

Introduction

Decisions about medical treatment that have consequences for the timing and nature of a person's death engender strong emotions in both health professionals and the public and raise difficult ethical issues for all concerned. They can often be a source of conflict between health professionals and patients' families, or between health professionals within a health care team. Ethical dilemmas arise when there is a perceived conflicting duty to the patient, such as a conflict between a duty to preserve life and a duty to act in a patient's best interests, or when an ethical principle such as respect for autonomy conflicts with a duty not to harm. Decisions at the end of life are among the most frequently discussed issues in a clinical ethics committee, in the context of both individual cases and in determining Trust policy. In this section we provide a brief overview of the ethical and legal approaches to end of life decisions and then look at some specific issues that may be brought to committees by clinicians. We illustrate these with some hypothetical cases. The section concludes with some suggested further reading on the issues.

This section does not provide a comprehensive overview of the issues around end of life decisions, and does not make recommendations about what an ethics committee should do. It highlights issues that a committee may wish to consider and provides some ethical and legal frameworks for approaching the subject.

Ethical considerations

A number of ethical theories and principles are relevant when considering treatment decisions at the end of life.

Sanctity of Life Doctrine

The argument underpinning this doctrine is that all human life has worth and therefore it is wrong to take steps to end a person's life, directly or indirectly, no matter what the quality of that life. This is in keeping with both traditional codes of medical ethics and a general perception of what doctors and other health professionals should do, that is save and preserve life. One challenge to this principle in the context of health care is to ask should life be preserved at all costs. Is there no place for consideration of quality of life? One of the problems with considering quality of life is the question of how this is defined and by whom. An objective view of someone's life may be very different to the view of the person who is living that life. However, this problem does not remove the challenge to the sanctity of life doctrine. There may be some circumstances where a person's quality of life, however defined, is so poor that it should not be maintained even if it is possible to do so. Some ethical arguments have been developed to address this challenge.

Acts /omissions distinction

This distinction argues that there is a difference between actively killing someone and refraining from an action that may save or preserve that person's life. Thus it is morally wrong to push someone into a river to their death but we may not have a moral duty to leap into the river to save someone who is drowning. In a medical context this distinction would mean that a doctor could not give a patient a lethal injection to end his/her life, whatever the circumstances, but could, withhold treatment that may sustain it. Withholding treatment would only be permissible if the patient's quality of life was so poor, and the burden of treatment so great, that it would not be in the patient's best interests to continue treatment. For example, it might be permissible not to ventilate a patient if he/she was in chronic respiratory failure, or not to use tube feeding if he/she was in a permanent vegetative state.

Doctrine of Double Effect

The doctrine of double effect argues that there is a moral distinction between acting with the intention to bring about a person's death and performing an act where death is a foreseen but unintended consequence.

The doctrine of double effect allows that performing an act that brings about a good consequence may be morally right even though the good consequence can only be achieved at the risk of a harmful side effect. Prescribing pain relieving drugs which in large doses shorten the life of a terminally ill patient is often used as an example of double effect. The intention is to relieve pain and the foreseen but unintended consequence is that the patient's life will be shortened. Current practice in palliative medicine and the range of drugs available may reduce the appropriateness of this doctrine.

Respect for autonomy

The principle for respect for autonomy acknowledges the right of a patient to have control over his or her own life, including decisions about how his/her life should end. Thus a competent person should be able to refuse life saving treatment in both current situations and future foreseeable situations. Should respect for autonomy mean that a person can request assistance in ending his/her life? Some would argue that this is the case but as assisted suicide is currently illegal in the UK this is not an issue that a clinical ethics committee should need to consider. Does respect for autonomy mean that a patient can request treatment that the clinician does not think is in his/her best interests, or treatment that is futile? In these situations the principle of respect for autonomy comes into conflict with other ethical considerations, such as preventing or avoiding harm, or distributive justice.

A duty to act in the patient's best interest (Beneficence)

The duty of beneficence, that is to act in a way that benefits the patient, is an important ethical principle in health care. In treatment decisions at the end of life the dilemma often revolves around what course of action will be in the patient's best interests. It is difficult to see how death can be a benefit or in the patient's interests, but in some circumstances, if existing quality of life is so poor, or treatment is very burdensome, then the balance of harms and benefits may suggest that continuing treatment is not a benefit to the patient.

