) We have to concede that doctors will want to be absolutely sure that a decision which is made by the patient is a valid and continuous expression of that patient's opinion. We do acknowledge that perhaps there is a tendency to automatically assume that the patient must in some way be mentally incapacitated. In our view, my Lord Chairman, where the doctor is involved he should be closely questioning the patient himself, he should unquestionably seek a second opinion if he has any clinical reason to suppose that the decision may not be a valid one and if necessary we would not exclude the possibility that the court should be involved. I think Ms Sommerville has something to add.

(Ms Sommerville) We noted that the Law Commission has also been looking at the question of when is the patient's choice the true choice?

75. Yes.

(Ms Sommerville) We thought it was very important in some cases to perhaps involve the people close to the patient to see whether the choice being made is consistent with the long term views

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and opinions of the patient and not a manifestation of an illness.

76. You are making clear that this particular question and your answers relate to the adult patient and not to the child under the age of 16?

(Ms Sommerville) Yes.

77. We have just received and will be circulating to all Members of the Committee the Law Commission's Consultation Document on Mentally Incapacitated Adults and Decision Making. We shall be considering that very soon.

(Dr Fisher) There is the other situation where sometimes patients refuse treatment not as a result of long held convictions but because of confusion or some alteration in their psychiatric state arising from the acute illness. That is the other situation which of course doctors, clinicians, must take into account if decisions are not to be wrongly made. That is really the mirror image of the first situation we were looking at. These situations can occur and it is important that doctors recognise them.

Baroness Warnock

78. There is an assumption here that people never change their minds, that is to say if you have never expressed any particular view or expressed a view contrary to the view you now express this is taken to be a sign of possible psychiatric illness. It might be you made a perfectly conscious and deliberate decision you probably would not have made before you got ill, that does not necessarily mean you have gone mad.

(Dr Fisher) Absolutely not. It is quite clear that the kind of decisions we may take in the cool light of day when we are not facing a major illness or a major decision in our lives may be different when we are up against them. That is one of the problems a doctor has to be prepared to recognise and the autonomy of the patient and the fact that patient's consent must be with the well informed understanding of their clinical situation at that time. Changes of mind must always be recognised.

Lord Rawlinson of Ewell

79. Do you consult and speak with relatives and if you do, do you try and discover what interest a relative might possibly have in the decease of the particular person?

(Dr Horner) That situation is often known to the doctor but I am not sure we specifically explore it. Certainly we would try to approach the relatives in terms of verifying that what we are being told by the patient is in fact supported by their own judgment as to what the patient thinks best.

80. Apart from their judgment do you look at it at all to see whether there is any possible motive as to convenience of the burden resting upon particular relatives or the financial interest that might arise if a person does accept this?

(Dr Horner) Not deliberately, Lord Rawlinson, no.

Chairman

81. In your document on the persistent vegetative state you mention that, of course, legally the views of relatives carry no weight but nevertheless consultation with them will prove to be one of the matters that you take into account in the decision-making process.

(Dr Horner) What we are trying to do, my Lord Chairman, is exclude the suspicions of mental illness and having done that then it is reasonable to assume that the patient is giving a valid judgment which, as you said, must be respected.

Lord Hampton

82. I am interested in Advance Directives. This seems to be as far as I can see to my mind, what I know of it, fairly straightforward. Do you think difficulties would arise in relation to specific legislation on this matter?

(Dr Horner) We find it difficult to understand how legislation would actually help beyond the present situation. We have said in our document that an Advance Directive must be respected as a valid expression of the patient's wishes but inevitably the doctor will have to take other things into account: is the specific situation, the clinical situation, in which the patient now finds himself covered by the terms of that Directive? Is it appropriate? Is it possible, as Baroness Warnock was saying a moment ago, that the patient may have changed their mind and so on? We are concerned that the introduction of legislation may actually restrict the freedom of doctors to do what their patients wish.

Chairman

83. May I take that point up because we were certainly intending to come to the whole issue of Advance Directives? You say clearly in your paper that the BMA now supports the principle very strongly but then you say that you are opposed to legislation. I do not know whether you have had an opportunity of seeing the Bill by Lord Allen of Abbeydale which has had its first reading. Essentially it is an enabling Bill, one of its intentions being to have on the statute book something which would perhaps protect the doctor who implements an Advance Directive on behalf of a patient. The Bill has been referred to us for consideration and makes it quite clear that there can be no legally binding obligation on the doctor to accept the terms of the Directive although in ordinary circumstances he or she would be expected to do so. I wonder why you feel that an enabling Bill of some sort might not be appropriate?

(Dr Horner) I think there are two concerns. One is the concern at the change in the climate of opinion that the introduction of an Act of Parliament might introduce into the practice of medicine. The doctor is likely to be concerned about whether an Advance Directive exists, where it is, what its contents are etc., and that knowledge may perhaps inhibit the doctor in clinical decisions that he ought to be taking at this moment in time. That is a general point. We have a more specific concern, that in fact however

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well the legislation is drafted the effect in practice may be limitation. It is difficult, of course, to know whether we would like an act until the act is promulgated, and we do have experience that bills come into this House and leave in a very different form.

84. Have you actually seen this particular Bill?

(Dr Horner) I personally have not.

(Ms Sommerville) Yes, we did look at it. The BMA's position is not that we are opposed to legislation, it is just that we do not see it as being necessary. We understand the common law position as a result of *Re T* and *Bland* affords support to Advance Directives in law but we think respect for them can be achieved by educating doctors and by educating the public and that would be a better form. It would be better to have dialogue between doctors and patients and achieve it that way other than by specific legislation.

