

THE PRACTICAL GUIDE TO MEDICAL ETHICS AND LAW

Second Edition

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Chapter Five

THE CASES

HOW TO USE THIS CHAPTER

This chapter contains a variety of cases that draw their inspiration from actual events. You may like to discuss how you would approach these situations and why, either individually or in small groups. Medical teachers may wish to use the cases to stimulate discussion of generic ethical or medico-legal issues.

We do not necessarily give all the solutions to these cases, but that is because sometimes there *are* no right answers – or none that are more right than your own. What this chapter *will* do is give you some key information that you need to know, in terms of laws and important ethical theories. This will help you to be able to reach decisions, both within the context of the following cases and in your own practice. More importantly, it will allow you to justify and explain your position with reference to well-reasoned principles.

Each case is followed by a summary at the end. In addition a reading list which can be referenced for more information, or greater detail on existing information. Within the cases, points for discussion and revision have been marked with the following symbols:

☆ **Discussion point** and ★ **Revision point**

Most of the cases deal with a range of different issues. If you want to revise particular themes, refer to the overleaf list, which shows which cases cover which aspects. This list of themes was drawn up by the Consensus Group of Teachers of Medical Ethics and Law, as a core curriculum in medical ethics and law for medical schools in the UK (Consensus Group of Teachers of Medical Ethics and Law in UK Medical Schools. Teaching medical ethics and law within medical education: a model for the UK core curriculum. *Journal of Medical Ethics* 1998; 24: 188–92).

CASE 1: THE DVLA AND THE EPILEPTIC PATIENT

Issues

Driver and Vehicle Licensing Authority

Patient's versus society's interests

Breaching confidentiality

You are a recently appointed specialist registrar (SpR) in neurology. Following investigations during a recent hospital stay, one of your patients, Mr Evans, a middle-aged taxi driver, was diagnosed as having epilepsy. Before he left the hospital you advised him to stop driving, and that he should contact the DVLA to make them aware of his epilepsy. Although this meant the end of his livelihood, he undertook to do so.

One month later he is due to attend an out-patient appointment at your clinic. On the morning of the clinic, one of the specialist nurses (a neighbour of the patient) tells you that he has continued to drive. Furthermore, she believes that he has not yet told his wife and family of the diagnosis – let alone his employer or the DVLA.

- **What are your responsibilities in this case?**
- **Would you tell:**
 - **the DVLA?**
 - **the family?**
 - **the police?**
 - **the employer?**
- **Should you take any action?**

Driver and Vehicle Licensing Authority

It is the patient's responsibility to inform the DVLA of health conditions that might cause them to pose a risk to themselves or other road users by driving. These conditions include:

- psychiatric disorders, eg chronic schizophrenia
- neurological disorders, eg epilepsy
- diabetes mellitus
- visual problems, eg monocular vision, diplopia.

Informing the DVLA does not necessarily lead to automatic suspension. The DVLA will assess whether the condition is severe enough to warrant a driving ban, either indefinitely or for a limited period. Certain other medical conditions, such as cardiovascular disorders and procedures (eg myocardial infarction or angioplasty) require driving restrictions, although the DVLA need not be notified. Doctors should inform their patients if they will need to abstain from driving for a period of time for medical reasons.

If a patient neglects their responsibility and continues to drive then the doctor is morally and professionally obliged to take action (see GMC guidance¹ on confidentiality for specific advice relating to this situation). In the first instance you should try to persuade patients to tell the DVLA themselves. In this case, the patient should be persuaded to tell his family the diagnosis too, as this is in his best interests, eg they could be educated to provide appropriate care should he have a seizure at home. However, if the patient still refuses what can you do?

☆ Doctors are bound by a duty of confidentiality that covers any information they acquire in their professional capacity. However, this is not an unqualified or absolute duty.

☆ What is confidentiality? What does it mean to the patient and has it been explained to them? What does it mean to you as a doctor?

☆ Telling the DVLA constitutes a breach of the patient's confidentiality. On what ethical grounds could you justify such action?

