End of Life Ethics

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The good host

David H. Smith uses the following metaphor of a "good host" to help us think about end of life ethics: 1

A couple invite friends to dinner. Food and drink are pleasant; the conversation bubbles. The good host is hospitable and courteous to his guest, no matter what his shifts in mood. But there comes a time when the party 'winds down' – a time to acknowledge that the evening is over. At that point, not easily determined by clock, conversation or basal metabolism, the good host does not press his guest to stay but lets him go. Indeed he may have to signal that it is acceptable to leave. A good host will never be sure of his timing and will never kick out his guest. His jurisdiction over the guest is limited to taking care and permitting departure.

Questions:

- 1. How helpful is the image of the "good host" as a picture of the doctor's role in end of life care?
- 2. What would it look like if a doctor became a bad host who:
 - a. Compelled the guest to stay
 - b. Kicked the guest out
- 3. How can doctors deal with the uncertainty of their timing?

¹ Smith, David H. quoted in Gilbert Meilaender. 1996. *Bioethics: A Primer for Christians* (Carlisle: Paternoster), p.68.

Biblical foundations

It would be impossible in this space to consider every relevant part of Scripture, but I will seek to outline some biblical principles around key issues that impinge on end of life ethics:

The value of human life

The scriptural basis for the value of human life is found in the concept of creation in the image of God (Genesis 1:27). The meaning and significance of this concept is discussed at length in another document of mine entitled What Does it Mean to Be Human?² It serves, however, as the basis for preservation and sanctity of human life when after the Flood God tells Noah:

Whoever sheds the blood of man, by man shall his blood be shed; for in the image of God has God created man. (Genesis 9:6)

This statement comes immediately after God gives permission for human beings to eat animals, and distinguishes the value of human life from animal life. This value is maintained throughout Scripture and there is no exception to the principle on the grounds of age, disability or mental capacity. The result is that murder, the deliberate ending of the life of another individual, is consistently presented as sinful and wrong in both Old and New Testaments (Exodus 20:13; Matthew 5:21-22; 1 Timothy 1:9; Revelation 21:8). Again there is no exception based on a supposed judgement of the value of the individual's life. Every human being deserves equal protection. The only circumstances when it is justifiable for the life of a human being to be taken are when they are found guilty of a capital offence and executed by the State and when they are a combatant in a just war. Both of these exceptions are found clearly in the Old Testament but both are questioned by many Christians for numerous reasons. Neither is relevant to the issues being considered in this paper.

The purpose of human death

Death entered human experience after sin and is the direct result of human sin (Romans 5:12). In one sense, therefore, it is supremely unnatural – it was not God's intended pattern for life. In another sense, however, it is utterly natural, a universal and inevitable occurrence and a transition from one phase of existence into another. God introduced death to human experience in part as a judgement for our sin but primarily because He did not want to allow us to live forever as sinful people, alienated from Him and suffering the results of our sin and the sin of others (this is why God banished Adam and Eve from the Garden, thus preventing them from eating the fruit of the tree of life and living forever - Genesis 3:22). Endless life in the bodies we currently inhabit is impossible because of aging and undesirable because of our own flawed sinful nature. Death is not the end from a biblical perspective – it marks the point of final reckoning when we will give account to God (Hebrews 9:27). As such, it is possible for death to be a longed for event, but it should never be something we seek to bring about (see Paul's tension in Philippians 1:22-24). Furthermore, we realise that there are some situations where death is not the greatest evil. Consider, for example, the martyr who dies for his faith. In Gilbert Meilaender's words, "Forbidding suicide and honouring martyrs, Christians recognized life as a real but not ultimate good – a great good, but not the highest good". Christians should not fear death, although we will naturally be apprehensive, even fearful, about the process of dying. We seek to live for Christ so long as we are alive, but we recognise that death is gain (Philippians 1:21). Death is an enemy, not a friend, but it is a defeated enemy because of Christ's resurrection from the dead (1 Corinthians 15:25-26). The confidence that through faith in Him we too will be raised when Christ returns (1 Thessalonians 4:13-18) gives us the boldness to ask "Where, O death, is your victory? Where, O death, is your sting?" (1 Corinthians 15:55).

The Bible mentions two cases which may be thought of as instances of voluntary euthanasia. The first involves Abimelech's armour bearer, who killed him at his request when he was fatally wounded to prevent him being killed by a woman (Judges 9:52-55). The text does not indicate any judgement about whether or not this action as acceptable – it simply recounts what happened. The second was when King Saul was allegedly (because the story appears to be different from the account of Saul's death in 1 Samuel 31) killed by an Amalekite at his own request when dying from his wounds on the battle field (2 Samuel 1:6-9). In this case King David actually ordered the Amalekite's execution for his action! Although the action was taken particularly seriously by David because Saul was the anointed king, it is clear that David accounts the Amalekite as being morally responsible for Saul's death. The fact that Saul would have died in any case is irrelevant.

² Coulter, Paul. 2011. What Does it Mean to Be Human? Available: http://www.bethinking.org/who-am-i/advanced/what-does-it-mean-to-be-human-contents.htm (accessed 7 March 2012)

³ Meilaender, Gilbert. 1996. Bioethics: A Primer for Christians (Carlisle: Paternoster), p.70.

