

Bioethics Briefing

Number 6: Issues at the End of Life

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General Introduction

Lord Joffe's Bill on Assisted Dying for the Terminally Ill, debated in the British Parliament in 2004 and again in 2005 and 2006 was the latest attempt to make it lawful for doctors to participate actively in ending the lives of terminally ill patients. The term *assisted dying* is crucial here: the Bill did not propose the legalisation of euthanasia *per se* but of assisted suicide. In the event the bill was defeated but opinions amongst medical personnel and the wider public remain strongly divided. One of the concerns raised by opponents of the Bill was that if the law had been changed in this way, legalisation of actual euthanasia would not have not been far behind.

The Bill has focussed attention on one particular issue that may occur at the end of a person's life but there are several others. In this Briefing we have dealt with them as two groups, firstly euthanasia and related issues and secondly withholding or withdrawing treatment.

Euthanasia - Introduction

The 2006 debate on Lord Joffe's Bill certainly brought the topics of euthanasia and assisted suicide into a wider public awareness but this is by no means a new topic. In Ancient Greece, although doctors who took the Hippocratic Oath were forbidden from undertaking active euthanasia, they were

permitted to stop treatment if the patient's condition was hopeless. They were also permitted, under very specific circumstances, to assist someone to commit suicide. In some city states, including Sparta, 'deformed' babies were killed or allowed to die; Plato approved of this in relation to his eugenic ideals for improving Greek society.

However, with the rise of Christianity in Europe, even assisted suicide became taboo and remained so for many centuries. It was not until the 20th century that assisted suicide and euthanasia re-emerged as topics for active and widespread discussion. Societies advocating the legalisation of voluntary euthanasia were established in the 1930s in the USA and UK. In the UK, the Voluntary Euthanasia Society was founded in 1935 and has been actively promoting its cause ever since. In January 2006, the society changed its name to *Dignity in Dying*, a change that provoked criticism from doctors and nurses working in palliative care whose motivation is to enable patients to die with dignity. In the 1980s a separate Scottish Voluntary Euthanasia Society split from the main UK organisation. It has since re-branded itself as *Exit* and is as active as its parent organisation in promoting what they call, perhaps euphemistically, self-deliverance. Further, these UK organisations, along with their counterparts in other countries, argue that, with current trends in medicine (see below), there



is increasing need to permit voluntary euthanasia and assisted suicide. Thus both Dignity in Dying and Exit were strong supporters of Lord Joffe's Bill.

Despite the high profile given to these issues from time to time, it is apparent that much of the debate is not well-informed. Before setting out the ethical issues, it is therefore important to get our definitions straight and our background facts correct.

Firstly, the word '**euthanasia**' comes from Greek and means a 'good death' or a 'quiet and easy death' which is something we suppose all of us would wish but in this context is referring specifically to the death of a terminally ill person.

Secondly, **Voluntary euthanasia** is:

- the deliberate ending of a person's life
- at their request
- because that person finds their illness or disability intolerable.

Behind this definition are two important assumptions. The first is about the person's condition, namely that the suffering is intolerable and cannot be relieved. The second concerns agency: it is understood that someone else will do it; that person will usually be a doctor who will administer a lethal dose of a drug.

Thirdly, voluntary euthanasia thus differs subtly from **assisted suicide** in which the patient, wishing to take matters into their own hands, is helped to do so by the provision of drugs which they or, if they are physically incapacitated, someone else will administer.

Fourthly, **Involuntary euthanasia**, by contrast, is:

- the deliberate ending of a person's life
- without their request
- because *some other person* or party considers that their life is intolerable or its quality is not worth having¹.

A question that arises from these definitions is whether there is an ethical distinction between voluntary euthanasia and assisted suicide. This is a difficult question. The version of Lord Joffe's Bill debated in 2006 made the distinction. In voluntary euthanasia, the doctor commits the final act, albeit at the request of the patient. In assisted suicide, the patient is provided with the means of killing themselves, which they do at the moment they are ready. The doctor is not directly involved in the final act. However, opponents of the Bill pointed out that in many cases, the means of suicide is the self-administration of lethal drugs which need to be prescribed or provided by medical practitioners. The end result (and indeed the intention) is the same, whether or not it is the doctor who actually administers the dose. In this Briefing we have viewed the two as being equivalent and therefore do not discuss assisted suicide as a separate ethical issue.