Chairman] Of course, the Law Lords' judgment in the *Bland* case was not particularly concerned with Advance Directives, but they did make it clear that there were a number of problems with the existing law which would still make it necessary in any similar case to refer the case to the courts for a decision.

Archbishop of York

85. Just following on from what has been said. It seems that the approach which you adopt depends very heavily on a close relationship between patient and doctor with time for consultation, with consultation about Advance Directives, with updating Advance Directives and so on. I am just wondering whether that rather leisurely relationship is real in practice given the conditions under which doctors now have to operate, given the fact that patients complain they never see the same doctor twice, given the amount of time the ordinary GP has for consultations?

(Dr Horner) I am sorry, my Lord Chairman, if we are giving the impression of a leisurely process. I would prefer the title "thoughtful". Certainly the implication is not that this can be considered at a very leisurely pace. I do come back to my point that it is likely that a minority of people will avail themselves of the powers that Parliament will give them and that inevitably puts a doctor in some difficulty as to know whether this patient is the one that has made an Advance Directive. I made the point earlier, and I make it again, that of course in the emergency situation then the doctor must get on and do what he believes to be best. This is where the *Bland* judgment in my view is so helpful, because a decision was taken in the case of Tony *Bland*, quite rightly, on the day of the Hillsborough disaster which proved three years later to have been the wrong decision and if it were not possible to undo that decision at a later date then it seems to me that doctors would have been placed in an impossible position. Similarly with an Advance Directive, having resuscitated the patient we now have the opportunity of finding out what the patient's wishes truly are and we can act in accordance with them. We have made the point in our paper that we are

aware of cases where, in fact, decisions were made at the time which turned out in the end not to be in the patient's best interests although by then it was too late because the patient was dead.

Baroness Warnock

86. Could I ask for clarification: in what sense do you say that the decision taken immediately after Hillsborough turned out to be the wrong decision? I thought that in any case in a case like that it would be right to keep the patient alive for six months, a year, whatever?

(Dr Horner) That is exactly the point I am trying to make, Baroness Warnock. If the doctors could have known with the benefit of hindsight they may have been persuaded not to have introduced all the procedures that they did at the time. Having rightly erred on the side of saving life, the fact that they were later able to withdraw those procedures seemed to me to be helpful.

Chairman

87. Let us accept the very point that you yourselves make in your paper; the diagnosis of the persistent vegetative state is something that cannot be made in the early stages after resuscitation; it is only much later, and perhaps after 12 months, as you indicate, that it might then be appropriate to withdraw treatment?

(Dr Horner) That is exactly the point I am making, my Lord Chairman, that that particular condition in our view should not be diagnosed with our present diagnostic facilities in under 12 months.

Baroness Jay of Paddington

88. Just following on what Baroness Warnock said, I think I am misunderstanding this—sorry to interrupt—it is about this question: I thought in your paper on PVS you very firmly took the position that one of the elements of diagnosis over the longer period was to engage in very active intervention in the early stages so you could then establish precisely what the clinical state was. In a sense the non-response to the very active intervention during this first period was one of the signs correctly to diagnose PVS over the long period. I still do not quite understand the response you gave to Baroness Warnock.

(Dr Horner) I am sorry if I misled your Lordships, I was trying to make the point that doctors make judgments all the time in an acute clinical situation as to whether they introduce a form of treatment. If, having made that decision, we were committed forever and a day to prosecute that treatment then that would make the doctor's decision very much more difficult than now when we have the knowledge that at an appropriate time it may be appropriate to withdraw it.

(Dr Fisher) I think I get the feeling behind the current questioning: of course when we are faced with an acute situation we must always do our very best for the patient. We do not know what the outcome will be and we have to throw absolutely everything into the acute situation. When it is evident that despite all the care and effort that has

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[Baroness Jay of Paddington *Contd*]

been put in and after time for the diagnosis to be made, we can see that that treatment is of no avail to that patient, then we are able to withdraw it, (which is the suggestion of their Lordships after the *Bland* case), having gone through the correct legal processes. We can never *not* enter into treatment of a patient because we think it may not be successful, you can never tell. So we always have to fight for the patient: but sometimes we later have to recognise that we had lost the fight almost before we began, but we cannot make that judgment in advance.

Baroness Flather

89. We were talking about justice for patients and respecting patients' wishes, then we jumped on to the Advance Directives, now it is a continuation of that, is it not, the Advance Directives, because the patient has expressed his or her wishes before he is in a position that he is likely to find himself in? In the event he is not then able to express his or her wishes then I think we have to look at that in that light, that it is respecting the patient's wishes and the two are in that way related but are also separate in as much as in one case the patient at that time expresses his or her wish and you then have to decide whether they are competent to do so and in the other, they are clearly not competent to do so at that time otherwise there is no requirement for an Advance Directive but perhaps they made an Advance Directive. I must say I find it rather strange you feel it would inhibit a doctor from doing what they want to because there may be an Advance Directive because clearly if there is one there is one, if there is not it does not matter. There is no requirement. There will never be a requirement everyone should make an Advance Directive. I do not see why the doctor should be inhibited in that. I would like your views on that.

(*Dr Horner*) The point I am seeking to make is that the fact that we have a patient in an acute clinical situation in front of us now and there is a perception that this patient may have made an Advance Directive may influence the doctor in the way that he approaches the decision, in the way he treats the patient at this moment in time.

90. But ought it not to, that is the point. If there is an Advance Directive ought it not to be so?

(*Dr Horner*) Indeed. This comes back to the Archbishop's point that efforts need to be made to find it but that can only be done over possibly a sequence of weeks.