The limits of human autonomy

The Bible presents the individual as a person capable of rational choices with real consequences. Biblically, human beings have real freedom to make decisions within the range of possible options, although they are responsible to make these within the limits of morality (right and wrong) as defined by the will and character of God and with the exercise of godly wisdom, which is based on a reverential fear of God. Although we may be able (free in this sense) to act in ways that are unwise or morally wrong, we are ultimately accountable to God for our decisions and actions (1 Peter 4:5). We are not the ultimate masters of our own destiny. Specifically in the context of death, we do not have moral freedom to judge when is the appropriate moment for an individual to die, either ourselves or another. To intentionally end the life of another individual, even if motivated by compassion, would be to transgress our freedom into the realm of God's sovereign decision. Likewise, to end our own life intentionally (suicide) is morally unacceptable. This assumes, of course, that the action to end one's own life is taken by a person of sound mind, free from pressure and without mental illness (e.g. depression).

It must be said clearly in this context that the idea, common in some Christian traditions, that suicide is an unpardonable sin is not scriptural. Although suicide is sin, all sins can be forgiven on the basis of repentance and faith in Christ. This includes sins committed after we have trusted in Him and after which there is no possibility of repentance. To think of suicide as a 'mortal sin' is to introduce an unbiblical classification of different sins and to deny the efficacy of Christ's death for our sins to fully atone for sin.

The potential of human suffering

The Bible has much to say about human suffering and we could write a whole series of papers on this subject alone. The biblical perspective is that suffering is bad, it is an evil which results directly or indirectly from human sin. It is bad because it was not part of God's original creative intent. Scripture does, however, introduce a very important principle of the potential of suffering to lead to growth of human character. In other words, God can redeem even the evil experiences of our lives - He can, and will, work all things together for good for those who love Him (Romans 8:28). In the Old Testament, from the book of Job, we realise that human suffering can have cosmic significance as God vindicates Himself and demonstrates His power and His faithfulness through it. In the cross of Christ we realise that it is through entering into our suffering, rather than staying distant from it, that God transforms the world and redeems us, making possible a future without suffering. Christ chose to suffer in our place, bearing God's wrath against our sin, so that we could be forgiven and set free from sin. As Christians we realise that although suffering is not to be sought, we can learn to trust God in new ways and can develop character through suffering (Romans 5:3). We look forward to God's ultimate new creation when there will be no more suffering (Revelation 21:4). Our goal in this life, then, is to be faithful to God and to face every circumstance with a desire to learn from Him, honour Him, grow to be more like Him and bear testimony to Him. We will not be driven by an overarching aim of minimising suffering but of maximising Christ-likeness. We seek first not our own comfort but His Kingdom.

The duty of holistic medical care

Christian doctors seek to care for patients in ways that ultimately honour God. We recognise that to fail to do the good we ought to do is sinful in the same way as actively doing what we know to be wrong (James 4:17). This motivates us to care for our patients positively. We recognise that our ability to care is a gift from God and that every means at our disposal is a gift from Him, either directly or indirectly through the use of human intelligence and design. We practice medicine for various reasons, but we seek to prioritise these reasons and our values in ways that may not be shared with the wider medical profession. Of all the good goals that we may seek – to maximise care, minimise suffering, maximise longevity, minimise mortality – our over-riding principle is to be faithful to God. Our ultimate desire for our patients is, likewise, that they may come to know Him and to have the real life that only He can give. We seek most to help them grow as people to be healthier in every sense of the word and only secondly to free them from suffering or prolong their life. We understand that true health is more than physical – it is emotional, social and, not least, spiritual. The implications of all that we have said about biblical foundations for thinking about life and death are drawn out by Gilbert Meilaender:

On the one hand, we ought not to choose death or aim at death. But on the other hand, neither should we act as if continued life is the only, or even the highest, good. It is not a god, but a gift of God. Thus we should neither aim at death nor continue the struggle against it when its time has come. 'Allowing to die' is permitted; killing is not. Within these limits lies the sphere of our freedom.

⁴ Meilaender, Gilbert. 1996. *Bioethics: A Primer for Christians* (Carlisle: Paternoster), p.69.

Case studies

Double Trouble 5

'Doctor, you've got to help me. I'm in terrible pain and I know I'm dying. Put me out of my misery. Kill me swiftly and painlessly now. I can't go on any longer.'

'Let me get this straight,' replied Dr Hyde. 'Are you suggesting that I should, say, give you a very high dose of painkillers – 20mg of morphine sulphate perhaps – a dose so high that you would soon lose consciousness and shortly afterwards die?'

'Yes! Please be merciful,' said the patient.

'I'm afraid that's something I can't do,' replied Dr Hyde. 'However, I can see that you are in pain, so here's something I can do. In order to relieve your pain, I would need to give you a very high dose of painkillers, say 20mg of morphine sulphate, a dose so high, however, that you would soon lose consciousness and shortly afterwards die. How does that sound?'

