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End of life decision-making

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Introduction

A medical man does not have to use all the techniques of survival offered him by a constantly creative science. In many cases would it not be useless torture to impose vegetative resuscitation in the final stages of an incurable sickness? The doctor's duty here is rather to ease the suffering instead of prolonging as long as possible, by any means whatsoever, a life no longer human (Cardinal Jean Villot, Vatican Secretary of State, 1970, quoted in Maguire 1975, p. 75).

Death is an intrinsic part of life. Increasingly, however, the techniques of modern medicine are making it possible for us to delay death and in many cases to enable those who would have previously died prematurely to recover and to live full and healthy lives. However, such techniques also allow us to exert a greater degree of control over the processes of dying even when full recovery is not possible. This means that, in addition to those who recover, there are people who would previously have died of their injuries, or condition, who can now be kept alive by medical interventions but who will never recover sufficiently to live an independent, or in some cases even a conscious, life as a result. The use of these techniques raises important ethical questions about the withholding and withdrawing of such life-prolonging treatment at the end of life. Indeed, the application of modern medicine at the end of life raises a

wide range of ethical questions, many of which require a reconsideration of the purpose of medicine itself. When healing is no longer possible, what ought to be the goal of medicine and of the healthcare professional? In this chapter we investigate some of these questions by means of a series of real cases. We look particularly at the ethics of palliative medicine and attempt to answer the question: to what extent are the ethical implications at the end of life different from, or the same as, the ethics of medicine more generally?

Section 1: Withdrawing treatment

We begin this chapter on 'Decisions at the end of life' with a case from Greece. We decided to use this case as the starting point both because it raises important ethical questions in itself and also because it brings to the fore questions about how we ought to define the goals of medicine at the end of life. Are there important morally significant differences between palliative medicine and medicine at other periods of life? If so, what are their implications for the practice, and indeed the goals, of medicine?

THE CASE OF MARIA

Maria was an 82-year-old woman who lived in Athens. She had been seriously incapacitated by arthritis for over 2 years, and was also virtually blind following recent unsuccessful cataract and glaucoma treatment. As is very common in Greece, Maria was being cared for by her family in the family home. Although Maria's family found this quite difficult, they were coping reasonably well.

However, Maria's condition deteriorated drastically when she suffered a severe cerebral vascular accident (or stroke) and was admitted into hospital. The result of the stroke was that Maria was left in what her physicians called a 'semi-coma'. The doctors at the hospital immediately began to provide Maria with artificial nutrition and hydration by means of a naso-gastric tube, but they told the family that they felt that no other treatment was appropriate as Maria was very unlikely to recover.

Maria's family visited her regularly at the hospital, but they found these visits very upsetting. Maria found it extremely difficult to speak and was clearly very distressed. Whilst recognizing the severity of Maria's condition, her relatives, who cared for her a great deal, and the staff at the hospital were careful not to discuss this in her presence. Despite this, it was clear from the start that Maria herself found her situation intolerable and, during the first 6 weeks of her hospitalization, repeatedly expressed her wish to be allowed to die. She did this through the use of signs and hard-fought words, even though this was itself extremely difficult and distressing for her. As she became increasingly frustrated, Maria also made several repeated attempts to remove her feeding tube.

Clearly, this was also very upsetting for Maria's children, who were spending quite a lot of time with her at this stage. They knew that their mother had a lifelong aversion to hospitals and medicine, and they felt also a duty to respect her clearly expressed wish to die. After having discussed this

among themselves, Maria's children together decided to approach her physician about the possibility of withdrawing treatment and allowing her to die, as she wished.

At their meeting with the physician, however, he made it very clear to the family in no uncertain terms that he would not consider acceding to such a request. He said that he felt that this would go against his responsibilities as a doctor to his patient. He also argued that Maria's requests to be allowed to die should not be taken at face value as Maria had a recent history of mild depression. Maria's family were unhappy with this decision and with the doctor's reasoning, but felt that they had no choice other than to accept it.