91. You cannot make the efforts, either there is or there is not. You said you must take into account the patient's wishes, could not the situation be exactly the same in an acute position and the patient says: "No, I am here and I know what you are going to do and I do not want it done." Would you not be in the same dilemma?

(*Ms Sommerville*) We have said that we accept that.

(*Dr Fisher*) I think we agree entirely with what you are saying. All we are saying is at the end of the day there are going to be clinical decisions for doctors to make and they may be things like: "Is this Advance

Directive overridden by the patient's oral opinion now? Is this Advance Directive overridden by the decision of a proxy decision maker?" In the end they are going to have to weigh it up and we are saying entirely what you are saying, that Advance Directives must be accorded a great deal of respect and in law they probably are already binding. The only thing we are saying on that is we do not actually see the need for further legislation. We are entirely happy with the situation and we think we can educate doctors to observe Advance Directives with the degree of respect you want without further legislation but we would not oppose it if you produce legislation which dealt with the point.

Chairman

92. We may well come back to this particular issue but it is quite clear from what you say that you are in favour of Advance Directives whether they are enshrined in law or not provided they are not legally binding on the doctor and do not override clinical judgment. The neurological situation is—may I take it—that whereas you say you must take every effort in an acute situation to resuscitate the patient because you do not know what the outcome will be, nevertheless you do accept, I believe, the Royal Conference of Colleges' definition of brain death? Hence, if after a period of only a few days it is clear that the brain stem is dead, you regard that as effectively equivalent to death and agree that supportive treatment can be withdrawn. That is quite different from the Persistent Vegetative State where you have to wait for 12 months.

(*Dr Horner*) We accept that absolutely, my Lord. We are talking about patients who do not satisfy the criteria of brain death.

Lord Mishcon

93. Can I follow on what the Archbishop said and also try and deal with any opposition to legislation? I know it has been said if legislation were appropriate there would be no strong objection but is there not a great advantage in having legislation which will publicise more than any Code of Conduct in the BMA? Would it not be of advantage, first of all, that the public would then know of the existence of such a thing and secondly would it not help doctors, rushed in many cases as the Archbishop was intimating, that there was an obligation upon them to make a reasonable enquiry generally of the general practitioner involved because the advice is a copy should be given? Would it not help not only the patient to know there was an obligation: "Once I sign this advanced requirement of mine", but would there not be great advantages in legislation?

(*Dr Horner*) It is not for doctors to determine how patients may react. It is sad if you feel that they have to have the law on their side. We personally feel that the doctors should themselves be discussing these issues with patients. A competent Advance Directive is going to need a lot of thought and we would certainly urge it be discussed with doctors. We are very concerned, my Lord, and we want it to come over clearly to your Lordships, that legislating

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[Continued]

[Lord Mishcon *Contd*]

on this matter may in fact restrict both the freedoms of doctors and of patients.

(*Dr Fisher*) May I just pick up one point? I do believe it is very important that the public does understand about Advance Directives but really as an expression of what we believe is the modern approach to clinical care which is that it should be a genuine partnership between the patient and a professional, in our case the doctor who is looking after them. In any case, however rushed the doctor is, there is no possibility for decisions on treatment to be made without genuine discussion in terms that make sense to the patient about what the treatment involves and about what the outcome is likely to be. Consent is only valid, and consent for all forms of treatment has to be present, if the patient has understood that. An Advance Directive is actually extending the principle of a partnership between the doctor and patient.

Chairman

94. You have made it quite clear that you regard euthanasia, active euthanasia, as being a positive act of ending life and you are opposed to that for all the reasons you set out in your paper. However, may be it is relevant to the point which has just been in discussion where it has been suggested that the trust between doctor and patient may already be undermined in some cases by fears that current medical practice may prolong dying and may result in suffering and indignity. How would you take action to see that that trust is restored and maintained?

(*Dr Horner*) It seems to us that it is curiously illogical to suggest that if trust between doctors and patients has broken down to the extent that the question implies, then the logic must be to trust the doctors even more by giving them even greater powers over the patient's life and death. I am not sure that we do accept that trust has broken down. It is a proposition that certainly needs to be tested. Over the last five years the BMA has consistently been saying that to continue intrusive medical treatments that are inappropriate to the care of patients is bad medicine. I think that is now widely accepted practice in this country.

Chairman] Thank you. Do not for one moment think that we are suggesting that we believe the trust has broken down; however, some have suggested to us that it has been undermined to some extent by this fear.

Lord Meston

95. Could I just go back to the objections to specific legislation. You talked about legislation changing the climate, did I understand that you were suggesting if there was legislation for Directives one effect might be that there would be less regard for those patients whose wishes had not been expressed in an Advance Directive or for whom a Directive could not be found?

(*Dr Horner*) The fear has been expressed to me, my Lord, by our members that doctors will feel uneasy about their authority to act in an acute clinical situation because of some hesitancy that they may

not be acting in accordance with the patient's express wishes.

96. Could that not be met by the legislation creating some form of statutory presumption that in the absence of a Directive the patient could be treated as wishing to be dealt with in a certain way?

(*Dr Horner*) There are legal ways of addressing all of these questions, my Lord, but I think we have to ask why is it necessary.

97. It is necessary, is it not, because you are trying to resolve how a patient would like to be treated?

(*Dr Horner*) Yes. As Ms Sommerville was saying earlier, we believe that the law currently indicates that there is a presumption that Advance Directives should be respected, and we say that too, but we do not wish to put doctors in the situation, as I understand has happened in certain of the United States of America, where they feel that patients' wishes are being compromised by the terms of the Advance Directives that they have signed.