¹ See, for example, the account of the death of King George V summarised in Searle (2002)

Euthanasia - Scientific and Medical Background

In the world's developed countries, life expectancy has increased dramatically since the early days of the 20th century. In general this may be ascribed to better social conditions, clean water supplies, better nutrition (notwithstanding current worries about the increasing incidence of obesity), better control of infectious diseases by antibiotics and other drugs, almost universal immunisation and much improved and more sophisticated healthcare. The 'three-score years and ten' of the Psalmist (Psalm 90:10), for centuries a rather longer life-span than enjoyed by the average inhabitant of northern Europe, is now regarded as nothing special. In the UK in 2006, for example, people may expect on average to live to around 80 years² but that figure is going up all the time.

Although these data give a very positive picture, there are also more negative aspects. It is true that far fewer people die from previously common infectious diseases but that does not guarantee a disease-free life. Inevitably, as people live longer, so we see more examples of progressive degenerative and malignant diseases which in their later stages may be distressing for the patient and/or for their family and friends. Thus we have media focus on high profile cases in which the English courts have refused to grant permission for spouses to help their partners to die or where the patient travelled to another country in which assisted suicide and/or euthanasia are legal. Early in 2006, for example, Dr Anne Turner, accompanied by a camera crew and a reporter from BBC TV, was helped to end her life by Dignitas³ in Zurich (BBC News, 2006a). Cases like this again brought the topic to public attention. Voices are raised both in favour of and against legalising euthanasia and assisted suicide, radio phone-in programmes are devoted to the subject and there will doubtless be calls for further Parliamentary debate, despite the defeat of Lord Joffe's Bill.

Further, although UK law forbids it, it is clear that there are doctors who have agreed to their patients' requests to end their lives; several of these doctors have been prosecuted.

Indeed, based on anonymised surveys, it is likely that this practice is more widespread than indicated by the small number of cases that reach the courts. However, it is difficult to ascertain exactly what proportion of doctors would support the legalisation of either assisted suicide or voluntary euthanasia. What is clear is that opinion among doctors is divided (Branthwaite, 2005; George *et al*, 2005). Thus, in 2005, the Annual Conference of Representatives of the British Medical Association overturned the Association's long-standing opposition to euthanasia and assisted suicide and voted to take a neutral stance on these issues. However, the 2006 Conference voted, by a two-thirds to one-third majority, to oppose the legalisation of both assisted suicide and euthanasia thus reversing the 2005 decision (BBC News 2006b). Nevertheless, if the one-third minority voting in favour of legalisation is representative of the profession as a whole, there are clearly many doctors who, as mentioned above, would like the law to be changed. This number doubtless includes those doctors who have actually complied with a person's request to end their lives.

² However, we note that life expectancy is much lower in areas of social deprivation

³ Dignitas is a charity dedicated to helping terminally ill people commit suicide (see www.dignitas.ch - last accessed by the authors on 02/08/2006). Assisting a suicide is not illegal in Switzerland

The ethical arguments for voluntary euthanasia

There are three main arguments put forward to support making voluntary euthanasia lawful:

- Openness
- Necessity / Compassion
- Autonomy

Openness

It is quite often assumed, when an elderly and terminally ill patient dies in their sleep, that the doctor had given them something to hasten death, in other words that the doctor knowingly gave the patient an overdose of a drug to ensure that he or she slipped away quietly. Such an act is unlawful in Britain, but the fact is that doctors recognise that while their intention in giving a drug like morphine or heroin to a dying person is primarily to make them comfortable, the person does often die quietly in the sleep the drug induces because breathing is depressed. Indeed such practice has almost certainly been seen as 'good medicine' for many years and is a clear example of the 'double effect'. However, although, as indicated by the recent vote (see above) the British Medical Association is, at least for the time-being, officially opposed to voluntary euthanasia, there is a lot of evidence, as indicated earlier, that many doctors in the UK would like the law to be changed. The argument is that the law is out of step with what actually happens quite frequently in current compassionate medical practice.