'Just like your first suggestion,' replied the puzzled patient.

'Oh, but there's every difference in the world!' replied the doctor. 'My first suggestion was that I killed you, the second that I relieved your pain. I'm no murderer and euthanasia is illegal in our country.'

'But either way I'm out of my misery,' protested the patient.

'Yes,' said the doctor. 'But only one way spares mine.'

Questions:

- 1. Do you accept the argument that Dr Hyde's two suggestions are different and that his conscience can be clear in proposing the second alternative?
- 2. Would the situation be different if the patient was not asking for 'mercy killing'?
- 3. What else would you like to know about the patient's condition and treatment?

Life Support ⁶

Dr Grey was depressed. One of his terminally ill patients was being kept on a life-support machine. Before she lost consciousness for the last time, she had repeatedly asked that the machine be switched off. But the hospital ethics committee had ruled that it would be wrong to take any action intended to shorten the life of a patient.

Grey disagreed with the committee and was disturbed that the wishes of the patient had been ignored. He also though that holding off death with the machine was merely prolonging the agony of her friends and relations.

Grey stood looking mournfully at his patient. But then something odd happened. A hospital cleaner caught the power cable that led to the life-support machine and pulled it out from the socket. The machine emitted some warning bleeps. The cleaner, disturbed by the sound, looked at the nearby doctor for guidance.

'Don't worry,' said Grey, without hesitation. 'Just carry on. It's all right.'

And indeed for Grey it was now all right. For no one had taken any deliberate action to shorten the life of the patient. All he was doing by leaving the accidentally unplugged machine turned off was not taking any action to prolong it. He now had the result he desired without breaking the instructions of the ethics committee.

Questions:

- 1. Do you agree with the hospital ethics committee's decision in this case? Why or why not?
- 2. What do you think about Dr Grey's reasons for disagreeing with the committee?
- 3. Was Dr Grey correct to do nothing about the unplugged machine?

⁵ Reproduced from Baggini, Julian. 2005. *The Pig That Wants to be Eaten: and Ninety-Nine Other Thought Experiments* (London: Granta), p.157.

⁶ Reproduced from Baggini, Julian. 2005. *The Pig That Wants to be Eaten: and Ninety-Nine Other Thought Experiments* (London: Granta), p.211.

GMC guidance for end of life care

In 2010 the GMC issued guidance for doctors in treating patients at the end of life (defined as patients who are likely to die in the next 12 months) under the title *Treatment and Care Towards the End of Life: Good Practice in Decision Making*. This document acknowledges that (paragraph 1):

Providing treatment and care towards the end of life will often involve decisions that are clinically complex and emotionally distressing; and some decisions may involve ethical dilemmas and uncertainties about the law that further complicate the decision-making process.

It is intended to help doctors make good decisions in this context. The Guidance recognises that (paragraph 3):

The most challenging decisions in this area are generally about withdrawing or not starting a treatment when it has the potential to prolong the patient's life. This may involve treatments such as antibiotics for lifethreatening infection, cardiopulmonary resuscitation (CPR), renal dialysis, 'artificial' nutrition and hydration (for the purpose of this guidance 'artificial' is replaced by 'clinically assisted') and mechanical ventilation. The evidence of the benefits, burdens and risks of these treatments is not always clear cut, and there may be uncertainty about the clinical effect of a treatment on an individual patient, or about the particular benefits, burdens and risks for that patient. In some circumstances these treatments may only prolong the dying process or cause the patient unnecessary distress.

The Guidance recognises three underpinning principles:

- **1. Equalities and human rights** (paragraphs 7-9) all patients, irrespective of age, disability, ethnicity and expected duration of life, deserve equal quality of care and must be treated with dignity, compassion and respect.
- 2. Presumption in favour of prolonging life (paragraph 10) decisions concerning treatment that may prolong life must not be motivated by a desire to cause the patient's death but must start with the presumption of prolonging life. "However, there is no absolute obligation to prolong life irrespective of the consequences for the patient, and irrespective of the patient's views, if they are known or can be found out.
- **3. Presumption of capacity** (paragraph 11) it must be assumed that every adult, irrespective of age, disability, behaviour, medical condition, beliefs or ability to communicate, has capacity to make decisions about their own care. This includes patients who make a decision that others disagree with or consider unwise. This includes a duty to maximise a patient's capacity to decide. Where patients lack capacity the doctor has a duty to make decisions in consultation with those who are close to the patient to treat in a way that maximises overall benefit to the patient and causes least restriction to the patient's future ability to make choices.

Although not stated in these terms, these principles reflect three underlying values that should be considered carefully by Christians, namely the belief in equal rights (which is entirely consistent with the scriptural view that all people are created in God's image), the preference for prolongation of life (which is a core medical value but is not indisputable), and the centrality of autonomy (which Christians should respect but about the limits of which we may have concerns, especially if it becomes a basis for arguments in favour of assisted suicide or voluntary euthanasia).