After a further week, however, Maria's condition had deteriorated to such an extent that she was now in a full and irreversible coma and, after further discussion with the family, the physician agreed to withdraw nutrition but continued to refuse absolutely to withdraw the supply of hydration.

Maria survived for another 2 weeks without respiratory or other complications, but then died rather suddenly when she suffered a second stroke.

After the death of his mother, Maria's son complained bitterly to the physician about the way his mother had been dealt with. He argued that, had the physician agreed with the family's request for the withdrawal of all kinds of treatment when this was originally requested, his mother would have died sooner and would have suffered a great deal less than she did. He argued that, when it is clear that a patient is going to die, the doctor's duty is to alleviate their suffering, and that this means that it can sometimes be wrong to keep a patient alive for as long as possible and at all costs.

ACTIVITY: Maria's son felt that the doctor in this case was being paternalistic and ignoring the wishes of both Maria and her family. This raises the question of who should decide in this kind of case. Stop here

for a moment and write down all the reasons you can think of both for and against withdrawing treatment when it was first requested by the family.

If one comes to the conclusion that the patient has the moral right to be allowed to die, it is tempting to jump from here to the claim that it is the doctor's duty to allow the patient to die, but clearly this need not be the case (we will be returning to this point in Sections 2 and 4 of the chapter). The doctor in the case of Maria continued to argue that, in his opinion, hydration was not simply another 'form of treatment' and was in fact the most fundamental form of care that he as a physician felt it his duty to provide to *any* patient. He argued that, whilst he was not in favour of prolonging unnecessarily a dying patient's life, he felt that allowing a patient to die from lack of hydration was not what he considered to be a dignified and peaceful death and would, in fact, contravene his duty of care as a doctor. Moreover, he argued, to do so would have been against any medical and religious tradition of his country, Greece, and against his personal beliefs.

ACTIVITY: To what extent do you agree with the doctor? What counts as treatment? Does hydration? Is the withdrawal of hydration a violation of the doctor's fundamental duty of care for the patient?

The dispute between the doctor and Maria's family appears to come down to one about what the goals of medicine ought to be in cases like that of Maria. The family argued that, in situations where healing is no longer possible the central goal of medicine ought to be the alleviation of suffering. They ask, what was the aim of preserving Maria's life, when in the event she had another stroke and died? Did she suffer more than she would have done were she simply allowed to die after the first stroke? The doctor's view, on the other hand, appears to be that both the with-

drawal of hydration and allowing a patient to die constitute violations of the deepest kind of the goals of medicine and of his duty of care to his patient.

ACTIVITY: Stop here for a moment and consider what you think of as the goals of medicine. Make a list of activities and attitudes which you consider to be part of the goals of medicine in general as you see them (i.e. not simply at the end of life) and another of those which you would consider to constitute an absolute violation of these goals. Then spend some time reflecting on your list and ask yourself which of these is no longer appropriate at the end of life, in palliative medicine, if any. In this context which of the list would you remove and what new activities and attitudes would you add?

After you have done this, we would like you to go on to read the following extract from a paper called 'Physician-assisted death, the moral integrity of medicine, and the slippery slope', by Dr Ron Berghmans from the Netherlands. The reason we introduce the paper at this point is because it raises and attempts to address this question of whether the goals of medicine in the broadest sense are in tension with, and perhaps even conflict with, what we would consider ethical treatment or care at the end of life. Are the ethical and moral dimensions different when questions of life and death are at issue in this setting? Whilst you are reading Berghmans's paper we would like you to bear these questions in mind as they will form an important thread throughout the chapter.