Necessity

Necessity is emotionally a powerful argument which says that if a person with a terminal illness is suffering great pain and distress, why not help them to die? In this way their suffering will be relieved. Because they are dying, it is cruel to allow them to go on suffering. Our compassion for our fellow humans should not allow a person to endure intense suffering that the person finds intolerable. It is often said that we would not allow our domestic pets to suffer like this - they would be 'put down' - so why should

we make a human being endure such pain, discomfort and loss of dignity. It is a position based on virtue and has a strong emotional pull, especially for those who have observed relatives or close friends in the late stages of terminal illness. This argument is beautifully set out in the book *'Wrong Rooms'* by the journalist Mark Sanderson (2002) which deals with the illness and death of his boyfriend, Drew Morgan. Drew was dying from a malignant melanoma and his suffering was so awful that Mark eventually smothered him with a pillow and killed him. Mark said that what he had done was not murder but rather an act of love in response to the intense need of his lover. Further, it is argued that, even if hospices are able to provide extensive relief of the pain and other symptoms of terminal illness (see below), some of the symptoms or effects of certain neuro-degenerative conditions are not controllable, even within the care of skilled and dedicated hospice personnel. It was the knowledge that they would inevitably suffer such symptoms that has led several UK citizens to seek assisted suicide in Switzerland.

Autonomy

The concept of 'rights' has become very important in 21st Century Western society. Personal autonomy, the right accorded to a person to decide for themselves what is best for them, plays a key role in both private decisions and public policy. It is also one of the key principles of medical ethics (Beauchamp and Childress, 2001). In relation to voluntary euthanasia the question is this: do we accept the right of human beings to decide how and when they will end their lives? The position is clearly put in Brian Clarke's play, *'Whose Life is it Anyway'* in which the main character says, *"I have coolly and calmly thought it out and I have decided that I would rather not go on. Each must make his own decision."* Or, as it was put by Dr Anne Turner, suffering from a neuro-degenerative disease, and by her family, it was for her to choose the time at which she would die with dignity.

The ethical arguments against voluntary euthanasia

The arguments set out above certainly appear to be powerful ones in favour of voluntary euthanasia. But what are the arguments on the other side? Three questions arise:

- Is it necessary to kill a person in order to control their pain and suffering?
- Is there another side to autonomy?
- Is deliberate killing of a person consistent with medical ethics?

Controlling pain and suffering

The growth of the hospice movement over the last 40 years has had a major impact on the care of terminally ill people in the UK. Hospice staff help dying people by controlling pain and other distressing symptoms and supporting them and those close to them as they come to terms with what is happening. In general, patients are encouraged within the constraints of their illness to make the very best of what life is left to them. In giving evidence to the House of Lords Select Committee on Medical Ethics in 1994, the Association of Palliative Medicine provided evidence that in 99% of people dying, for example from terminal cancer, pain and other distressing symptoms can be controlled (House of Lords, 1994). They also argued that in the one-percent in whom this may be difficult, hospices can still provide a reasonable quality of life over the last weeks and days of life. The argument here is why kill somebody when you can offer them the opportunity to make the very best of what life is left to them? Furthermore, relatives often observe that in the hospice where their family member is being cared for there is an atmosphere of peace and dignity. Indeed, requests for euthanasia in hospices are almost unheard of (Gilbert, 1996).

The other side of autonomy

The freedom to make our own decisions about our lives is a key principle in a free society but that freedom can only be exercised so long as it does not restrict the freedom of others to make their own decisions about their lives. In arguing the autonomy case for voluntary euthanasia so strongly it is assumed that it does not impinge on or restrict other people's

freedom. However, there is some evidence that this view may be mistaken.