Lord McColl of Dulwich

98. Thank you for the way you answered the question about trust. I think it was rather like one of those questions "have you stopped beating your wife". They might have added another sentence, that others might suggest that trust is being undermined by fear sometimes medical practice in some countries hastens dying and so causes some distress. Could I go back to the *Bland* case? I am glad you have clarified the issue about the doctor not being at fault for resuscitating him on the spur of the moment. I would like to ask you what you feel about the coroner's advice before Tony Bland actually died when he was asked was it all right to discontinue medical treatment, and the advice from the coroner was that no such discontinuation of medical treatment in the form of antibiotics could be considered. I wonder what you thought of that view?

(*Dr Horner*) I think most doctors in the Association would have been surprised by that advice. It was not their understanding of what current medical practice was at that time and that is why we were so glad to have the Lords' judgment which made it clear that it is permissible for doctors to withdraw legitimate and proper medical treatment when that treatment is no longer serving a useful purpose.

Lord McColl of Dulwich] Would you conclude that the coroner was at fault in making such a statement?

Chairman

99. You did not agree with the coroner; is that the point which is being made?

(*Dr Horner*) I am grateful to you, my Lord Chairman.

Lord Colwyn

100. I wonder if we can get into some of the practicalities of this. Actions intended to cause the death of a patient are unlawful, actions intended to relieve pain which may as a consequence hasten death are

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[Continued]

[Lord Colwyn *Contd*]

not. Could you expand on that? How does this distinction operate in practice? How does it vary between hospital and general practice and perhaps in the hospice movement? You say that it is unexceptional that a patient's distress cannot be fully relieved in your paper but I do not understand that, the palliative treatment involved.

(Dr Fisher) We are fortunate in the United Kingdom that palliative care is a highly developed specialty. It has been strongly supported by those working in the hospice movement. The specialism of pain relief is certainly extensively practised here and in that respect we are different from some European countries. Relief of pain is not, as some of us who have been qualified for a long time like myself may have been brought up to believe giving continuously increasing doses of opiate drugs, it is very much more sophisticated. It is a specialty in its own right. Practitioners, including general practitioners, know part of it but there are situations where the patient's pain or symptoms may be so difficult to resolve that specialist advice is needed. It is just as in any other kind of medical treatment these days, it is not only one individual doctor, very often because of the highly developed nature of the specialty we need to call in other experts to assist us. The management of patients with a complex situation, of pain and miserable symptoms (for instance persistent vomiting) is actually a specialist matter and the general practitioner would call in either a pain specialist, someone from the hospice, or a MacMillan nurse. These are people who are skilled in symptom control. The evidence that we have been given from experts in palliative care is that now there is only a very, very small number of patients who cannot be relieved of their symptoms and that usually means to say it needs a good deal more thought, care. Each treatment has to be specifically tailored to the individual, there is not a cure-all approach. That is what we mean. General practitioners nowadays are increasingly skilled, skilled in accessing that kind of specialist care for their patients. It is yet though not as widespread as we would like to see it in the profession. Maybe that is a matter of education.

Chairman

101. May I take it then that you are in general support of the Report of the Standing Medical Advisory Committee and Standing Nursing and Midwifery Advisory Committee on the principles of palliative care?

(Dr Fisher) Yes.

Archbishop of York

102. In your memorandum you are talking about this extreme logical difficulty of drawing the line between withdrawal of treatment and deliberately killing a patient. You say: "Nevertheless ... almost all doctors and most other health professionals feel there is a gulf between the two". You then go on to talk about something being "alien" to one's role as a healer. It seems to me here that this crucial argument is being based on the medical profession's own self-understanding. I was wondering whether that was the main place where you would want to

draw the distinction between killing and letting die? Following on from that, if it is in your sole understanding as a profession, how do other professionals working alongside you see that because I have been struck by the evidence which has come from some of the nurses who seem to observe doctors behaving in what they think are unprincipled ways, although I am sure the doctors themselves know what they are doing. There seems to be a failure of communication on this point.

(Dr Horner) I think the doctors have not always been good at identifying the objectives of treatment in terms of a patient who is dying. There has been a tendency in the past to assume that the objective is still to try and stop the dying process in some way and that has led to the lack of trust that we were referring to earlier on. What we are saying quite clearly is that when the patient is dying the objective has changed. The objective is now to keep that patient comfortable and that should be, one would hope, an objective that all health care professions would accept and support. What we do not accept on the grounds of professional intuition if you like, though surely that is as equally valid as logic, we do not accept that the only response to the dying patient is to get rid of that patient as quickly as possible.

Baroness Warnock

103. I think part of the difficulty is that if there is such an enormous insistence on the gulf which you suggest between killing the patient, that is doing something which will cause them to die tomorrow or in an hour, if there is such a huge gap between that and either giving him more medication or conceivably withdrawing some form of treatment which is found to be futile, that does leave open a different intuition on the part of the nurses particularly who are left with the prospect of nursing this person for a long time, maybe weeks, months, when it would have been easier for them if the doctor had actually given the lethal injection. Nursing a patient who is known to be dying, everyone acknowledges there is no hope but he is being given a form of treatment or no treatment which involves his lying there and being cared for constantly, this does give rise to a different perception about what the morally best way to proceed is. I think it is the doctors who have this view that the one thing they must not do is give a lethal injection.