Patient's versus society's interests

To justify *legally* breaching confidentiality, reference is made to the interpretation of a case (*W v Egdell* [1989] 1 All ER 1089) in which the court held that where there is a serious risk of physical harm to an identifiable individual or individuals, a doctor can (but not necessarily must) breach confidentiality. In order to breach confidentiality, not doing so would have to pose a risk to the patient or to others. In the

circumstances of this case the doctor can probably be satisfied that this is the case and is justified in breaching confidentiality. However, breaches of confidentiality should be on a 'need to know' basis only, with need being defined as the minimum necessary to protect the safety of others. Therefore telling the DVLA would therefore be justifiable, but telling the local population, on the basis that they might get into the patient's taxi, would not be.

☆ If this is so, why not just go ahead and tell the DVLA yourself in the first place, instead of depending on a perhaps unreliable patient to do so? What effect would this have on patient care?

☆ If doctors had no code of confidentiality and patients knew that bodies such as the DVLA, insurance companies, the police and the government could have unlimited access to their health information, how would this change medical practice?

☆ What is the point of having a requirement to maintain patient confidentiality?

☆ In this case, you are told by a third party that the patient is continuing to drive. What happens in situations where you do not have access to such information? How can you be sure that the patient will stop driving? How far can/should you go in trying to find out whether they have stopped driving?

Writing to the GP, explaining that you have discussed with the patient the need to inform the DVLA, is an obvious first line. Doctors are justified in sharing medical information with other healthcare professionals involved in providing care for their patient, thus ensuring optimal continuity of care for the patient. It is good practice always to tell the patient that you will write a letter to their GP with a summary of your meeting and the results of any investigations done so that you keep them informed. Better still, many hospital doctors these days write a letter to the patient, copied to the GP. However, patients do have the right to ask that even medical personnel are not told certain information.

The guidelines for medical students are slightly different. As a medical student you may well receive information that is pertinent to a patient's care but which the patient asks you to keep from the rest of the team, eg non-compliance with treatment. As a student you cannot offer complete confidentiality, particularly where to do so would be to compromise the patient's care. You must explain that confidentiality is within the healthcare team and as a student, you would like them to discuss what they have told you with someone more senior. If the patient refuses, you

should explain that you will have to discuss it with your seniors and why this is the case.

☆ Would you be happy to pass the buck to the GP, ie assume that the GP will make sure the patient tells the DVLA or, if necessary, tell the DVLA themselves? Do you feel that both you and the GP share this responsibility? Would you feel responsible if the patient caused an accident because he had an epileptic fit while driving?

Breaching confidentiality

If a patient feels that a breach of confidence was not justified they can make a complaint. Although the patient also has the right to take legal action, this can be costly and may not result in the award of any monetary compensation even if the court finds in favour of the claimant. If the GMC determines that the doctor was not justified in breaching patient confidentiality, then the doctor could be liable for professional misconduct in the most serious cases and could be struck off the medical register.

The GMC gives details of several possible situations which would allow a doctor to disclose patient information.¹ The areas are summarised below:

- If the patient gives written consent, eg for research.
- If disclosure would be in the patient's best interests but it is impracticable to obtain consent, eg sharing information with others providing care to an incapacitous patient. This includes other healthcare professionals but may, exceptionally, also include a close relative, eg in cases of dementia.
- If disclosure would be in the public interest:
 - if required to do so by a court order or Act of Parliament, eg notifiable diseases, Prevention of Terrorism legislation
 - if failure to breach poses a risk of death or serious harm to the patient or others, eg child abuse, rape, serious violence.

Although the law is broadly in agreement with GMC guidance, the legal standpoint is less clearly defined. Legally, doctors are justified in breaching confidentiality *without* the patient's consent in the following circumstances:

- When ordered to do so by law:
 - by a court order
 - under Acts of Parliament, eg in the case of notifiable diseases.
- When it is in the public interest.

☆ What is the difference between a *duty* to breach confidentiality and an *entitlement* to do so?

Breaching confidentiality 'in the public interest' is a very difficult decision to make and may ultimately be down to the courts to determine. In an English case (*Hill v Chief Constable for West Yorkshire* [1987] 2 WLR 1126) it was decided that there was no **duty** to inform in the public interest.

However, a different view was taken in a famous American case (*Tarasoff v Regents of the University of California*, 131, Cal Rptr 14 Cal S Ct of CA (1976)). Mr Poddar, a male college student, told a university psychiatrist during a therapy session that he wanted to kill a fellow student (Tatiana Tarasoff) who had been refusing his advances. The doctor informed the campus police, who then assessed the man but released him when he appeared rational and promised to stay away from Ms Tarasoff. Poddar then went ahead and murdered Tarasoff on her return to campus from holiday. The parents sued the university for failure to inform their daughter of the risk. The US court found the doctor liable for negligence because he had not warned Tatiana of the potential risk to her life. The judge stated 'the protective privilege ends where the public peril begins'.