Voluntary euthanasia has been practised openly in the Netherlands⁴ for 20 years and that openness has been recently enshrined in law. Two studies, one in 1991 (Van der Mass *et al*, 1996) and one in 2001 (Sheldon, 2003) showed that there were between 2000 and 4000 cases of voluntary euthanasia each year in the Netherlands. However, there were also about 1000 people each year whose lives were ended by their doctors, not because they had requested it but because other people thought that their lives were intolerable and it would be better to relieve their suffering by ending their lives⁵. What was voluntary for some people has become *involuntary* for others. When voluntary euthanasia was last considered in Britain in 1994, the House of Lords Select Committee rejected it for this reason. The Committee accepted the right of every person to refuse medical treatment but concluded that if voluntary euthanasia became lawful it would threaten the weak, the vulnerable and those without capacity.

Medical ethics

Although the proponents of assisted suicide and voluntary euthanasia have argued, often in a very articulate way, that these practices are consistent with accepted medical ethics, opponents are equally adamant that they are not. For example, the World Federation of Doctors who Respect Human Life⁶ points out that in the Geneva Oath formulated by the World Medical Association in 1948, a doctor pledges that '*The health and life of my patient will be my first consideration*' while the Helsinki Declaration of the WMA states that '*The duty of the doctor is to promote and preserve the health of the human being.*' The argument is that deliberate killing of a patient for whatever reason is not consistent with these statements. Indeed, many doctors cannot equate wilful ending of a patient's life, for whatever motive, with the general medical ethical principle of **beneficence** (Beauchamp and Childress, 2001), although it is recognised that some treatments administered to ease the suffering of very sick patients may hasten death: the 'double-effect' dilemma.

⁴ Interestingly, there are very few hospices in the Netherlands

⁵ It is estimated that in 2005, as many as 2.5% of deaths in the Netherlands were brought about by voluntary or involuntary euthanasia

⁶ For example see <http://www.donoharm.org.uk/doctorsfed/index.htm> and <http://www.euthanasia.com/belgium.html>

Withholding or withdrawing treatment - Introduction

In the preceding sections we have discussed ethical issues arising from actively ending the life of patients or of actively providing the means for the patient to end their own lives. The ethical arguments are relatively clear and most people are able to come down one side or the other in the debate. Much less clear are the arguments around the withholding or withdrawing of life-sustaining treatment. Is there an ethical difference between directly bringing about the end of a patient's life and letting them die by withholding treatment? There are three main areas to consider here:

- the right to refuse treatment
- the 'living will'
- making decisions for people who cannot make them for themselves.

The right to refuse treatment

In the UK, any person who has capacity has the right to refuse medical treatment. Capacity is defined in law as the ability to

- understand the information relevant to the decision
- retain that information
- use or evaluate that information as part of the decision making process
- communicate the decision

Where this ability is absent a person lacks capacity. Formerly such individuals were said to be 'mentally incompetent'.

Even when it is clear that the treatment is in the patient's best interests, he or she can ask that it not be given or that it be discontinued. Sometimes, refusal to be treated occurs on religious grounds. Jehovah's Witnesses, for example, will not have blood transfusions and one of the authors of this Briefing has had to let a Jehovah's Witness die when a blood transfusion would have been life-saving. Interestingly (and perhaps controversially) however, where the patient is a minor and a child of a Jehovah's Witness, the child is taken in to the care of the Courts, thereby removing from the parents the right to make decisions for that child.

There have also been occasions in which the medical team treating a patient wishes to continue the treatment while

the patient wishes it to be discontinued. Here, as the recent case of 'Miss B' in the UK has shown, the law is on the side of the patient. Continuing treatment against the will of a mentally competent patient is against the law, even if withdrawing treatment will result in death⁷.

The 'living will' (formally termed advance decision or advance directive)

On occasions a person with capacity wishes to indicate in advance that, in the future, under specifically defined conditions, they do not wish particular treatments to be initiated or continued. This wish needs to be made in writing and is known as an advance directive or advance decision (or colloquially as a 'living will'). A very important point is that it can only be acted on if the patient lacks capacity at the time the treatment is proposed (*i.e.* is not able to make a decision). In these circumstances, a doctor does not incur liability by observing a valid advance decision. However, if the patient has capacity at the time the treatment is proposed they will need to re-state their wish to refuse it.