The Guidance proceed to outline specific pathways for decision making the case of patients who have capacity to decide and those who do not as well as addressing related issues about decision making in specific contexts. It also highlights the importance of advance care planning and provided advice about how doctors should proceed with it. Another significant point in the Guidance relates to the withholding of information from the patient:

Apart from circumstances in which a patient refuses information, you should not withhold information necessary for making decisions (including when asked by someone close to the patient), unless you believe that giving it would cause the patient serious harm. In this context 'serious harm' means more than that the patient might become upset or decide to refuse treatment. If you withhold information from the patient, you must record your reasons for doing so in the medical records, and be prepared to explain and justify your decision. You should regularly review your decision and consider whether you could give information to the patient later, without causing them serious harm. (paragraph 59)

In general it should be evident from the above quotations that doctors still have considerable leeway for decision making in end of life care. They are to presume in favour of prolonging life, but this is not an absolute directive and withdrawal of treatment may be appropriate. They are to presume in favour of giving all information to a patient who wants it, but if this is likely to cause "serious harm" to the patient they may choose to withhold information.

⁷ GMC. 2010. *Treatment and Care Towards the End of Life: Good Practice in Decision Making*. Available: http://www.gmc-uk.org/static/documents/content/End of life.pdf (accessed 1 March 2012)

Advance care planning

In recent years there has been an increased interest among patients in the possibilities of planning aspects of their care in advance. Their desire is to ensure that, should they lose the mental capacity to make decisions regarding their own care, their wishes will still be respected. Advance planning may include:

- Designating an individual to act as an attorney, empowered to make decisions on the patient's behalf.
- Detailing aspects of care the patient would not wish to receive under certain circumstances.
- Detailing aspects of care the patient would wish to continue to receive.

Various terms are used to describe the expressed wishes of patients. Advance decisions (previously known as advance directives) relating to the refusal of treatment have a basis in law (see below). Advance care plans are broader and may include preferences regarding treatment.

Jim Paul identifies three trends in society that have led to an increased interest in advance care planning: $^{
m 8}$

- 1. **Autonomy** the growing belief in the autonomy of the individual to make decisions about their own life and care. This was a major shift from the past paternalistic approach of the medical profession. Some doctors increasingly feel like gatekeepers to services that the patient has already decided they want to access.
- 2. Loss of trust the democratisation of information and advent of postmodernism has led to a decline in trust for professions previously regarded as authority figures. Although doctors still command greater public confidence than most other professions, they are not immune to this trend. High-profile cases such as Harold Shipman haven't helped either. Similarly, with the rise of litigation, many doctors no longer trust their patients entirely, fearing that they may be sued. A major element in the loss of trust has been the 'depersonalisation' of medical care that has resulted from changes especially within General Practice. Patients often do not have the same relationship with their 'family doctor' that they may have expected in the past and the withdrawal of GPs from out of hours care has meant that patients have no certainty that the person caring for them in emergency situations will know their case.
- **3. Medical progress** advances in medicine have been hugely successful in prolonging life and reducing pain but only moderately successful in preventing debilitation and improving quality of life. It is common now for people to fear an undignified old age more than they fear death. Medicine has still not taken sufficient account of the importance of quality of life and a good death.

The following table, from Patient.co.uk, suggests areas that should be considered when an advance decision is planned:⁹

| Matters to consider when planning an advance directive | | | | | | |
|--|------------------------|------------------------------|-------------------------|-------------------------------|---------------------|--|
| Opinion about the following situations | Would prefer to die | Would probably prefer to die | Uncertain either way | Would probably prefer to live | Eager to stay alive | |
| Permanently paralysed but able to relate to others. | | | | | | |
| Totally dependent on others. Needs to be fed. | | | | | | |
| Aware but unable to communicate. | | | | | | |
| Confused and very poor memory. | | | | | | |
| Constant uncontrolled pain. | | | | | | |
| Brain damage. In coma. If regained consciousness, markedly impaired. | | | | | | |
| Terminal illness, not necessarily cancer. | | | | | | |

⁸ Paul, Jim. 2002. *Advance Directives*, CMF File 19. Available:

http://www.cmf.org.uk/publications/content.asp?context=article&id=155 (accessed 1 March 2012)

⁹ Table available at: http://www.patient.co.uk/doctor/Advance-Directives-(Living-Wills).htm (accessed 1 March 2012)

Legal situation in the UK

The Mental Capacity Act 2005 ¹⁰ came into force in England and Wales in October 2007. It clarifies the procedure for determining whether an individual has mental capacity to make decisions surrounding their own medical treatment and allows individuals who currently have capacity to make two decisions regarding their future care should they lose capacity:

- a) To appoint an individual with **Lasting Power of Attorney**, who will be able to make decisions on their behalf in their best interests.
- b) To produce a legally binding **advance decision** to refuse aspects medical care in the event of future loss of mental capacity. If the refusal relates to life-sustaining treatment then the decision must be written, signed and witnessed.

It should be noted that the legal provision is for advance decisions to refuse treatment, not to demand certain forms of treatment. It remains the prerogative of the medical practitioner to determine what treatment is appropriate for a patient. The Mental Capacity Act 2005 has not been extended to Scotland or Northern Ireland and advance decisions in those jurisdictions are decided under common law. In practice, it is unlikely that any court in Northern Ireland or Scotland would rule against the implementation of an advance decision.