In the UK it is unlikely that a similar decision would have been reached since courts in the UK are reluctant to make one person liable for the crime committed by another (this was confirmed in the cases of *Clunis v Camden and Islington Health Authority* [1998] QB 978 and *Palmer v Tees HA* [2000] PIQR 1).

The GMC requires that confidentiality should be maintained even after the patient's death (see Section 5 of *Confidentiality: Protecting and Providing Information*¹; the law, on the other hand, may not require this. Note that solicitors and police officers have no special right to confidential information. Disclose information only if you decide that it is justified under one of the above conditions.

Breaching confidentiality to relatives

Disclosing information to relatives is sometimes difficult to judge. If it can be assumed that the patient would give consent for information to be disclosed to their family, the doctor can probably go ahead and impart information to the relatives without consulting the patient, who may be either too sick or unable to communicate. This should be done tactfully however, and confidential information should never be given over the phone. However, if the patient has expressly forbidden such communication, this wish should be respected. The patient has a right to maintain confidentiality even when the doctor considers it not to be in the patient's

best interests. Therefore, in the case of the epileptic driver, it may well be in his best interests for his family to know his diagnosis, but if he states that he does not want them to know, you cannot tell them.

Conditions when doctors are legally required to breach confidentiality

- If required to do so by a court of law. Judges will do their best to ensure that any breaches of confidentiality are kept to those relevant to the trial:
 - doctors can be subpoenaed (ordered) to give evidence in court
 - doctors (unlike lawyers) may not refuse to answer questions or withhold evidence.
- Prevention of Terrorism Act 1989:
 - doctors (like any member of the public) must take the initiative to inform the police of any information regarding terrorist activities.
- Police and Criminal Evidence Act 1984:
 - doctors must answer police questions or provide any evidence requested by them
 - police can have access to medical records but must abide by certain conditions.
- The Public Health (Control of Disease) Act 1984.
 - notifiable diseases include cholera, plague, smallpox, relapsing fever and typhus (note that HIV/AIDS is not a notifiable disease)
 - other diseases can fall under this Act should an epidemic occur.
- Accidents at work.
- Incidents of food poisoning.
- Life events:
 - doctors must report births, deaths and abortions.
- Misuse of Drugs Act:
 - doctors must report details of known drug addicts.
- Health administration:
 - doctors must provide information on request to the Department of Health, regional and district health authorities among others.

☆ Can you see any discrepancies in these conditions? It has been argued that people with HIV will be deterred from seeking medical treatment if it is a notifiable disease and that it is therefore not in the public interest to make it notifiable. However, details of drug users must be reported.

Under the Police and Criminal Evidence Act 1984, if the police contact the doctor, the doctor must answer their questions and provide evidence if necessary. However, if the doctor knows that a patient has, or is about

to, commit a criminal offence, they are under no legal obligation to take the initiative to contact the police.

It could be argued that all citizens have a moral duty to society to prevent and report any crime. The law is excusing doctors from this duty because it believes that there may be situations when it can be in the public interest for doctors to maintain patient confidentiality rather than for certain criminals to be convicted. Moreover, a lot of the information doctors may receive is in the context of their therapeutic relationship rather than as 'citizens'.

The exception to this rule is if the information pertains to terrorist activities. Section 18 of the Prevention of Terrorism Act 1989 states anyone (including doctors) in possession of such information must *take the initiative* to disclose it to the police.

If in doubt, seek legal advice from your defence organisation!

Summary

- Doctors are bound by a duty of confidentiality to their patients.
- Deciding whether to breach confidentiality requires a careful balance of risk of harm to the patient versus risk of physical harm to others.
- The law requires doctors to breach confidentiality in certain situations.
- It is the patient's responsibility to inform bodies such as the DVLA or their employer but, if the patient refuses, the doctor must take action.

Reading

- DVLA. www.dvla.gov.uk – go to driver's information, and medical rules.
- Epilepsy Action. www.epilepsy.org.uk – go to information, then driving.
- General Medical Council. *Confidentiality: Protecting and Providing Information*. London: GMC, 2000: section 5 and appendix 2.
- Montauk L, Morrison V. Crime, confidentiality, and clinical judgment. *Lancet* 364 (Suppl 1).
- Shorvon S. Epilepsy and driving. *BMJ* 1995; 310: 885–6.