Physician-assisted death, violation of the moral integrity of medicine, and the slippery slope

Dr Ron Berghmans

Those who take the view that physician-assisted death involves a violation of the moral integrity of medicine argue that doctors must never be a party

to intentional killing, because that would go against the very essence of the medical profession (Singer & Siegler, 1990; Pellegrino, 1992; Momeyer, 1995). The essence of medicine from this perspective is considered to be healing and the protection of life. This view is opposed to the possibility of physician-assisted death in all circumstances. Those who defend this view refer to categorical claims such as the inalienability of the right to life, the sanctity of life, the absolute prohibition against killing other human beings, and to healing as the single and ultimate goal of medicine. I want to focus on this last claim.

On this view, the essence of medicine is to be found in the *telos* of benefiting the sick by the action of healing. It is worth asking, however, just what is the status of this claim. It should be recognised that the practice of medicine and the ends it serves are of human invention, and not 'naturally given' activities deriving from the structure of natural order. The practice of medicine is shaped by human beings in order to serve human purposes. It involves human choice with regard to value systems, and choosing such a value system requires moral argument and justification, not an appeal to the 'nature of things'. Whatever the goals of medicine are, or should be, is thus a matter which is open to rational debate, and cannot be decided without reference to value considerations.

But even if, for the sake of argument, we agree that the *telos* of medicine is healing – and not, for instance, the relief of human suffering or the promotion of the benefit of patients – then we still are left with the question of exactly what moral force such an end or goal of medicine has. If we look at the actual practice of medicine, it is clear that healing is more an ideal than an unconditional goal of medical endeavour. Take for instance the case of refusal of treatment by the patient. A well-considered refusal of treatment ought to be respected, even if the physician takes the view that treatment would be beneficial to the patient. The reasons for respecting competent refusals of treatment are twofold. The first reason is that non-consensual intervention where a person has decision-making capacity invades the

integrity of the person involved. The second is that competent persons ought to be considered the best judges of their own interests. Only the competent person himself can assess the benefits, burdens and harms of treatment in view of his or her wishes, goals, and values. So, if a person refuses treatment because he or she does not value treatment in his or her personal life, then such a refusal ought to be respected, even if this might result in an earlier death. Thus, as this example shows, healing as an ideal in medical practice implies that other goals and values can and do operate as constraints upon medical actions serving this ideal.

More directly related to the issue of physician-assisted death is the consideration that the ideal of healing can become illusory, for instance in cases of severe and unbearable suffering in which no prospect of alleviation exists. The goal of relieving the suffering of the patient then becomes the primary goal of the physician, rather than healing.

Part of the moral integrity argument is the claim that, if physicians assist in suicide or euthanasia, then the public will begin to distrust the medical profession, and as a result the profession itself will suffer irreparable harm (Pellegrino, 1992; Thomasma, 1996). Against this objection it can be argued that, if physician-assisted death is categorically rejected, the result may also be a loss of trust in the medical profession. The public may experience this as a lack of compassion and personal engagement on the part of physicians in those cases where no adequate means of relieving the suffering of the patient are available and the patient wants some control over how to die, but is left alone by the doctor.

My conclusion is that, in principle as well as in practice, euthanasia and physician-assisted suicide do not necessarily go against the goal or goals of medicine, or the moral integrity of the medical profession. The Hippocratic vow of 'helping the sick' and of exercising medical skills for the benefit of patients does not prohibit the co-operation of physicians with requests for euthanasia and assisted suicide, so long as they are convinced that this is what is in a patient's best interests and to

the degree that the physician is committed to respecting a patient's own values.

The involvement of doctors in the dying of patients is inescapable. In many cases, a decision of a doctor leads to a hastening of death, although that decision may not always be considered the direct cause of the death of the patient (i.e. the decision to respect the treatment refusal of a patient). In euthanasia and assisted suicide, the causal role of the actions of the doctor is more clear-cut, and the practice of physician-assisted death raises a number of issues regarding the proper role of the physician and the self-understanding of the medical profession. Although the primary task of the physician is to preserve the life of the patient, preservation of life is not an absolute goal. This would demand an unconditional obligation to preserve life by all possible means and under all circumstances. If the relief of suffering is also a proper goal of medicine, then in particular circumstances a weighing or balancing of the goal to preserve life and the goal of relieving suffering becomes inescapable.