Ethical considerations

In general, the Christian view that we are called to be responsible stewards of our lives and bodies and the belief that death is not final mean that Christians should be prepared to think carefully about the end of their lives. It might be helpful to think of some scenarios:

- When a person knows and trusts their doctor, advance care plans will be worked out with that doctor and legally binding advance decisions may be unnecessary. If out-of-hours care was fully integrated with GP records then the patient could be certain of a consistent approach. In practice, however, there can be no confidence for most patients of this being the case.
- When a person trusts their closest relatives or friends, the appointment of an attorney would seem to be a better option than an advance decision. It may be impossible to cover all eventualities in an advance decision and this option allows for an individual with capacity to make decisions according to their knowledge of and love for the patient. In practice, however, this kind of relationship is not always present and the emotional burden placed on the attorney of having to make decisions for their loved one should also be considered.
- Advance decisions may present the best option for some patients, especially if they have no close person who is willing, able and trusted to act as an attorney.

There are, however, two major issues that some ethicists raise with advance directives:

- a) They assume that the person's view will not change as their circumstances change

 The reality of human nature is that people change their minds. How we feel about a situation in the 'cold light of day' when it is far removed from us may be very different from the way we feel in the 'heat of the moment'.

 Our other circumstances can change as well. For example, we may decide to seek withdrawal of treatment but when the decision must be made we may feel differently, perhaps because of a relationship that has been damaged in the interim and which we would now like time to restore.
- b) They assume that the 'present self' has capacity to make decisions for the 'future self'

 There is a serious ethical debate about the relationship of our self in the present with our self in the future.

 Although these 'selves' represent the same individual at two points on the timeline of one life, this is not equivalent to saying that they are the same person. If I am not the same person now as I will be in the future, what right do I have to make decisions about the treatment of my 'future self'?

In balance, then, advance decisions may be necessary and helpful (there would appear to be no biblical reason to oppose them in principle) but they may not be the best option. In an ideal situation where a patient knows and trusts their doctor(s) and has a loving supportive family, detailed advance decisions should be unnecessary.

http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Publicationsandstatistics/Bulletins/theweek/Chiefexecutivebulletin/DH 4108436/ (accessed 1 March 2012).

¹⁰ The Mental Capacity Act 2005 is available online at: http://www.legislation.gov.uk/ukpga/2005/9 (accessed 1 March 2012). A summary is available at:

Euthanasia and assisted suicide

Defining the terms

Euthanasia

Means literally 'good death' (from the Greek *eu* [well or good] + *thanatos*] death]). It was used in the ancient Roman world simply to describe a peaceful death free from pain and distress. It later came to be used in a medical context (originally by Francis Bacon in the 17th Century) to refer to the doctor's duty to ensure a peaceful, pain-free death for the patient (similar to our modern concept of palliative care). In modern times, the word has come to mean more specifically, "the painless killing of a patient suffering from an incurable and painful disease or in an irreversible coma" (New Oxford Dictionary of English).

Euthanasia must, therefore, entail four elements:

- Two people one person (an *agent*) who causes the death of another person (the *subject*)
 An action something must be done by the agent that causes the death of the subject
- **3. Intentionality** the intention of the agent's action must be to cause the death of the subject
- **4. An outcome** the subject must die as a result of the agent's action

It may be added that the action taken must be intended to cause death without (or with minimal) pain or discomfort to the subject.

Euthanasia can be further classified depending on two further criteria:

- Active or passive Is death caused by an active intervention by the agent, for example administration of a lethal drug (active euthanasia), or by the passive the withdrawal of treatments that may have prolonged life such as antibiotics or hydration and nutrition (passive euthanasia)?
- Consent Has the consent of the subject been obtained? This question allows for three answers:
 - o Voluntary euthanasia when the subject has explicitly consented
 - Non-voluntary euthanasia when the subject is unable to give consent (they lack capacity to consent)
 - o Involuntary euthanasia when the action is taken against the will of the subject

There is considerable debate amongst ethicists as to whether or not the term euthanasia should be restricted for only some of these sub-categories. Some argue that it is only euthanasia when consent has been given (to distinguish between euthanasia and murder) or when it is active. So-called 'passive euthanasia' will be considered in the section on 'Withdrawal of Treatment'.

Assisted suicide

When an individual voluntarily ends his/her own life but another individual has been involved in providing him/her with some of the means necessary to do so. Although most countries have decriminalised suicide, it remains common for assisting someone to cause their own death to be a criminal offence.

Legal situation in the UK

Voluntary euthanasia is legal in Belgium, Luxembourg and the Netherlands, with assisted suicide also being covered by the legislation in Luxembourg and the Netherlands. Switzerland, although not officially legalising assisted suicide, does not prosecute in cases where the individual took the final action to end their life themselves (e.g. ingesting medicine or pushing a button to cause a lethal injection). Between July 1996 and March 1997 euthanasia and assisted suicide were legalised in the Northern Territory of Australia. In the USA, the states of Montana, Oregon and Washington have legalised assisted suicide.