(Dr Horner) I am not sure that Lady McFarlane would agree with your interpretation of what nurses believe but I will ask Dr Fisher to respond.

(Dr Fisher) We are quite clear, in the BMA, that managing the patient with any condition, but particularly a patient who is dying or somebody with a chronic condition, is no longer the business just of the doctor. This is a business of team management. The doctor may lead that team but the decisions, the observations, the discussions with the relatives, discussions with the patients, the things that other members of the team can offer, are very important in making the decisions. At the end of the day, of course, it is not the doctors, the nurses or the family who have to be considered, it is always the patient who must be the doctor's first consideration. It is

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[Continued]

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vital, particularly in these difficult cases, that there is genuine dialogue between the doctor and the whole of the team on decisions about withdrawing treatment or how to treat. It is vital that the decisions are arrived at by all the team who understand how they are arrived at. There should not be any schism between doctors and nurses, that is not good practice. However, it does happen as we know but we believe as the professions get better at communicating with each other and better at team working, (which is a very skilled business), those occurrences will be fewer and fewer.

Baroness McFarlane of Llandaff] I just wanted to come back on Dr Horner's remark. I think there are probably as varied views amongst nurses as amongst doctors but certainly the majority of nurses I know would not want to expedite the death of a patient by a deliberate intervention because I think the motivation to care is so very strong amongst nurses. I think that gap between withholding or withdrawing medical treatment and deliberate intervention to end life is a very grey area nowadays and becoming increasingly grey. How one makes the distinction between withholding treatment and deliberately intervening to cause death is a very difficult one indeed.

Baroness Jay of Paddington

104. I wanted to come back to the discussion you had with Lord Colwyn because there does seem to be some difference of opinion about the point about whether or not the cases where the patient who is distressed and becomes fully relieved are totally exceptional. We have had one paper, for example, from the Institute for Social Studies on Medical Care which has been looking at the particular question of people with AIDS. In that, in the survey they conducted—and I do not think this is an unusual survey but I just refer to it because it is something which we have had put in front of us—less than half the doctors and only a third of the other professions who were involved in this sort of research felt able to estimate that the symptoms of AIDS could be satisfactorily relieved in the terminal stages. I think that is relevant to making a judgment from your professional point of view about whether it is truly exceptional that patients' symptoms can be relieved and whether, in fact, a lot of that evidence is not just derived from palliative care applied to the treatment of cancer, for example. If that is the case, in fact, that there are more patients with different types of terminal illness who may not be able to have their symptoms relieved in the way you say is usual, what then is the proper course of action with people like that given that one's feeling is they are probably less exceptional than your statement says?

(Dr Horner) I am sorry to be evasive in front of the Committee but I have to say that is not the advice that we have received. We have looked into this very carefully and the information we have been given is what we have relayed to the Committee. I am really not prepared to commit myself to a particular situation when I do not accept the premise.

105. May I press this a little further and ask

whether the information you have received is mainly from the type described, the conventional treatment of cancer in a palliative care hospice?

(Ms Sommerville) We have received a range of information. That is one potent source of information we have been looking at. Also, although we are reluctant to bandy figures about what is happening in the Netherlands, one of the things which is quite noticeable there is that people seem to agree that pain at the end of life is only an important factor in five per cent of requests for euthanasia. Fear of degeneration, general fear, neglect, isolation and a whole lot of psycho-social factors are very important in the vast majority of cases. To be absolutely correct, I should say that pain is a factor in 35 per cent but it is only the main factor in five per cent of people who actually request euthanasia. The evidence that we have received from a lot of people is that pain alone is not the thing which motivates people to ask for euthanasia, a lot of people fear pain but they are motivated to want to end their lives because of a lot of other reasons which we could in fact tackle if wanted to within our society and we could diminish those worries.

Chairman

106. Effectively then are you saying that adequate mechanisms for the relief of pain, distress and suffering in the broadest sense are available but as yet our educational system and the application of these methods has not been as widely applied as you would have wished?

(Ms Sommerville) I think we are saying in theory it is available but do we as a society make people feel wanted and needed and loved and supported and all those other things? We doubt that we do.

Lord Mishcon

107. May I selfishly from my own point of view complete my mental process on what Baroness Warnock and Lady McFarlane were discussing before. You say in your paper that you recognise, I believe I am right in interpreting it in this way, that there is a very thin moral line of distinction between cessation of all treatment and a deliberate overdose to produce death. You then say: "The BMA does not support any change in legislation prohibiting murder or manslaughter". Do you take the view on behalf of your members that when there is a clear case of—I am using shorthand—mercy killing by a doctor, that he should be charged with murder, that he should be convicted of murder with a life sentence imposed by the judge which goes on the record against him that he has been convicted of murder and he has got a life sentence irrespective of whether the Home Secretary decides to limit that to a matter of months in prison or no prison at all? Do you think that we ought to have some crime known to our law which is of a lesser degree of seriousness than murder or manslaughter in a case of that kind?

(Dr Horner) No, sir. We agree with the moral philosopher who has written that there are barriers not to be crossed. There are some limits beyond which people must not be allowed to go. The way that you describe seems to us to put at risk the lives

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[Continued]

[Lord Mishcon *Contd*]

of other patients and that is what I meant in my opening introduction by saying that there needs to be justice in the health care system. We have not had a chance to discuss the health care situation in Holland but we could spend much time discussing the Dutch evidence which in our view fully supports the contention that once you cross that barrier then you are in a wholly new situation which at this stage cannot be foreseen in this country. We know what is happening in Holland.

108. You did realise I was not suggesting that a criminal offence had not been committed, what I was saying was do you on behalf of your membership think it is right that there should be a charge of murder?