Withdrawing or withholding treatment from people who are unable to decide for themselves

Examples of people who lack capacity are babies, children, people with dementia or who are unconscious. Under such circumstances somebody else has to make the decision whether or not to withhold or withdraw medical treatment. In general, the criterion applied is that of 'best interests', which is the decision is based on what are deemed to be the best interests of the patient. That decision about best interests will usually include an analysis of benefit *versus* harm: does the possible benefit conferred by a treatment outweigh the harm that may also result from the treatment? In law, it is only the doctor(s) looking after the person who can make that decision but of course the doctors consult other people such as the person's partner, close relatives, carers or persons with power of attorney. However, a decision thus made may be challenged in court, for example by relatives of the patient and in such cases, the final decision is left to the court.

⁷For further details of this case see Bryant *et al* (2005)

Withholding or withdrawing treatment - scientific and medical background

There is no doubt that increasing sophistication in medical treatment and in life-supporting medical technology has saved the lives of many patients who in earlier years would have died. However, it is equally true to say that in some instances such treatments present us with ethical dilemmas. Three general examples will make this clear:

- Aggressive treatments for cancer
- Babies with severe congenital disorders
- The difficulties in defining death

Aggressive treatments for cancer

Despite the pressure from some doctors to be allowed to end the lives of terminally ill patients, there is also a desire amongst many medical practitioners to preserve a patient's life for as long as possible. Thus some cancer patients, often those in the later stages of the illness or whose cancer is particularly aggressive, may be offered very unpleasant treatment regimens. Such treatments may indeed prolong life but questions then arise as to the quality of that life. This situation was beautifully illustrated in the 2001 TV-film, *Wit*, starring Emma Thompson as a university professor being treated for ovarian cancer. It is a very powerful film, leaving one with the question as to whether the professor, had she known how extremely unpleasant the treatment (which did not in the end save her life) was going to be, would have exercised her right to refuse it.

Babies with severe congenital disorders

The care of very ill babies, including those born very prematurely, is another area of medicine in which great strides have been made in recent years. The reasons include the establishment of more special care baby units, increased knowledge of the physiology and metabolism of premature and very young babies, greater understanding of genetic disorders and, as mentioned before, increased sophistication and effectiveness of medical technology. Thus many babies who would have previously died in the first hours, days or weeks of life now survive. In the main this is a cause to be thankful but sometimes the survival of a very poorly child can bring particular problems, as exemplified by Charlotte Wyatt.

Charlotte was born, three-months premature, in Portsmouth in October 2003. At birth she weighed only 480 gm, was only ca 12cm in length and had severe damage to her lungs, kidneys and brain. For the first three months of life she was kept on a ventilator. She was not expected to live more than a few weeks

and it was certainly the medical care that kept her alive over those first few weeks. Despite this care her doctors believed that her breathing and brain functions were actually deteriorating and they thought that the damage was irreparable. In addition she was diagnosed as being blind, deaf and incapable of voluntary movement. Nevertheless, at the time of writing she has now survived for nearly three years although to all intents and purposes she is still like a very ill premature baby. For much of that time she has remained in hospital and has been fed through a tube.

Difficulties in defining death

It used to be easy to define death: when the heart had stopped beating and breathing had ceased, the person had died. Since 1976 in the UK, cessation of brain stem function has also been taken as an indication of death. However, with our increased understanding of the relationship between heart, lung and brain function and our technological ability to provide replacements for at least some of those functions, defining death has become more difficult and this has led in turn to cases in which deciding about continuing or stopping treatment is very problematic. The condition known as Permanent Vegetative State (PVS) typifies these dilemmas, as illustrated very well by the case of Tony Bland.

Tony Bland had been a victim of the Hillsborough football stadium disaster in Sheffield in 1989 and by mid-1992 he had been in PVS for three years as a result of the head injuries he had received. In PVS the higher centres of the brain are destroyed and there is no evidence of cognitive function. Despite this, people with this condition do show sleep-wake patterns and their spinal reflex responses (for example, withdrawing the foot if a toe is pinched) are normal. They cannot swallow and have to be fed through a tube passed into the stomach through the nose. With expert nursing care people with PVS can remain in this state for years.