Reference

1. General Medical Council. *Confidentiality: Protecting and Providing Information*. London: GMC, 2000.

CASE 2: WITHDRAWAL OF VENTILATION

Issues

Advance directives/statements ('living wills')

Consent

'Do not attempt resuscitation' (DNAR) orders

Quality-of-life issues

Acts and omissions and the doctrine of 'double effect'

The cases of Diane Pretty and Leslie Burke

Communication issues within the healthcare team

Allocation of resources

You are a senior house officer (SHO) working in general medicine. A 19-year-old man was diagnosed with motor neurone disease when he was 17. The disease was very aggressive and rapidly progressive.

At a time when his communication was already limited he made it known that he wished to state in an advance directive that should he suffer a cardiopulmonary arrest he would not want to be resuscitated.

He did suffer a respiratory arrest and was ventilated. You were part of the crash team that attended him. The nurses on the ward did inform the team leader of the advance directive but were told not to interfere.

- **Would you have resuscitated and ventilated this man?**
- **What should be done now that he is on a ventilator?**

Advance directives/statements (living wills)

An advance directive (or living will) is a statement (usually a written document) in which a person stipulates the circumstances under which they would or would not wish to receive medical treatment (or to what extent they would want to receive active treatment). It is intended to provide directions if and when a situation arises when they are not competent to make their own decisions. In discussing this case, one would probably look at the situation that the patient was in when the advance directive was made, and consider the validity of that directive.

☆ How do *you* feel about advance directives? What are their pros and cons? Should they be legally binding?

☆ Would you be happy to act according to an advance directive if an unconscious patient was brought in to you? Does your answer to this depend on when the directive was written? If so, do you think they should have an 'expiry date'? How specific does it need to be?

Courts in the UK have confirmed that a person's advance refusal of treatment should be respected (*Re T (Adult: Refusal of Treatment)* [1992] 4 All ER 649; [1992] WLR 782). This depends, however, on the 'consent' or 'refusal' being valid. Cases have confirmed that an advance directive will be valid, provided it was made:

- by a competent patient . . .
- voluntarily . . .
- on the basis of sufficient information . . .
- and is applicable to the circumstances that have now arisen.

This last requirement can be particularly difficult, but if you decide in good faith that the directive does apply (and you have documented this appropriately), you are advised to honour its terms. This common law position is retained and clarified by the Mental Capacity Act 2005 (see below).

☆ What do you think should be required to ensure that consent is valid?

Consent

To be considered valid, consent should be voluntary, informed, continuing and made by a competent individual. There is a case law ruling that consent given by a patient who may have been coerced or under duress to make a certain decision is *not* valid (*Re T (Adult: Refusal of Treatment)* [1992] 4 All ER 649; [1992] WLR 782).

Consent is considered to be 'informed' when the patient has received relevant information necessary to make a decision. Interestingly, the law requires doctors to give as much information as a reasonable doctor would provide; in contrast, the GMC requires doctors to give such information as would be required by a 'reasonable patient'. Such information includes details of common side-effects and risks, as well as information on the potential benefits and the consequences of both treatment and non-treatment.

☆ How much do you think you ought to tell someone about a procedure to ensure that they give informed consent? Think about this in relation to:

- taking blood
- taking a chest X-ray
- performing an endoscopy/bronchoscopy
- performing a vasectomy.

Types of consent

Consent can be verbal or written, and it can be explicit or implied. In other words, if somebody rolls up their sleeve and holds their arm out when you ask to take a blood sample, this is implied consent, which is just as good as them saying, 'I give consent for you to take my blood'. Note that a signed consent form does not *prove* that a patient gave informed consent, it only *proves* that they signed their name on the form. Therefore, when obtaining a patient's consent, the goal is *not* to get the form signed but to ensure the patient gives informed consent. Although in theory verbal consent can be valid for any procedure from venepuncture to an anterior resection, in practice, you will usually need to get the form signed, following the Department of Health's introduction of standardised consent forms.

Capacity for consent

The law is pretty clear that a person's valid consent or refusal of treatment should be respected. However, to give 'valid' consent, a person must have 'capacity', or 'competence' to make decisions.