A duty not to harm (Nonmaleficence)

The concept of nonmaleficence - an obligation not to inflict harm intentionally, is distinct from that of beneficence - an obligation to help others. In codes of medical practice the principle of nonmaleficence (*primum non nocere*) has been a fundamental tenet. However, in the context of health care it can sometimes be difficult to comply with this principle depending on the definition of harm. Many medical treatments may have harmful side effects but save or improve lives. In end of life decisions the question of how much harm is caused by the treatment needs to be considered, as does the question of whether death itself is always a harm.

Legal considerations

The legal position on end of life issues is clear but the application of the legal principles to actual cases can cause difficulty. The legal principles can be seen to derive from some of the ethical principles discussed in the previous section.

- It is illegal to actively bring about someone's death, either with or without the person's consent. This covers both physician assisted suicide and the situation of giving a lethal injection to an incompetent patient.
- An omission to act that (intentionally) results in the patient's death is permissible where it is not in the patient's interests to continue treatment (*Airedale NHS Trust v Bland* [1993] 1 All ER 821).
- Court approval should be sought in all cases where treatment is proposed to be withheld / withdrawn from a patient in Permanent Vegetative State (*Airedale NHS Trust v Bland* [1993] 1 All ER 821).
- Withholding and withdrawing treatment are both considered omissions to act.
- A competent patient can refuse treatment, including requesting that ongoing treatment is withdrawn, even if that results in the patient's death (*Re B Consent to treatment: Capacity*, 2002). The clinician would not be assisting a suicide. Treatment given in the face of a refusal would amount to battery.

- A competent patient cannot request that a positive act is taken to end his/her life (R (on the Application of Pretty) v DPP [2002] 1 All ER 1). This would amount to assisted suicide. No right of self-determination in relation to death is created by the Human Rights Act 1998.
- Where a clinician owes a duty of care to provide treatment to a patient then failure to do so will be a culpable omission. However the duty to provide life sustaining treatment is not absolute. There are exceptions including when a patient refuses such treatment or when the patient is incompetent and it is not considered in the best interests of the patient to be kept alive, for example, patients in persistent vegetative state or when life involves extreme pain, discomfort or indignity (R (on the application of Burke) and the General Medical Council. [2005]EWCA. Civ 1003).
- If, as a side effect of giving pain - relieving drugs, the life of a terminally ill patient is thereby shortened, this is lawful under the doctrine of double effect (see above) where the intention is to relieve pain.

Bland (*Airedale NHS Trust v Bland* [1993] 1 All ER 821)

Anthony Bland was 21 years old when overcrowding at the Hillsborough football stadium led to him being badly crushed. He was left permanently unconscious, in persistent vegetative state. Three years later the hospital Trust applied to the court for a ruling whether it would be lawful to discontinue artificial hydration and nutrition, resulting inevitably in his death.

The House of Lords considered that:

Artificial nutrition and hydration is regarded as a form of medical treatment.

There is no distinction between an omission to treat a patient (withholding) and discontinuance of treatment once commenced (withdrawing).

In making the decision whether or not to provide medical treatment the question to be asked is whether it is in the best interests of the patient that his life should be prolonged.

Previously stated wishes of the patient should be taken into account in the assessment of best interest.

Pretty (*Pretty v UK* (Application 2346/02) [2002] 2 FLR 45)

Dianne Pretty suffered from motor neurone disease which left her paralysed. She wanted her husband to be able to assist her suicide without fear of prosecution (assisting a suicide is a crime under the Suicide Act 1961) so that she could choose the time of her death and die with dignity. She argued that Article 2 (right to life) of the European Convention on Human Rights protects the right to life and the right to choose the manner of death.

However the House of Lords and the European Court did not find that Article 2 created a right to die and indeed that the need to protect vulnerable citizens justified the prohibition of assisted suicide.

In the past ten years there has been ongoing debate on the issue of physician assisted suicide. The Assisted Dying (terminally ill) Bill [Joffe Bill](#) calling for legalisation of PAS was blocked by the House of Lords in the UK Parliament in 2006. In 2010 a similar Bill ([the End of Life Assistance \(Scotland\) Bill](#)) was submitted to the Scottish Parliament. Also in 2010 the Director of Prosecutions in England published a [policy on prosecution of assisted suicide](#). The policy sets out public interest factors in favour of and against prosecution in such cases.

Professional guidance

Various professional bodies, including the BMA and GMC, have issued guidance on end of life issues.