Euthanasia and assisted suicide are illegal in the UK. There have been a number of attempts to introduce assisted suicide in the UK, including four led by Lord Joffe in the House of Lords. His most recent attempt, the *Assisted Dying* for the Terminally III Bill, was rejected by the House of Lords on 12th May 2006 by 148 to 100.

Although assisted suicide remains illegal in the UK, the position taken by prosecutors has been to decide on a case by case basis whether or not to bring a case to court. The Crown Prosecution Service for England and Wales published guidelines for prosecutors to enable them to decide whether or not to prosecute in cases of assisted

suicide.¹¹ The guidelines first require the prosecutor to be satisfied that there is sufficient evidence that assisted suicide has occurred but then secondly to decide whether prosecution would be in the "public interest". This second test depends on a number of factors including the age of the victim, proof of the victim's settled decision, absence of pressure, evidence that assistance was necessary for the person to end their life in this way, the history of the relationship between the victim and the person giving assistance and evidence that the only motivating factor in the assistance given was compassion.

Ethical considerations

Based on what we have said earlier about the biblical view of human life and death, euthanasia and assisted suicide cannot be morally acceptable. Of course, other arguments are proposed by those who are in favour of voluntary euthanasia, but for a Christian the principle of the sanctity of human life must prevail over these. The two main arguments for euthanasia are based on either:

- a) Respect for human autonomy but as we have seen, human autonomy is not unlimited. Christians realise that we are accountable to God and must act morally. Even if we thought of autonomy as an absolute right, we must still recognise that assisted suicide and euthanasia are not simply actions within one individual's free autonomous decision they involve another person who assists or causes the person's death. That person is morally accountable for their actions.
- **b)** Compassion for human suffering but as we have seen, suffering is not the greatest evil. In fact, the proper response to suffering is increased care. Often arguments for euthanasia arise out of cases where care has been suboptimal.

One problem with both of these lines of argument is that they raise important questions about the extent of euthanasia. If human autonomy is given ultimate value, what of people who lack capacity to make autonomous choices (e.g. advanced dementia or severe learning disability)? Would non-voluntary euthanasia be acceptable since these individuals lack such a core element of 'personhood'? The Christian would say 'no', because we regard these individuals as persons on a par with all others. Similarly, does the argument from the desire to reduce suffering not lead inevitably to the view that the suffering of those who do not request euthanasia should also be ended, whether non-voluntarily?

There are other practical problems with the concept of voluntary euthanasia including the following:

1. Palliative Care provides an alternative

Having worked in the medical specialty of palliative care, I can vouch that there is a huge amount of support for terminally ill patients. This speciality, which originated with the Christian hospice movement, is based on a holistic understanding of health and life and has made huge advances in helping terminally ill and dying patients prepare for a good death in a context of compassionate care. It is possible in the vast majority of cases to achieve a peaceful death, at times including terminal sedation, in which the patient is sedated with medication at the end of life. This is neither illegal, nor unethical. In cases where patients are adequately cared for requests for voluntary euthanasia are actually very rare.

2. The 'choice' made by patients is seldom 'free'

many patients who are terminally ill are depressed, fearful and anxious about the "burden" they present to others they care for. In these circumstances it is not surprising that some people in this situation express a desire to die or feel that things would be better if they were already dead. However, to consider giving in to these requests is often to ignore the real issue of their mental state and their need for affirmation of their value. In fact, the last stages of life are often an extremely valuable time for patients and their families in terms of healing rifts and

3. It gives too much power to doctors

It is a dangerous thing when professionals have too much power. Doctors are in a position of power with respect to patients who are terminally ill, and it is easy for them to influence patients in favour of a decision. Legislation for voluntary euthanasia can be exploited to bring in non-voluntary euthanasia, as has already happened in the Netherlands (in 1991 of over 3000 euthanasia deaths over 1000 were confidentially revealed by doctors to have been non-voluntary). The results of a minority of doctors with lax ethical standards who

¹¹ Director of Public Prosecutions. 2010. 'Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide'. Available: http://www.cps.gov.uk/publications/prosecution/assisted suicide policy.html (accessed 7 Mar 2012)

were given freedom by the government was seen in Nazi Germany where the non-voluntary euthanasia of people with mental handicaps was practised.

The principle of double effect

There are situations in which dying patients (i.e. those who are in the last hours of life, rather than those who have a terminal condition) are in pain or discomfort. In such cases it may be appropriate to administer doses of pain relief (or other medications) that have the potential to hasten the patient's death. The vital distinction to be made in this situation is between consequence and intention. The doctor's intention in administering the drug is to relieve pain. Death is a possible, perhaps even likely or foreseeable, consequence of the action. In such cases the ethical principle (or doctrine) of double effect is often brought to bear. This principle maintains that an action that is not in itself morally wrong may be morally acceptable even in situation when it could have a morally undesirable outcome if it is undertaken with a morally good intention. In the case of pain relief in the last hours of life, the administration of the drug is not morally wrong and the intention is morally good (to relieve pain), so this action may be morally acceptable even if death may be hastened by it. A few additional comments are in order, however:

- It is often impossible to tell whether death was or was not hastened by the administration of drugs.
- In practice pain relief in well managed palliative situations is generally gradually increased through a syringe driver or other continuous methods of administration (often together with other drugs intended to reduce nausea, decrease respiratory secretions or cause some sedation if the patient is anxious) rather than in large individual boluses.
- The principle of double effect cannot be applied to situations where death is not expected to be imminent.
- The doctor must be clear in his or her own mind that the intention in this case is to relieve suffering rather than to cause death. Use of drugs that could only cause death (e.g. potassium chloride) or inordinately large doses of painkillers could not be justified.