Euthanasia and assisted suicide do not necessarily violate the moral integrity of medicine.

ACTIVITY: Ron Berghmans's argument for the claim that the withdrawal of treatment in palliative care does not violate the *telos* or goal of medicine is a powerful one. But can you think of any counter-arguments to this?

Two of those which Berghmans mentions are, firstly, the claim that if the public sees the medical profession engaged in 'letting die' it may undermine the way in which the medical profession is perceived, and, secondly, that allowing the withdrawal of treatment under certain circumstances will lead to a slippery slope in which it is allowed in more and more cases which were not envisaged as being appropriate at the beginning. In his article Ron Berghmans rejects each of these criticisms, but we will be coming back to explore them in more detail later on in the chapter.

In this first section of the chapter we have raised the question of the goals or 'telos' of medi-

cine at the end of life. Both Berghmans and Maria's son have proposed the hypothesis that the goals of palliative care ought to be the alleviation of suffering, even if this sometimes goes against our sense that, in general, medicine ought to concern itself with healing. In the rest of this chapter we shall be going on to explore the ethical implications of this claim in a variety of different ways. In Section 2 we shall be going on to consider the ethical implications of a decision not to resuscitate a patient.

ACTIVITY: Stop for a moment and make a list of the key points raised by this section.

Section 2: Deciding not to resuscitate

In the Greek case study examined in Section 1, the patient was semi-comatose, although she appeared to express her wish to have the feeding tubes withdrawn by trying to pull them out, making signs, and uttering a few hard-fought words. In this section we will begin with another case in which the patient lacks capacity to consent to treatment. Here the issue is not whether to continue intravenous feeding and hydration, but whether to resuscitate a severely disabled patient if he suffers a cardiac arrest. Although the clinical picture is very different in this case, however, the same theme arises. Because this patient, known as 'Mr R', appeared to be in considerable suffering, this case gives rise to the same question as did the Greek case: is it part of the *telos* of medicine to avoid the imposition of unnecessary suffering by treating at all costs? Is it actually in the best interests of a suffering patient to impose treatment? Even in terms of the doctor's values and the *telos* of medicine, rather than the rights of the patient, we will need to draw boundaries that avoid a form of *iatrogenic* harm:

imposing burdens without corresponding benefits of treatment. In the case of patients who are not competent to accept or refuse treatment, doctors' main concern will be to avoid the imposition of unnecessary suffering.

THE CASE OF MR R

(Re R [1996] 2 FLR 99)

R was born with a serious malformation of the brain and cerebral palsy. At 8 months of age he developed severe epilepsy. At the age of 23 he was spastic, incontinent, and apparently deaf and blind (with possible vestigial response to a buzzer and to light). He was unable to walk, to sit upright, or to chew; food had to be syringed to the back of his mouth. His bowels had to be evacuated manually because his limited diet resulted in serious constipation. He suffered from thrush and had ulcers 'all the way through his guts', according to testimony. When cuddled he did indicate pleasure, and he also appeared to respond to pain by grimacing. Although he was not comatose, nor in a persistent vegetative state, his awareness on a scale of 1 to 10 was rated somewhere between 1 and 2 in an assessment by Dr Keith Andrews of the Royal Hospital for Neurodisability at Putney, London, who said:

It is my opinion that he has very little, if any, real cognitive awareness at a level where he can interpret what is going on in his environment. He reacts at the most basic level by responding to comfort, warmth and a safe environment by being relaxed and producing the occasional smile. He responds to discomfort, pain and threatening situations by becoming distressed and crying. These are very basic level responses and do not imply any thought processes.