General Medical Council

The GMC published new guidance [Treatment and care towards the end of life](#) in 2010. The publication followed extensive public consultation and provides advice on a range of issues relating to end of life care including frameworks for decision making for people who have capacity and those who do not, the role of families, working in teams, dealing with uncertainty, emotional issues and resource constraints. The principles underpinning the guidance are set out in paragraphs 7-13.

British Medical Association

The BMA has a range of publications on issues related to end of life decision making which can be found on the ethics page of its website. In 2009 they published the BMA's [views on end of life decisions](#). The guidance covers three main areas:

- contemporaneous and advance refusal of treatment
- withholding and withdrawing life-prolonging medical treatment
- assisted dying - euthanasia and assisted suicide.

The guidance summarises some of the BMA's other guidance in this area.

The BMA has also published guidance on cardiopulmonary resuscitation in collaboration with the UK Resuscitation Council and the Royal College of Nursing.

[Decisions relating to cardiopulmonary resuscitation \(2007\)](#)

Royal College of Paediatrics and Child Health

The RCPCH sets out a framework for decision making and identifies ethical issues arising in decisions to withhold or withdraw treatment from children.

[Good Medical Practice in Paediatrics and Child Health, Royal College of Paediatrics and Child Health \(2002\)](#)

Issues that may present to a CEC

- Do not attempt resuscitation(DNAR) orders
- Advance Directives
- Decisions to withhold or withdraw treatment

These issues are discussed below using a short hypothetical case to illustrate some of the points to be considered.

DNAR Orders

A "do not attempt resuscitation", or "DNAR" order is an advance decision that Cardiopulmonary resuscitation (CPR) will not be attempted. The [guidelines](#) issued by the BMA RCN and UK Resuscitation Council sets out a framework for developing a policy for DNAR orders. It is important to consider not only whether CPR will provide a benefit to the patient, but also the potential harm that may be caused by CPR. It would not be in the patient's best interests to prolong treatment where it is futile to do so. The importance of discussing the decision with the patient and/or their relatives is highlighted in the professional guidance.

Case study:

John is a 55 year old man with lung cancer which initially responded to chemotherapy but has now relapsed. He is now nearing the end of a trial of a new chemotherapy regime with no sign of remission of his cancer. In discussion with the medical team John expresses a belief that he may respond to treatment although his consultant has told him that no further chemotherapy is possible and that he has only a few weeks left to live. As a result of his advanced disease, it is likely that vital organs such as his kidneys and heart will fail. The consensus of opinion from the medical team is that, if John has a cardiac arrest while on the ward, attempts at resuscitation would not be appropriate. This is because it is highly unlikely to be successful and it would inflict damage because of John's fragile ribs (he has secondary deposits of cancer in his ribs) and because he will die very shortly from his cancer. After discussion with his consultant John says he wants everything done for him, including CPR.

Should John be given CPR in the event that he suffers a cardiac arrest?

At first glance this case seems to be a conflict between John's autonomous choice and the objective view of the clinicians regarding his best interests. However further exploration of the clinicians' reasons for not wishing to attempt CPR and John's reasons for his choice is required.

If the clinicians think that CPR would be futile this raises questions about what is meant by futile treatment and how different people would regard the predicted level of success or failure in this case. For John, even a small chance of success may be seen as far from futile if he has the chance of another week of life.

In considering John's autonomy it is necessary to know if he has understood what CPR entails and the likelihood of success or failure. Is he making an informed choice?

In considering his best interests, have the clinical team taken into account his personal perspective? Perhaps his daughter is getting married next week and he wants any chance, however small, to be able to see her married.

Should the possible effects on medical and nursing staff of attempting CPR on a patient with virtually no chance of success be considered? It maybe that with fuller discussion between John and his clinicians a consensus view will be achieved. If this is not possible, the joint BMA, RCN, and UKRC guidance advises that the patient's wishes should be respected but that, in the event of a cardiac arrest occurring, the decision about precise measures to be taken should be made by the clinician.