Withdrawal of treatment

Doctors may be faced with decisions to withdraw treatment which may prolong life either at the request of the patient or because of their own clinical judgement. Although some people describe this process of allowing patients to die as 'passive euthanasia', it is more helpful to speak of 'withdrawal of treatment' since this makes a clear distinction between the decision to actively do something to cause death and the decision to allow 'nature to take its course'. We have already concluded that the Christian position must be that it is unacceptable to actively take life, even if the motivation is compassion. It is important to realise that decisions to withdraw or withhold (by the doctor) or to refuse (by the patient) treatment are also active decisions (even though the result of the decision is to passively allow death to occur) and must, therefore, be considered carefully. Christian doctors and patients should recognise that withdrawal of treatment is a valid approach in some circumstances, given our understanding that death is not the end of the story and that life is not to be prolonged at all costs. The complications arise because Christian doctors are also aware that to fail to do good to another person when we are able to do so is sinful (James 4:17). Christian patients will also seek to honour God in their decisions about refusing to receive treatment. The challenge is to be able to decide when a treatment is genuinely 'good' for the individual. Our concern here is not with situations where doctors are unable to offer a treatment to the individual, perhaps because of supply shortages, limited financial resources or the simple fact of being unable in emergency situations to treat two patients who both require treatment simultaneously (in such cases triage is necessary to decide priorities). Rather, our focus is on treatments that are available and could be given to a specific patient.

Christian ethicist Gilbert Meilaender expresses the Christian perspective on life and death and its implications for decisions to withdraw treatment helpfully: 12

Life is not our god, but a gift of God; death is a great evil, but not the ultimate evil. There may come a time, then, when it is proper to acknowledge death and cease to oppose it. Our aim in such circumstances is to care for the dying person as best we can – which now, we judge, means withdrawing rather than imposing treatment.

What criteria can we use to decide when a treatment can legitimately be withdrawn by the doctor or refused by the patient? Meilaender suggests two criteria – when the treatment is either:

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¹² Meilaender, Gilbert. 1996. *Bioethics: A Primer for Christians* (Carlisle: Paternoster), p.71.

- a) Useless it no longer provides any discernible benefit to the patient. This may apply to all forms of treatment in the last hours of life or to various treatments at an earlier stage. It cannot apply to treatments that have a realistic potential to save life. In these cases the doctor should not withhold the possibility of treatment although the patient may still decide to refuse it.
- b) Excessively burdensome the treatment itself makes the patient's life more burdensome compared with the alternative of receiving no treatment. This may lead to a cancer patient refusing a course of chemotherapy where cure is not a hoped for outcome or to the withdrawal of some treatments to patients with advanced dementia where they are unable to understand the treatment's purpose and it may be distressing for them.

Meilaender describes the implications of these two criteria as follows: 13

Treatment may be refused or withdrawn when it is either useless or excessively burdensome. In either of those instances, refusal of treatment is not the forbidden suicide or euthanasia. [...] If we can honestly describe a possible treatment as either useless or excessively burdensome, then in rejecting that treatment we can still choose life. But if the treatment itself carries no excessive burden (even though, of course, the patient's life itself may be burdensome), and if the treatment will benefit the life the patient has (even though, given alternatives, we would not desire that life), we ought to choose life both for ourselves and for others.

Implicit in this statement is a distinction between making judgements about the value of a patient's life and the likely effect on their life of a planned treatment. To withdraw treatment because we deem a patient's life not to be worth living is ethically unacceptable. In that case we would have made ourselves the judge of life's value and have decided against life. To withdraw treatment because it would add to the burden of a person's life to an unacceptable degree is, however, to respect the individual and to exercise compassionate care. It is choosing for life, because it respects the dignity of life.

Permanent vegetative state

One specific situation in which withdrawal of treatment has made high-profile headlines is in the case of patients with 'permanent vegetative state' (PVS), which is defined as: 14

a clinical condition of unawareness of self and environment in which the patient breathes spontaneously, has a stable circulation, and shows cycles of eye closure and opening which may simulate sleep and waking.

This is different from brain death, which means that the brainstem has been damaged and the patient is no longer capable of spontaneous breathing. Legally, a brain dead patient is dead but a patient in a permanent vegetative state is very much alive.

Cases of PVS have proven controversial in cases where either the patient's family or the medical team caring for the patient have sought to withdraw nutrition and so to end the patient's life. The most widely publicised case of this nature in the UK was the case of Tony Bland, who was injured in the Hillsborough football disaster of 1989. He suffered extensive brain damage and was maintained alive in a persistent vegetative state. After a lengthy legal procedure, the House of Lords, as the highest court in the land, concluded that he should be allowed to die. His tube-feeding was withdrawn after this decision and he died in 1993.