☆ What do you consider to be important factors in determining a patient's competence to give consent?

☆ Who should obtain consent for which procedures?

British courts considered this matter in a case about a man suffering from schizophrenia, who was an inpatient at Broadmoor Prison Hospital (*Re C*

(*Adult: Refusal of Treatment*) [1994] 1 All ER 819; [1994] 1 WLR 290; [1994] 1 FLR 31; [1994] 15 BMLR 77). The man, C, developed gangrene in two of his toes. His consultant surgeon believed that he required a below-knee amputation to save his life. The surgeon felt that C's chances of survival without amputation were about 15%, but C stated that he would prefer to die with two feet than live with one. The courts considered whether the mental illness sufficiently reduced C's capacity to understand the nature, purpose and effect of the proposed amputation, therefore making his refusal invalid. The test described by the High Court in determining an adult's capacity to give consent was as follows.

★ Can the patient:

- take in and retain treatment information?
- believe the information?
- weigh that information, balancing risks and needs?

The judge decided that, despite his mental illness, C was able to do all of the above, therefore making his refusal of consent valid. In the absence of treatment, C's gangrenous toes fell off by themselves and his health was not otherwise affected.

Subsequently another case of (*Re MB (Adult: Medical Treatment)* [1997] 8 Med LR 217 at 224) clarified the test, but it did not include the criterion of belief. The need to believe information is not incorporated into the test of capacity in the Mental Capacity Act 2005 either, which is expected to come into force in 2007. It is worth remembering that, as a doctor you play a role in assessing someone's capacity. The language you use, the time and place in which the assessment takes place, the opportunity for questions and discussion all have a bearing on whether or not a patient can understand, retain and consider what you are saying.

☆ Considering the 'Re C test' in the present case, think about whether the patient with motor neurone disease would have been competent to give consent at the time he made his feelings known. We know that the patient in this case had impaired ability to communicate but we are not given any information as to his mental capacity.

☆ This patient's disease was described as 'aggressive and rapidly progressive'. Do you think that time could have been a factor in his emotional state and therefore affected his ability to make a competent decision on his views on resuscitation? Is emotional state relevant to the assessment of capacity using the *Re C* (as amended by *Re MB*) criteria? If so, how?

Prisoners and consent

☆ Do you think prisoners have their autonomous decisions respected? Should they be able to give consent and decide what happens to them, or should this right be removed?

This concept has been tested in English common law (*Freeman v Home Office* [1984] All ER 1035; [1984] 2 WLR). A prisoner serving a life sentence claimed that he was unable to give consent as he felt he could not really refuse treatment recommended by those who have the power to discipline him. The initial ruling affirmed this idea, but the Court of Appeal found that there had been no coercion although it did not need always to consider the facts of the case as to whether consent can be valid before accepting it. For example, if a doctor has the power to influence a patient's situation and decision, that patient's consent may not be valid. This could happen in all cases, not just those involving prisoners.

Prisoners are able to give consent, the same as anybody else. The validity of the consent must, however, be certain before it is acted upon.

'Do not attempt resuscitation' (DNAR) orders

Decisions regarding the 'resuscitation status' of patients in hospitals are essentially advance directives. These should, ideally, be made following discussion together with the patient, but this is often not possible. In cases where the patient is not competent to make a decision, it is the responsibility of the doctor in charge of the patient's care to act in the best interests of the patient. The courts have confirmed that it is good practice to involve relatives and loved ones in decisions relating to the treatment of incompetent adults (*F v West Berkshire Health Authority* [1989] 2 All ER 545, HL).

☆ Sometimes DNAR orders are assigned to competent patients without their knowledge on the basis of 'clinical futility'. Is this right? What happens where you work?

☆ Sometimes DNAR orders are *withheld* from patients in situations even where resuscitation would *not* be in their best interests, simply because their son/daughter is a medical professional or other hospital employee. Should this have any effect on the care that a patient receives? Whose best interests are at stake in such circumstances?

☆ Do you think that relatives should be able to make decisions on the resuscitation status of a patient? Why/why not? Imagine what it would be like to have a relative who is unconscious in hospital. Remember the need

for a doctor to consider the patient's best interests and think about the wider situation of the patient's surroundings when you consider their 'best interests'. For example, how does the involvement and wellbeing of the family affect the patient? Will it help the patient to get better if they have strong family support? Are the family necessarily best placed to be the patient's advocate or represent his or her views, even if the family cannot give proxy consent?