Doctors cannot be required to give treatment contrary to their clinical judgement, but should be willing to consider and discuss patients' wishes to receive treatment, even if it offers only a very small chance of success or benefit. Where attempted CPR has a reasonable chance of successfully re-starting the heart and breathing for a sustained period, and patients have decided that the quality of life that can reasonably be expected is acceptable to them, their wish for CPR should be respected. (section 7.2)

Advance Directives

- [Mental Capacity Act 2005 sections 24-26](#)
- [GMC Treatment and care towards the end of life](#) 2010 paragraphs 63-74
- [End of life decisions: views of the BMA](#) 2009
- The Patients Association. [Living wills. How to make sure your wishes are known when you can no longer make yourself understood.](#)

An advance directive, (also known as a 'living will') is a statement made by a competent adult about the way he/she wishes to be treated if, in the future, he/she becomes incompetent and therefore unable to make a valid choice as to treatment. As competent adult patients have a right to refuse medical treatment an advance directive is a way of prolonging autonomy. An advance directive cannot request treatment that is not in the best interests of the patient. The Mental Capacity Act recognises advance statements as legally binding if valid and applicable. However the Act specifies advance **refusals** of treatment.

Conditions for a valid advance refusal of treatment:

- The advance refusal is made by a competent adult (18 and over).
- It is entered into voluntarily - the individual was not coerced into making the statement.
- The individual is sufficiently informed about the medical prognosis if the advance refusal is respected.
- It is applicable to the circumstances that arise.

In general an advance refusal of treatment does not have to be written in order to be valid. However refusals of life sustaining treatment have to be written, signed and witnessed and specify that the treatment to be refused is life sustaining. Questions that a clinician or clinical ethics committee may need to consider:

- Does a patient have a valid advance directive?
- Is the advance directive applicable to the circumstances of the case?
- Is there any evidence that the patient has revoked the advance directive or changed their mind?

Case Study

Mr Z made a written advance directive 5 years ago. Mr Z suffers from chronic obstructive pulmonary disease and the advance statement provides that if he is admitted in respiratory failure he will not be ventilated. The advance directive is placed in his notes. Mr Z is brought into A&E in respiratory failure and is acutely confused because of low oxygen levels in his blood. He says that he wants 'everything done' in order to save him. The doctor in charge of his care decides to ventilate him.

What issues should an ethics committee consider in reviewing such a case?

The advance directive was an exercise of Mr Z's autonomy and an expression of how he wanted his future to be shaped in circumstances where his autonomy would be restricted by ill health. The principle of respect for autonomy requires that the advance directive be

respected, if it was written as an autonomous act (if he was competent, free from coercion and had enough information to make the decision) and if it is still an expression of his true wishes.

Mr Z appears to contradict his advance directive when admitted to hospital semi conscious. The question is whether his current wishes should override his previously made advance directive. If he was fully conscious this would clearly be the case. A competent patient can change his/her mind about treatment at any time. If Mr Z is semi-conscious he may not be considered competent to make decisions about treatment, precisely the circumstances that the directive was meant to cover. However, assessment of competence in these circumstances is difficult and ignoring his currently stated wishes will have serious and possibly fatal consequences.

This is a difficult conundrum and perhaps the best solution where there is a real issue about the validity of a revocation of an advance statement is to take the course that preserves future choice for the patient. If Mr Z's life could be saved by accepting his most recent statement of wishes then this preserves a future choice. This approach is reflected in professional guidance.

[GMC Treatment and care towards the end of life](#) 2010

para 73 If there is doubt or disagreement about the validity or applicability of an advance refusal of treatment, you should make further enquiries (if time permits) and seek a ruling from the court if necessary. In an emergency, if there is no time to investigate further, the presumption should be in favour of providing treatment, if it has a realistic chance of prolonging life, improving the patient's condition, or managing their symptoms.

Some clinical ethics committees have been involved in developing policies on advance directives. An example of such an exercise and the ensuing policy is described by Stephen Louw, Chair of Freeman Hospital Clinical Ethics Advisory Group in the section on [Committee Functions](#).

Decisions to Withhold and Withdraw Life-Prolonging Treatment

Difficulties may arise for clinicians treating patients at the end of their lives, whether children or seriously ill adults, who are unable to make decisions about continuation of treatment – is it in the patient's best interests?

The Mental Capacity Act 2005 has a 'best interests checklist' to guide clinicians and others making decisions for a person who lacks capacity. They should make reasonable attempts to seek the views of family and other carers of the person who may be able to provide information about the patient's previous wishes, views and values. Unless someone has a Lasting Power of Attorney to make decisions for the patient then these discussions are for information sharing and not for the family to make a decision on behalf of the patient (see section on the Mental Capacity Act).