(Dr Horner) Our view, my Lord, as listed in the current policy is that any doctor who goes beyond that barrier should, and I think the words say, "be liable to whatever imperatives the law may require".

Baroness Warnock] I too agree with these words because I used them myself, but I do not believe that this is a barrier of that kind for the very reason that Lord Mishcon has suggested, namely the identification of the barrier is in doubt.

Lord Rawlinson of Ewell] That is a matter for debate among the Committee.

Chairman

109. You have said that you have favoured the idea that there might be a mechanism of "substituted judgment" introduced for the mentally incapable which has been introduced in other countries. The possibility is suggested that there could be some kind of local committee mechanism which could assess the appropriateness of certain actions. I think you proposed three levels of seriousness in cases in which this might be considered at a local level, with the agreement that there should be a mechanism in the most difficult cases which could not be satisfactorily resolved or handled locally of reference to the High Court. Is that something you would stand by as being a proposal you would wish to see implemented?

(Dr Horner) Very definitely, my Lord Chairman. We have been concerned for some years that the state of the law until some of the judges have helpfully resolved it on a case basis is effectively denying treatment to certain groups of patients. Our procedure is intended to address that and we commend it to your Lordships.

110. May I take it that this is evidence that you will be presenting to the Law Commission in response to its consultation paper?

(Dr Horner) That has been done.

Examination of witness

Sir DOUGLAS BLACK, Past President of the Royal College of Physicians, called in and examined.

Chairman

113. Thank you very much for coming and representing the Conference of Medical Royal Colleges

111. Finally, do you have any comments on the question as to whether resource allocation plays a part in the consideration of all these matters and whether it should?

(Dr Horner) Our concern throughout, my Lord Chairman, has been to protect patients and to provide them with the most appropriate care. I think Ms Sommerville referred in an earlier answer to the responsibility of our society to ensure that those resources are available. Our proposals to withdraw treatment when it is no longer offering benefit are equally prompted by our wish to provide good care. The fact that in some cases the decision will reduce costs is a happy coincidence. We have a very real concern that resource considerations will come to dominate such decisions as we understand is beginning to happen in the United States. We believe that the judgment should be made when clinically appropriate, not when funds run out. I would just add one last thing, if the Committee will permit me: that is a responsibility on doctors, but it is also a responsibility on others within the health service, on health care managers, on members of health authorities, who must ensure that in the resource allocation decisions they take that they do not always become overwhelmed by acute technology and the clever things that doctors can do today but that they also remember some of the patients that your Lordships have been discussing round this table today.

Chairman] Thank you, Dr Horner and Ms Sommerville and Dr Fisher, for your help to the Committee. If there are issues you think we have overlooked discussing with you please come back to us in writing.

Lord Kennet

112. I would just like to ask one question. Just now you said in your answer to the last question that you thought that such considerations were beginning to dominate the scene in the United States. Can you tell us how you would recognise the moment when in a given society these considerations begin to dominate the scene?

(Dr Horner) When the decisions begin to be made on the basis of resource constraints rather than, as now, on clinical judgments. This is why we are keen that cases such as *Bland* should continue to be debated in public before a decision is made. If the thing becomes hidden and covert then the possibility of resource constraints being used as a restriction on clinical freedom is more likely.

Chairman] Thank you very much for coming and for your evidence.

and Faculties. May I take it that you are not accompanied, as we thought you would be, by Mr Friend from the Royal College of Obstetricians and Gynaecologists?

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[Continued]

[Chairman Contd]

(Sir Douglas Black) He is not here, no.

114. May we also take it then that you are in a position to represent to us the views of the Conference of Medical Royal Colleges and Faculties in relation to the work of this Committee?

A. I learned less than a week ago that I had been nominated to represent them. I have made some consultations but they have not been comprehensive. I should explain that I am a past Chairman of the Conference of Colleges and Faculties and I can claim to be in general contact with their thinking and I have had specific consultations with Mr Friend who has just been mentioned and also with the current President of the Royal College of Physicians.

115. If as a result of today's hearing there are other issues you believe the constituent colleges and faculties may wish to raise, would you please make it clear to the Conference that they are absolutely free to do so in writing.

A. I will make sure they have that information.

116. You have heard the discussion that we have had with the representatives from the BMA and you have heard their responses to the various questions that we posed. I wonder if we could begin really at the end in a sense by asking you if you wish to comment on what you see as being the significance of resource allocation in the present setting of the health service in the United Kingdom?

A. I would take refuge in the general claim that resources are a matter for politicians. They are so overwhelming in their impact that the big decisions on health service funding have to be made by the politicians. The doctors' role is to be conversant with the economic aspects of the care that they give to populations. I think in the interplay between the doctor and an individual patient economic considerations should be at the very end of a long road.

117. So you have no evidence that the issues of life and death, the issues of medical care for the incompetent patient of whatever age, have up to the present been influenced by resource concerns, or have they?

A. I hope they never will.

Baroness Jay of Paddington

118. Can we just turn the question round the other way. I think the burden of what I was trying to get at in talking to the representative of the BMA was that in order to achieve the kind of care which might be broader than simply pain relief or palliative care as it is understood at the moment to relieve distress which is a much broader concept, we would need the positive addition of resources, the positive input of resources for education of the different kinds referred to by the BMA in terms of understanding, of team work, of training and so forth. It is not just restrictions on resources leading to bad care but the necessity to inject resources to lead to good care in the broader sense than purely pain relief.