There are a number of problems with withdrawal of nutrition in cases of PVS:

- There is considerable dispute over the diagnostic criteria for PVS. Firstly, there is dispute over how unawareness can be confirmed. Secondly, there is a question over when a vegetative state should be regarded as irreversible. Generally, 12 months is currently regarded as the point beyond which recovery becomes highly unlikely, but there have been cases of recovery after this length of time. In some cases, for example where there is anoxic brain damage, 6 months may be a more appropriate time scale. The position as regards diagnosis of PVS is well documented in a BMJ article by Derek Wade and Claire Johnston. 15
- There is some dispute over whether or not nutrition should be regarded as 'medical care' or as a basic human right. In the case of PVS patients, the patient is unable to feed themselves or even to receive feeding without medical intervention (either a PEG tube or a naso-gastric tube). Their digestive system is, however, fully functional. Some people may argue that the use of a tube to feed is no different from the use of cutlery by able

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¹³ Meilaender, Gilbert. 1996. *Bioethics: A Primer for Christians* (Carlisle: Paternoster), p.75.

¹⁴ http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1116668/?tool=pmcentrez

¹⁵ Wade, Derick T., and Claire Johnston. 1999. 'The permanent vegetative state: practical guidance on diagnosis and management' BMJ, 319(7213): 841–844. Available: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1116668/?tool=pmcentrez (accessed 7 March 2012)

bodied people to assist with feeding. Others may argue that babies are also dependent upon help with nutrition but we would not sanction its withdrawal (to do so and cause the baby's death would be a serious criminal offence). In reality, the tube will be in place long before the diagnosis of PVS can be made – since it requires a period of months to elapse. To withdraw nutrition before this time would certainly be ethically unacceptable, since recovery is possible. The issue then is not whether to initiate artificial nutrition but whether to withdraw it.

• PVS is not a terminal condition. It is possible for a person in PVS to remain alive with nutrition indefinitely and some other condition would need to intervene (perhaps an infection or organ failure) to cause death. The decision to withdraw nutrition is not, therefore, in the same ethical category as decisions to withdraw treatment in dying patients. Decisions to begin new treatments (e.g. antibiotics for an infection or intravenous hydration should the digestive system fail) are, however, in a different ethical category.

Taking these points into consideration, I believe that the Christian doctor should seek to continue to provide nutrition for patients in PVS. There is a possibility of recovery, but even if this should never happen the patient is a person who deserves care and support. To deny them this is ethically no different from denying it to a conscious living person.

In England and Wales all cases when permission is sought to withdraw nutrition from a patient with PVS must currently be referred to the High Court.

And finally ...

I cannot write on these issues of end of life ethics without thinking about my own mortality, and perhaps you have been doing the same as you read. I want to leave you with a challenge to realise that a good death depends on having lived a good life. The apostle Paul, contemplating his death (departure) wrote these words:

For I am already being poured out like a drink offering, and the time has come for my departure. I have fought the good fight, I have finished the race, I have kept the faith. Now there is in store for me the crown of righteousness, which the Lord, the righteous Judge, will award to me on that day—and not only to me, but also to all who have longed for his appearing. (2 Timothy 4:6-8)

Could I say the same if I were approaching my death? Could you? I want to be able to speak in similar terms and my prayer for you is that you may be able to as well. Paul's confidence was not based on his own goodness or achievements but on the fact that according to "the faith" (the message about Jesus) that he believed in and shared with others, Jesus had died for his sins and had risen from the dead, defeating death and making his salvation possible. Paul was a man who placed his faith solely in Jesus to save him. Is your faith in Jesus too? Perhaps it is, and you are one of those people who longs for His appearing (the time when Jesus returns). The challenge then is to ask whether you are running the race faithfully, fighting the spiritual battle that God calls us to engage in. God has called you not simply to wait for Jesus to return but to live for Him in this world. Paul was a great example of someone who dedicated his life to the cause of Jesus Christ. I am deeply challenged by his words to do the same and urge you to do likewise. It is never too late to get right with God!

ABOUT THE AUTHOR

Paul Coulter was born and raised in Northern Ireland where he continues to live and work. He is married to Gar-Ling and they have two young children. Paul studied medical genetics (BSc with first class honours in 1997) and medicine (MB, BCh, BAO with distinction in 2000) at Queen's University, Belfast. He subsequently worked in NHS hospitals and then in the Northern Ireland Hospice before leaving his medical career to engage in pastoral ministry. He also holds an MA in theology, which he obtained with distinction in 2007. He is currently engaged in part time



doctoral studies in theology, teaches at Belfast Bible College, serves as a Lay Magistrate in Belfast, acts as a non-executive director of the Patient and Client Council for Health and Social Care in Northern Ireland, and engages in an itinerant Christian ministry as a Bible teacher, podcaster, trainer, seminar speaker, apologist and evangelist. You can contact Paul or access other materials by him through his website: www.paulcoulter.net.