Where the patient is a baby or young child then the parents make decisions about treatment in the best interests of the child. If there is a difference of opinion between the parents and clinicians about what is in the child's best interests then it may be necessary to ask the court for guidance. The key factor in considering whether treatment should be provided or withdrawn is an assessment of the benefits and burdens of treatment. Criteria for deciding best interests are the same as for adults and include the ability to interact and the capacity for self-directed action and whether there will be suffering of severe unavoidable pain and distress (Section 14 BMA Guidance for decision making, Withholding and Withdrawing Life-prolonging Medical Treatment).

In the case of *Re J* (1990) the court considered whether, if treatment were provided, the patient's life would be "so afflicted as to be intolerable". If so, then it would not be in the patient's best interests to provide treatment.

The GMC guidance [Treatment and care towards the end of life](#) 2010 sets out a decision making model for end of life care when a patient lacks capacity (paragraphs 15 and 16)

Case Study

Baby C born 8 weeks prematurely and contracted meningitis soon after birth. As a result she suffered severe brain damage and an inability to respond to stimuli. She was receiving artificial ventilation. The treating team thought that it was not in the baby's best interests to continue with artificial ventilation, without which she would die within an hour. With continuance of such treatment she would live for at most one year, probably experiencing pain and distress. For religious reasons her parents could not agree to withdrawal of treatment.

What issues should an ethics committee consider in reviewing such a case?

Withdrawal of treatment will result in the death of baby C. On the other hand continuance of artificial ventilation would mean the continuance of suffering. Although the principle of sanctity of life is a fundamental consideration it is not an absolute principle and the duty of beneficence, doing the best for the patient, may lead to the conclusion that continued treatment is not in the best interests of baby C. Legal cases have indicated that it would not be in the best interests of the baby to continue treatment in order to prolong a life where suffering is intolerable (for the baby). (See above, *Re J* 1990).

The parents should decide on the course of treatment that is in the best interests of their child. However, they cannot, for religious reasons, consent to withdrawal of treatment. If clinical opinion concludes that the suffering baby C would endure with treatment would be intolerable, then there is a potential for conflict with the parents.

'Best interests' is not purely an assessment of medical interests and although consideration of the parents views of the interests of the child is an important part of the assessment these views cannot determine the course of treatment to be followed. GMC guidance addresses this difficulty of conflicting views of best interests in the case of children.

[GMC End of life care](#)

108 If disagreements arise about what course of action would be in a child or young person's best interests, it is usually possible to resolve them by, for example, involving an independent advocate; seeking advice from a more experienced colleague; obtaining a second opinion; by holding a case conference or ethics consultation; or by using local mediation services. If, after taking such steps, significant disagreement remains, you should seek legal advice on applying to the appropriate court for an independent ruling. Approaching the court should be seen as a constructive way of thoroughly exploring the issues and providing reassurance for the child and parents that the child's interests have been properly considered in the decision.

Another consideration in a case like this is the use of limited health care resources. If this baby continues to be ventilated with no chance of recovery, then an intensive care bed will be required. The demand on intensive care beds is great and this may mean that another child requiring a bed will need to be moved to a different unit, possibly reducing their chances of survival. How can a just use of resources be included in the assessment of what would be the right thing to do in this case? The GMC offers some guidance

[GMC End of life care](#)

37 Decisions about what treatment options can be offered may be complicated by resource constraints - such as funding restrictions on certain treatments in the NHS, or lack of availability of intensive care beds. In such circumstances, you must provide as good a standard of care as you can for the patient, while balancing sometimes competing duties towards the wider population, funding bodies and employers There will often be no simple solution. Ideally, decisions about access to treatments should be made on the basis of an agreed local or national policy that takes account of the human rights implications. Decisions made on a case by-case basis, without reference to agreed policy, risk introducing elements of unfair discrimination or failure to consider properly the patient's legal rights

For an interesting discussion of the issues arising when a patient in intensive care is declared brain stem dead but according to the family's religious beliefs is still alive and should continue to receive treatment: see

Brain stem death: managing care when accepted medical guidelines and religious beliefs are in conflict Inwald, Jakobovits, Petros, Fisher, and Raper, BMJ, May 2000; 320: 1266 - 1268.

Further reading

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Thomas SL, Milnes S, Komesaroff PA. Understanding organ donation in the collaborative era: a qualitative study of staff and family experiences. [Intern Med J](#) 'Postprint'; doi:10.1111/j.1445-5994.2008.01826.x