A. Yes. I am a warm supporter of the hospice movement. I think that some of the things which are needed are actually free and I think these are some

of the most important things. I do not think there is any specific resource constraint limited to the care of terminal illness. I think in general the resource constraint is very serious but that is a different issue.

Chairman

119. As you have not been in a position to present us with written evidence on behalf of the Conference, could I ask whether in relation to the issues you have heard us discuss with the BMA representatives this afternoon you would like to make a statement about where you see the Conference standing in relation to these matters?

A. Thank you, my Lord. I have had sight of the BMA's written submission and I would like to express general agreement with that. I have also, as you know, heard their oral evidence and again I would like to express a general agreement, though there obviously might well be specific issues which you would like to ask about and on which I might have a somewhat different view, but I am speaking as a clinician with quite extensive experience of renal disease in the days before dialysis and transplantation and therefore I have acquired fairly considerable practical experience with the kind of problems you are discussing.

120. Could I ask you to comment upon the issue of what has been broadly and rather loosely termed "active euthanasia" and the attitude of the Colleges? Is the attitude of the Colleges the same as that of the BMA and in relation to what Lord Mishcon said do you see any need in this country to modify the present legal situation whereby a doctor taking a positive action to end a patient's life could be found guilty of murder?

A. As you may or may not know I gave evidence in the Leonard Arthur trial which I think was one of the earliest instances of this. I was very happy that through various circumstances Leonard Arthur was found not guilty, I think that was a good verdict. In a more recent case—which I will not name—I think the jury had no option but to find him guilty in the present state of the law. That does not in fact lead me to advocate a change in the law which would make the giving of a lethal injection legal. I would be very much in tune—and I am happy to say this—with the Archbishop of York in his paper in the *Journal of the Royal College of Physicians* commenting on the Dutch experience. Would it be relevant if I gave a view on the situation in Holland from some knowledge of it?

121. Please.

A. I do not like it, to be summary. I think, first of all, it is underhand because as I understand it the law in Holland still regards the giving of a lethal injection as a murder, it has to be explained away. The second thing about it is I think it could have a profound effect on how doctors perceive themselves, on what kind of people come forward to the practice of medicine, and on the way in which the public perceive doctors. I think that doctors should be perceived as people whose dual objective is to relieve pain and suffering and also to preserve life. Now splendid, when these two things are not in

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[Continued]

[Chairman *Contd*]

conflict but when they are in conflict there is real difficulty. There is a third which is that doctors must obey the law of the land in which they live. So I think I would be extremely worried, and I think the generality of doctors would be worried, if an obligation was laid upon them to give lethal injections. Again going back to past experience, I would have no real hesitation, but I would have sorrow, in pushing doses of sedatives. I would have no real hesitation in appropriate circumstances in refraining from treating pneumonia in a patient with terminal illness but I certainly would not ever give a lethal injection even though colleagues, whom I respect, I know to have done so. One has in the long run to live with oneself.

122. So you do not see that there is such a grey area, to which I think Baroness Warnock referred, between the positive act to end life on the one hand and the withholding or withdrawing of treatment or the giving of treatment which may hasten death but is given for some other purpose; you do not see a grey area between these extremes or do you?

A. I am extremely good at seeing grey areas, I fail to see one here.

Lord Mishcon

123. You do not see any need to reduce the charge from that of murder in the case of somebody who does, as Dr Cox did, give an injection of the kind we have been talking about? You do not see any reason why he should not be charged and convicted of murder as against a lesser offence which deals with mercy killing?

A. As I understand it, my Lords, he was charged with attempted murder. That, to me, is in essence the same thing. Technically it is a reduced charge but I am not a lawyer.

124. Accepting the correction that in his case it was thought that the lethal injection did not lead to death, it was something else that caused death, but if other circumstances had prevailed instead of being convicted of attempted murder he would have been convicted of murder. I am only suggesting, and asking for your view on this, that whilst it should be a criminal offence possibly because of the nature of the killing as against withholding treatment, you still say there should not be some lesser offence for which a doctor should be charged rather than murder?

A. No, I do not think I say quite that. I have every degree of human sympathy with Dr Cox and I have seen him and discussed this with him. I think there is no doubt in the world that on the present state of the law he committed a crime. I think he also committed something that I regard as an element of folly. I am not coming forth to support a lack of candour but one does not have to write everything down. I also think that he may or may not have committed a sin, but that is not for me to judge and I am happy to leave that to the theologians. I think he did but that is another matter.

Lord Mishcon] I must not persist.

Chairman

125. Would you have any comments to make upon the issue of Advance Directives, upon enduring powers of attorney in the field of medical treatment; what would be your view and that of the College?

A. I am in general terms in favour of Advance Directives because I think knowledge of a patient's own wishes must always be an advantage to a doctor in what are the very difficult circumstances of looking after someone whose illness appears to be approaching the end. I would like to say that one never quite has a 100 per cent assurance that illness is approaching its end, but that aside I think it must be an advantage to the doctor to know what the patient's wishes are. What the patient's wishes are in health when he makes an Advance Directive may not of course be those wishes in a state of terminal illness and one must always allow for that. I think I would be strongly in favour of Advance Directives. I would not be in favour of a Directive which was given the full mandatory force of a legal obligation on a doctor. I think that could be dangerous and what is more important disadvantageous to patients.

Archbishop of York

126. On this subject, I was somewhat surprised to see in the BMA evidence on this that it would be possible to write an Advance Directive such that the doctor was required or asked not to hydrate a patient. It seems to me that if you write an Advance Directive in those terms there is a very, very narrow dividing line between that and voluntary euthanasia.