In making decisions about treating such people we need to consider two important questions. First, are they alive in any normally accepted sense of the word? Certainly there is a human body that breathes but with higher brain function destroyed is it still possible to ascribe to them human personhood? Put more starkly, do we just have a body but no person? Secondly, is feeding through a tube an *artificial* means of support (and therefore a medical treatment) or a provision of basic needs? If it is a medical treatment, is it in the patient's best interests?

Ethical issues involved in withholding or withdrawing treatment

Introduction

The right, based in personal autonomy, of a person who has capacity to refuse treatment, presents no ethical difficulties for most people. Even if family members or a person's doctors disagree with the decision (as happened with 'Miss B', mentioned above), the right to refuse treatment is enshrined in law. It may well be that 'from the outside' of a case we may question the wisdom of the decision in relation to the people who will be affected by it (which may of course involve the personal ethics of those concerned) but in legal terms this issue is clear-cut. The autonomy of the patient is the overriding principle. However, when we consider the range of cases involving people who are not competent (lack the capacity - see definition given above) to make their own decisions we are in much muddier waters. To illustrate this we return to the case of a very ill young child, Charlotte Wyatt and that of an adult in PVS, Tony Bland.

Ethical discussion of the Charlotte Wyatt case

There is no doubt that expert medical care, especially in the first three months after birth, has kept Charlotte alive. However, the doctors looking after her believe that she has no prospect of recovery and will never lead anything that resembles in any way a normal life. Indeed, they further suggest that in her current state she experiences pain and discomfort. They therefore argue that if she gets worse, any further life-prolonging treatment such as artificial ventilation would not benefit her and should not be used. The question here is what is in the patient's best interests and the doctors' position is that any treatment, other than that designed to make Charlotte more comfortable, is not in her best interests and indeed would be futile.

In contrast to the doctors, the parents, Darren and Debbie Wyatt, believe that there has been some improvement and continue to want everything to be done to save their daughter, including using artificial ventilation. Their argument is that it is in Charlotte's best interest to be treated, giving the opportunity for further improvement and perhaps, very optimistically, a meaningful life. But there is also another factor in this case,

namely the best interests of the parents and indeed, they have suggested that in the light of the legal judgements (presented below) they had become victims. Nevertheless, in law, the best interests of the patient over-ride those of other interested parties, even, as in this case of the parents of very ill child.

In such cases where those acting for a patient disagree with the doctors treating the patient, the final decision is left to the courts. In October 2004, Mr Justice Hedley ruled in favour of the doctors' wishes that they should not use any further life-prolonging treatment, a decision which distressed the parents and which was opposed by 'pro-life' organisations. The judge has on three occasions reviewed the case and for a period in 2005 the original decision was reversed. However, in February 2006 Mr Justice Hedley renewed his order allowing doctors to withhold the treatment because Charlotte's condition had worsened, stating that *'Medical evidence speaks with one voice, that ventilation simply will not achieve the end for which no doubt the parents would wish'*. This ruling effectively leaves any decision about further life-prolonging treatment in the hands of the doctors responsible for Charlotte's medical care (Jones, 2006). Nevertheless, at the time of writing, she is still alive and is being looked after at home, albeit with a great deal of difficulty.

Ethical discussion of the Tony Bland case

By mid-1992, when Tony Bland had been in PVS for a little over three years, his family became reconciled to the fact that his case was hopeless: they would never be re-united with the person they had known and loved. This made it easier for them to agree with the doctors that further treatment was futile. However, this was high-profile case, not least because other aspects of the disaster were still being dealt with by the courts. Further, the issues involved were complex and thus the doctors and the hospital in which Tony Bland was being cared for asked that the case should be dealt with by the Courts. The Solicitor-General appeared on behalf of Bland. The case was deliberately taken from the Family Division, to the Court of Appeal and then for final judgement to be given

by the House of Lords. In February 1993 the Law Lords took the view that Tony Bland was not alive in any normal meaning of that word. They also accepted that feeding him *via* a tube was a form of medical treatment, which was a futile treatment because it conferred no benefit on him; it was not in his best interests. He had not consented to it and there was no prospect of him recovering. Following this judgement the feeding tube was removed and Bland died some days later.