☆ Can you imagine a situation where the relatives may not have the best interests of the patient at the forefront of their minds? Although most relatives are good judges of what patients would want, this is not always the case.

Clinicians only have a 'snapshot' of the patient's life and it is dangerous to make assumptions about the quality of the relationship or altruistic motives based solely on familial roles. See Case 3 for more on this.

Quality-of-life issues

It is an important part of any decision that a doctor makes in the 'best interests of the patient' to consider the quality of life that would result from any treatment that is administered. Saving somebody's life is not necessarily what the patient would want, as was demonstrated by the wishes of the man in this case. Putting his competence to make decisions aside, he was evidently thinking that life on an artificial ventilator would not be the kind of life that he would want to live. So often in medicine the philosophy of 'active treatment' means that care providers want to do everything they can to help their patients, and it may be difficult for them to accept that sometimes the best thing to do is nothing. However, some ethicists have argued that the notion of 'prospective autonomy' (the ethical basis for advanced statements) is problematic because the human condition is such that we can rarely know how we would feel in extremis (even if we believe that we do now).

Acts and omissions and the doctrine of 'double effect'

☆ Consider this question: Is the discontinuation of life-saving treatment any different from not initiating the treatment in the first place? If you do think there is a distinction between *withdrawing* and *withholding* treatment, on what basis would you argue the distinction? Does one appear more 'active' than the other? Do you believe the morality is to be found in the act or omission rather than the consequences? Does one seem to be more on a par with euthanasia than the other? If so, why?

The debate of 'stopping' versus 'not starting' is often used to illustrate the arguments that theorists have employed to distinguish between acts and omissions.

In a philosophical 'thought experiment' the issues around this real or imaginary distinction are illustrated by that of two uncles, both with a rich baby nephew from whom they stand to gain the entire inheritance if the nephew dies. Both uncles go up to the bathroom whilst the nephew is having a bath with the intention of drowning the child. The first uncle goes up to the bathroom and does just that. The second uncle goes up to the bathroom but as soon as he wants to drown his nephew, the baby's head slips under the water and the uncle watches him drown. Is there a moral difference between the two uncles?

- ☆ This example is used by both the supporters and opponents of the Act and Omissions distinction to support their argument. How do you feel about it? Do you think the uncles are both equally guilty of the babies' deaths or do you think the uncle who watched the child die is slightly less culpable than the one who actually pushed him?

Similarly, views about withdrawing treatment differ. Some argue that withdrawing treatment is no different from not starting treatment in the first place, while others believe once treatment has started, withdrawing is equal to euthanasia.

Another related argument is the 'doctrine of double effect'. This is an ethico-legal term (see *R v Cox* [1992] 12 BMLR 38) used in situations where one action may have two possible effects and separates the intention from the outcome. The Doctrine states that an act with a good intention is permissible, even if it has a foreseeable (even inevitable) bad consequence. The Doctrine is consequentialist in nature, in the sense that it suggests the ends justify the means. This is in contrast to Kantian ideology which diametrically opposes the idea.

- ☆ A thought experiment used to illustrate the Doctrine is the very politically incorrect story of 'Fatty in the Cave'. In the story Fatty and his friends are potholing when Fatty gets stuck in one of the narrow passages and blocks everyone else inside the cave. The other potholers have some dynamite which they can use to blast a hole to get them out, even though this has the inevitable consequence of also blowing up Fatty. The Doctrine dictates that this is permissible. Do you agree?
- ☆ Can you really separate the moral value of an act from its foreseen effects, or are they intrinsically linked?

☆ Can you think of any other applications of the Doctrine of Double Effect in moral discussion? How might the Doctrine be used to strengthen Bush and Blair's case for war in Iraq?

The one medical application of the Doctrine of Double Effect is when morphine is used to relieve pain in terminal care. The doses prescribed may also have the side effect of depressing the respiratory system and hastening death.

The intention is beneficent, ie to alleviate pain with effective analgesia, but there might be a foreseen 'double effect'. Some people feel that, as long as the intention is to treat pain and not to kill, this is acceptable. However, there are those who believe that the intention is not important – it is the outcome (death) that matters, and that may be a good thing or a bad thing. Similarly, views about withdrawing treatment differ. Some argue that withdrawing treatment is no different from not starting treatment in the first place, whereas others believe that once treatment has started, withdrawing it is equal to euthanasia.