A. I rather agree with that in actual fact because I was once dehydrated myself in the course of the war as an experiment and it is an extremely uncomfortable state. I do not think there is a total lack of cruelty in withdrawing food and fluid. It may be of significance that in the context of animal experiments this is one of the things which is expressly forbidden unless in very exceptional circumstances. I am not a strong advocate of fluid or food withdrawal.

Chairman

127. May I take you to the question of the principle of substituted judgment. The BMA have suggested that in the case of the mentally incompetent or incapable individual, whether by reason of mental handicap or mental disease, a mechanism might be established, say of a local committee structure properly constituted. They suggest that there should be three levels of decision making, one where it is perfectly straightforward where the doctor and those on the health care team can make a decision where it is for example, a simple matter of suturing a wound or dealing with scratches; then there could be a difficulty a second level where it should be a committee decision; and a third and more serious level still where there might be a major issue, for example whether or not to proceed with the sterilisation of a mentally handicapped woman as in the case of *Re F* which we have had mentioned to us. If the committee did not resolve this at local level then

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[Continued]

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these cases might have to go to the High Court. What is your view about this idea of substituted judgment?

A. I think in the BMA evidence the point is made that the courts may act on a timescale that is insufficient. I do not myself think that is rigidly true because in the case of a Down's Syndrome baby with an intestinal obstruction the courts acted with remarkable speed, I think the matter was settled within a few days. I think I would prefer to be operated on by a surgeon who is legally mandated to operate, I do not know what you think about that, but that is again a side issue.

Archbishop of York

128. I am still worried by this question of different perceptions between doctors and nurses. If I may just quote a couple of sentences from another piece of evidence we have had from the UK Central Council for Nursing, Midwifery and Health Visiting, the evidence says: "Nurses will, however, from time to time observe and even be party to resuscitation of a patient 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 had not sought to end their own lives." One gets the sense that here are people who are in a way much closer to the patients than the doctors who have had much shorter contact, much less opportunity to observe what is going on. I wonder whether from your perspective that you are aware of this gulf between what nurses perceive and what doctors perceive?

A. It is difficult to say what nurses perceive, but I think Lady McFarlane would agree with me that the ideal relationship is one of complete trust between doctors and nurses; but this is the world we live in and not an ideal world, so things are not always exactly like that. I am very aware of the dilemma which arises in relation to patients who have made two, four, six, eight attempts at self-poisoning, as it is now called. Should one be constantly bringing these folk round? I would personally bend things to the extent of—perhaps at the 77th attempt—being a little less than fully eager. There might even be a resource implication.

Chairman

129. To what extent do you feel that enduring powers of attorney might be used in addition to

Advance Directives in the field of medical decision-making in the terminally ill?

A. I noted that suggestion in the BMA evidence. I have some concerns about it. One would certainly want to choose a very good attorney. I was not sure if this was meant to be a solicitor or a friend or perhaps a new race of councillors. I think one would have to be rather careful who one chose.

130. I think their statement probably meant a power of attorney legally entered into by the individual in advance. Your comments on Holland were really quite striking; I think at first sight that the thought of a doctor discussing with a colleague the decision to give a fatal injection to an individual and then subsequent to the event reporting this to the coroner who then has to decide whether this was properly done within the law or whether the doctor was to be prosecuted did strike me as a rather odd way of handling the situation. One takes it, therefore, that you are, as the BMA is, opposed to active euthanasia as generally described even though, as you said at the outset, you have known colleagues whom you respect who may in the past have done it?

A. I have some evidence, admittedly subjective, I have been at a meeting at the College where the Dutch doctors who have engaged in what amounts to active euthanasia were describing their experiences. I had the quite horrible feeling that a lot of them had got to like what they were doing whereas to me the natural reaction would be to loathe what they were doing.

131. Finally, to what extent do you think the problems in this area that have arisen over the years have resulted from failure of communication between patients, their families and their doctors and the nursing staff? Do you think that this has been a major difficulty that has given rise to problems?

A. I think communication is never perfect. I think it may have made some contribution. I am one of those pragmatists and I think the facts are more important even than communication but nevertheless I cannot dismiss the possibility that faulty communication and worse still misunderstanding between members of the team may have contributed to the difficulties.

Chairman] That sound is not the Lutine Bell, I fear it is the Division Bell which is obviously, I am sad to say, cutting short your very helpful evidence. We can only say how grateful we are for you coming and giving your views. Thank you.

Memorandum by Sir Douglas Black

It is not easy to address ethical questions in summary fashion, and on reflection there are two issues raised on Tuesday, on which I would wish to clarify my attitude, on a personal basis.

Should there be some lesser charge than "murder" for a doctor taking active steps to end life?

I think this should always be regarded *prima facie* as a serious offence; but when it is committed under circumstances of great stress, and in the absence of any intent to "have the law changed", there should be an element of discretion both in deciding to prosecute, and in the charge to be brought. The stress on juries, and on all concerned, would be less if they could consider charges other than "murder" or "attempted murder"; it would be for lawyers to suggest an appropriate charge. In summary, in my anxiety to protect

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patients, I may have been less than charitable to doctors acting in good faith. But how is "good faith" to be diagnosed?

Moral equivalence of "active" and "passive" euthanasia

My assertion that there is a moral difference between these two activities does not include any claim that they differ either in *intent* or in *outcome*. My concern is limited to the ethics of the *process* which comes between intent and outcome; this seems to me, in the case of active euthanasia, to be at variance with mainstream medical ethics, and damaging to the perception of doctors by patients.

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