The judgement in this case did not receive universal approval and those who disapproved did so for three reasons. First, it was argued that Tony Bland was not dead according to previously used definitions of death. Secondly, it was held that food and hydration are basic human needs (and not a medical treatment) and while someone is alive they ought not to be denied them. Thirdly, it was suggested that because the intention of removing the feeding tube was that he would die, this action amounted to involuntary euthanasia.

However, there is a strong counter-argument to these points: in PVS there is little prospect of being in anything other than the PVS until the person actually dies. A function necessary to life has been taken over artificially: Bland could not receive and swallow food or drink because of the catastrophic brain damage that he had suffered. The Law Lords focussed on two essential questions before agreeing to withdrawal of the feeding tube. First, was there any possibility that Tony Bland might show any degree of recovery? Secondly, could he take and swallow food and fluid when offered in a cup or a spoon? If the answer to either question had been 'yes' then food and fluid must continue to be given. But if the answer to both questions was 'no' then his vital body system of swallowing had failed and he had no hope of recovery. 'Treatment' (in this case feeding *via* a tube) should therefore be stopped.

Central to this whole debate is the ability to diagnose PVS accurately because there are other neurological conditions in which an individual may appear to be in that state but is actually suffering from a different condition. Thus, there are agreed criteria which have to be met before the diagnosis of PVS can be made.

These key questions together with that of the balance of benefit and harm to which we referred earlier are now applied in other cases in which it is attempted to define the patient's 'best interests.' Where the treatment is judged not to confer any lasting benefit and would also cause more suffering, the decision now (as already discussed in the case of baby Charlotte Wyatt) is either to withhold or withdraw it.

Withholding or withdrawing treatment and euthanasia

Is there a difference between agreeing to a request for (voluntary) euthanasia and letting a patient die by withdrawing treatment? Those in favour of voluntary euthanasia say there is no real distinction; the result is the same – the person dies. Those who are against voluntary euthanasia but in favour of withholding or withdrawing treatment under certain circumstances argue that, while the outcome is the same, the motives and the methods are different. On the one hand, the motive is to relieve suffering by taking action to actually kill the person; on the other hand, the motive simply is to relieve suffering, recognising that any further treatment is futile and whatever is or is not done, the patient will die. The principle of beneficence - the imperative to do good - means that doctors and other health workers have a primary duty to save life. Where that cannot be done they have an absolute duty to care and to relieve suffering. In the Netherlands and Belgium they have concluded that this duty, under circumstances prescribed by law, can extend to actively killing somebody. It remains to be seen whether or not more countries follow suite but for the present in the UK a clear distinction is made in law between withdrawing or withholding futile treatment, now established as legal, and euthanasia which remains illegal. For further discussion of this topic see Bishop (2006a).

Mini-case studies

Case 1

You are parents. Two days ago your 18 year old son had a motor cycle accident. He has severe head injuries and has been in an intensive care unit on a life support machine for the last 48 hours. The doctors tell you that his brain is dead and can never recover. Will you agree to the life support machine being turned off?

Note for course tutors: There are parallels here with the Tony Bland case. Try to elicit from your students the key questions that must be asked before doctors decide that they recommend turning off the life-support machine. It may also be worthwhile to take the parents' position in discussion of this situation.

The important point here is that brain death means 'brain stem death'. Students need to realise that if the brain stem is damaged irreversibly spontaneous ventilation cannot occur – hence the need for a ventilator ('life support machine'). Furthermore, no information can pass through the brain stem without which the higher centre – the cerebral cortex - cannot function. Case law accepts that brain stem death equals death. In PVS (as with Tony Bland) the brain stem continues to function so the person breathes spontaneously. However, no cognitive function is present because it is the higher centres of the brain which are irreversibly damaged

Case 2

You are a general practitioner. You have a patient who is a man of 40 with a wife and two children aged 13 and 11. He has battled with cancer for three years and he is now dying. He has, you think, four to six weeks to live. One day when you are visiting him at home he says to you, "*Doctor, my wife and I have talked about this and we realise that there is nothing more that can be done for me.*"

Please would you give me an injection so that I can die peacefully in my sleep? We have a written request here which we have both signed and our next door neighbours have witnessed it." Would you give the injection?