☆ Thinking about withdrawing treatment – what do you consider to be 'treatment' and what do you think is a basic requirement of life? Are the following treatments or are they fundamental to life?

- Antibiotics to treat infection (where the primary diagnosis is cancer)
- Intravenous fluids
- Tube feeding.

Issues surrounding the withdrawal of treatment are discussed in detail in the case of Tony Bland, a football supporter who was left in a persistent vegetative state following the Hillsborough Disaster in 1989. The case was eventually passed to the House of Lords (*Airedale NHS Trust v Bland* [1993] 1 All ER 521; AC). In this case, Lord Goff stated that where a patient lacks capacity, a treatment can be discontinued where its use is no longer considered to be in the patient's best interests. Although doctors and medical students rarely need to read entire legal judgments, the judgment of Lord Goff of Chieveley in the *Bland* case is very important, as it provides a detailed analysis of the ethics and law surrounding this difficult and complicated issue. The case of Tony Bland now has to be read in the light of an on going case involving a man called Leslie Burke, which is discussed opposite.

The difficulty for the doctor lies in assessing the best interests of the incompetent patient, and it is important to remain alert to how your own values and beliefs about the sanctity of life and quality of life will influence this determination. New guidance from the GMC¹ is a useful

reference, and, of course, the patient may have made an advance statement, which describes what he or she would perceive to be in his or her 'best interests' in the event of incapacity. Indeed, the greater use of advance statements and the use of patient proxies to represent the incapacitated patient is a cornerstone of the legislative changes in the Mental Capacity Act 2005. It will be interesting to see whether these statutory developments make the assessment of an incapacitated patient's best interests any less vexed and complex.

However, should the patient be competent to make decisions for themselves, they would be able to say whether they wanted the treatment to continue. It is unusual, though not impossible, for a patient who is receiving artificial ventilation to be conscious and legally competent to decide on the future use of the ventilator. One situation where this could feasibly occur is in the case of motor neurone disease, where patients may be of sound mind. In such cases, the patient may be able to pull the endotracheal/tracheostomy tube out, therefore removing their own treatment. Other patients may be unable to move enough to do that. They could well be capable of deciding that they do not want the ventilator, but they would need help in the physical action of removing the equipment.

Therefore, if you thought that this patient's advance directive was valid in the first instance, you may consider it right to stop the ventilation. Or, if he turned out to regain consciousness and capacity after the arrest incident, he may ask you to remove the tube. If you were the doctor in charge and you considered that the advance directive was invalid but that continuation of artificial ventilation was no longer in the man's best interests, you may decide to remove the treatment. In summary, there is no right answer to this dilemma; as elsewhere you need to be able to apply ethical principles to the context of the particular situation.

The cases of Diane Pretty and Leslie Burke

The high-profile case of a 43-year-old woman with motor neurone disease may have crossed your mind when discussing the above situation (*R (on the application of Pretty) v Director of Public Prosecutions* [2002] FLR 268). It may be worth considering that in this woman's case she was not asking for any treatment to be removed. She said that she wanted to commit suicide and because she was unable to perform the act of putting pills in her mouth and swallowing them, or performing any other act of suicide, she asked the courts to allow her husband to help her do what she would otherwise do by herself. The House of Lords ruled that, despite

the patient's competence and autonomy, she was asking for her husband to perform an act of assisted suicide, which is not legal in the UK. The Human Rights Act 1998 did not affect the previous law, and the court essentially ruled that it was most important to protect life (under article 2, the right to life) and protect the vulnerable (those disabled people who might feel pressurised to accept assisted suicide). See Case 25 for more information on the Human Rights Act.

☆ Do you agree with the House of Lords' ruling in the case of Diane Pretty? Or would you have allowed her husband to help her to die?

☆ Diane Pretty took her case to the European Court of Human Rights where she ultimately lost her battle. Why do you think this was?

Ironically, the verdict was delivered just a few hours before the UK High Court granted another 43-year-old woman, known as 'Miss B', the right to die. (*Re B (Adult: Refusal of Medical Treatment)* [2002] 2 All ER 449). The crucial difference between the two cases was that Miss B was asking for a treatment to be stopped (a ventilator switched off), whereas Diane Pretty was requesting an intervention to help her to die.

☆ Is there an ethical difference between these two actions if the intention and the outcome are the same?

Diane Pretty died in May 2002, two weeks after the ruling and after 10 days of pain and breathing difficulties. She said of the court decisions: 'The law has taken all my rights away.'

Conversely, the recent case of Leslie Burke concerns a man who has cerebellar ataxia, a degenerative brain condition, which will eventually lead to loss of speech and movement; he will require treatment by way of artificial nutrition and hydration to keep him alive. Mr Burke was afraid that when he became unable to communicate, although he may still be conscious of what was happening to him, artificial feeding would be withdrawn with the effect that he would be starved to death. He therefore wishes to create an advance directive that will ensure hydration and nutrition continues, even if doctors believe that life-prolonging treatment is no longer in his best interests. Mr Burke sought judicial review of the GMC guidance (*Burke v the General Medical Council* [2004] EWHC 1879) on withholding and withdrawing life-sustaining treatment, arguing that doctors should not be able to withhold or withdraw treatment (nutrition and hydration) on the basis of 'quality of life'. On 30 July 2004, Mr Justice Munby ruled in favour of Mr Burke in the High Court. The GMC lodged an appeal on 30 September 2004. At the time of writing, the GMC's appeal had not been heard. Anyone practising, or training to

practice medicine should be aware of this case, however it is eventually resolved.

Communication issues within the healthcare team

In this situation the nurse on the ward told the arrest team leader that the patient had signed an advance directive. This raises some important issues about communication and the importance of keeping accurate records of actions in healthcare.

☆ Should it be the responsibility of the nurse looking after a patient to ensure that cardiac arrest teams are not called if the patient suffers an arrest? If you are a doctor on the cardiac arrest team and you are the first to arrive at the scene, should it be up to you to check the patient notes to find out if they are meant to have attempts at resuscitation, or should you start until somebody tells you otherwise?

All NHS trusts will have policies on decision-making regarding resuscitation and communication. Although these policies will be drawn from national guidance (eg the United Kingdom Resuscitation Council (UKRC) and the BMA), there may be local variation and it is important to familiarise yourself with the local guidance and procedures on resuscitation decisions when you begin working in any clinical setting.

Allocation of resources

Resources are always limited in healthcare, and rationing decisions therefore have to be made all the time. A patient who is successfully resuscitated following a cardiac arrest is usually transferred to an intensive care unit (ICU) for further treatment. Beds in ICUs are always in short supply, as well as presenting a huge cost to the health service.

☆ If a patient does not wish to be resuscitated in the event that they suffer a cardiac arrest, should the limited resources and funding influence the decision about whether or not to respect their wishes? Furthermore, if you think that it is acceptable to include resource constraints in the moral analysis of whether or not a patient should be resuscitated, who should have responsibility for weighing the claims of competing groups to, and allocation of, scarce resources?

Summary

- In UK law, a competent person's advance refusal of treatment should be respected.
- **Valid** consent is voluntary, informed, continuing and made by a competent individual.
- Capacity to give consent is specific to individual decisions, and should be assessed using the legal test established in the case of *Re C* and revised in *Re MB*.
- In England and Wales, people may not appoint a legal power of healthcare attorney to make proxy decisions. They may soon be able to do so under the new Mental Capacity Bill.
- In situations where patients are not competent to give consent, doctors may treat if it is in the best interests of the patient, having regard for the patient's medical and other (eg spiritual, cultural, familial) interests.

Reading

- BBC. www.bbc.co.uk/religion/ethics/euthanasia/
- British Medical Association. www.bma.org.uk – go to ethics, then physician-assisted suicide.
- Chan SY. Whose life is it anyway. *BMJ* 2005; 330: 486.
- Martin DK, Emanuel LL, Singer PA. Planning for the end of life. *Lancet* 2000; 356: 1672.
- Voluntary Euthanasia Society. www.ves.org.uk
- GMC, Seeking patients' consent: the ethical considerations, Nov 1998 (www.gmc.org/standards/consent/htm).
- *Case of Pretty v United Kingdom*. See the European Court of Human Rights website (www.echr.coe.int and search HUDOC for Application no. 2346/02).

Reference

1. General Medical Council. *Withholding and Withdrawing Life-Prolonging Treatments*. London: GMC, 2002.