Note for course tutors: In the UK, the written request has no legal standing. The patient is requesting euthanasia which is illegal. Similarly, assisted suicide (providing the means whereby the patient may kill himself) is also unlawful (at present). In the Netherlands and Belgium however, such a request will probably be granted, provided that a second doctor participates in the decision.

Case 3

You are 50. Your widowed mother is 85 and you are her only child. She is blind. She had a stroke two years ago and is confined to a wheel chair. She is mentally alert and cheerful and well looked after in a local nursing home. She has no financial difficulties. You will inherit a substantial capital sum after her death.

Three days ago she had a major bowel operation for cancer which the doctors say was curative. She has developed complications and is confused. The doctors want to do another operation to repair a leak in her bowel but they are not sure whether or not she will survive the operation. She will certainly die if she does not have the operation. Should she have the operation?

Note for course tutors: this is, of course, a case of whether treatment should be given or withheld. Before that decision can be made we need to know whether the widowed mother is competent (has capacity) to make the decision herself (in which case she should be allowed to do so) or whether she is so confused so that in legal terms she lacks capacity. If the latter, the doctors will make a decision based on what they consider to be the person's best interests (there is a checklist that must be adhered to); that decision may be challenged legally by the relatives. If the son or daughter has taken power of attorney, legally they may make the decision on the patient's behalf, again with the patient's welfare/best interests being the primary concern; the doctors must still be involved in making the decision. However, if the doctors disagree with the decision (for example, if the person with power of attorney goes against strong medical advice), again they may challenge it via the Courts.

Annotated References

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www.cmf.org.uk/index/euthanasia.htm (part of the Ethics section of the Christian Medical Fellowship web site; the organisation is opposed to euthanasia) Last accessed on 02/08/2006

www.dignityindying.org.uk (web site of the former Voluntary Euthanasia Society) Last accessed on 02/08/2006

www.donoharm.org.uk/doctorsfed/index.htm and www.euthanasia.com/belgium.html (web sites of two branches of the World Federation of Doctors who Respect Human Life) Last accessed on 27/07/2006

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Video and other media

BBC News Clinic assists doctor's suicide
news.bbc.co.uk/1/hi/health/4625538.stm Contains a video interview with Dr Anne Turner

Care not Killing DVD. Produced by the *Care-not-Killing Alliance*. Contains interviews with doctors opposed to euthanasia and assisted suicide. Some parts of the DVD may be viewed *via* the Care-not-Killing web site (see above)

Million Dollar Baby. Directed by Clint Eastwood, starring Clint Eastwood, Morgan Freeman and Hilary Swank, this film tells the story of a female boxer Maggie (Swank) who has an accident which results in paralysis from the neck down. Most useful clip as a discussion starter is 3 minutes long, starting 1 hr 45 mins into film where she pleads with her trainer Frankie (Eastwood) to end her life, which he eventually does.

Should Doctors Assist Dying? A TV programme which may be watched online at
http://www.cmf.org.uk/ethics/should_doctors_assist_dying.htm

Wit. Directed by Mike Nichols, starring Emma Thompson and based on Margaret Edson's 1999 Pulitzer Prize-winning play, this film deals poignantly with the issues around treatment of a patient with advanced cancer. The British Universities Film and Video Council hold a recorded copy (TRILT code: 001C1121).

Brian Clarke's 1972 play **Whose life is it anyway?** is hard to come by, but the 1981 American film version (directed by John Badham) is regularly repeated on satellite TV stations.

List of available Bioethics Briefings

The following Bioethics Briefings are freely available at
<http://www.bioscience.heacademy.ac.uk/resources/ethicsbrief.htm>

- Briefing 1: Ethics and Bioethics
- Briefing 2: Genetically Modified Crops
- Briefing 3: Pre-implantation Genetic Diagnosis
- Briefing 4: Xenotransplantation
- Briefing 5: Stem Cells
- Briefing 6: Issues at the End of Life

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