Until he was 17 R lived at home, where he was totally dependent on his devoted parents. He then moved to a residential home, but continued to return home at weekends. Now his condition was beginning to deteriorate: his weight had dropped to just over 30 kg, and he was extremely frail, suffering from recurrent chest infections, bleeding from ulceration of the oesophagus, and continued epileptic fits. In 1995 he was admitted to hospital

on five occasions, each time for a life-threatening crisis. After the last crisis Dr S, the consultant psychiatrist for learning difficulties who was responsible for his care, wrote:

To hospitalize R if he had another life-threatening crisis would, in my clinical judgement, be nothing more than striving officiously to keep him alive for no gain to him. In my opinion, this is tantamount to a failing against a basic duty of humanity. Indeed, at the last few admissions to hospital, I have had real concern as to whether it was ethical to treat him actively. That said, I would never withhold treatment against the wishes of his parents. In summary, taking R's best interests into account and whilst taking into account the basic premise of the sanctity of human life, it is in my judgement unquestionably in R's best interests to allow nature to take its course next time he has a life-threatening crisis and to allow him to die with some comfort and dignity. That would relieve him of physical, mental and emotional suffering.

ACTIVITY: Go through the consultant's opinion again and write down the ethically charged terms or concepts that are being used to construct an argument. After each term, write down the consultant's apparent interpretation of it. Do you agree with this interpretation? If not, write down your own. For example, 'withhold treatment' is crucial to the argument, and the consultant seems to be saying that withholding treatment is ethically acceptable provided that R's parents agree. Nothing is said about actively ending R's life; rather the emphasis is on 'passively' withholding treatment which could be undertaken, but which it would actually be ethically wrong to administer. We shall return later in this section to arguments about the ethical validity of the distinction between withholding care and actively initiating death. The British Medical Association published guidance on withholding and withdrawing life-prolonging treatment in 1999 in which they asserted that:

Although emotionally it may be easier to withhold treatment than to withdraw that which has been started, there are no legal, or necessary morally relevant, differences between the two actions (BMA, 1999).

What do you think about this claim? Can you think of any arguments in favour or against it?

See also the Government's White Paper 'Making Decisions', 1999.

How did you get on with the list of ethically charged terms? In addition to withholding treatment, we identified these key underlying concepts/arguments:

- (a) Best interests of the patient
- (b) Sanctity of life
- (c) Relief of suffering
- (d) 'Basic duty of humanity'
- (e) 'Gain' or benefit to the patient
- (f) Treating actively (as against the implied alternative of allowing nature to take its course)
- (g) Wishes of the parents
- (h) Death with dignity
- (i) Medical futility: the question of how to judge when treatment is no longer effective

Quite a full list for one paragraph. This exercise illustrates how tightly packed with ethical concepts an apparently clinical judgement can be.

Now please continue reading the case of Mr R.

THE CASE OF MR R (cont.)

The immediate question now was whether to resuscitate R in the event of another acute admission resulting in cardiac arrest. He was so frail that it was feared CPR (cardio-pulmonary resuscitation) might crush his ribcage. In addition, there was a risk of further brain damage from resuscitation. A subsidiary question was whether to administer antibiotics if he developed pneumonia. After R's fifth hospital admission, in September 1995, the consultant, Dr S, discussed the position with R's parents. They agreed that R would not be subjected to CPR if he suffered a cardiac arrest in future. Accordingly, Dr S signed a DNR (do not resuscitate) direction, signed by R's mother under the heading 'next of kin'.

This decision was opposed by staff at the day care centre which R had been attending; they felt that he did, in fact, have some 'quality of life'. In

addition they interpreted Dr S's decision as a 'no treatment' policy, which Dr S denied: the only treatment which she was withdrawing, she argued, was cardio-pulmonary resuscitation. Agreement could not be reached, and a member of the day care centre staff applied for review of the decision by a court, on the basis of information provided by social workers involved in R's day care. The basis of the application was that the DNR (do not resuscitate) decision was irrational and unlawful in permitting medical treatment to be withheld on the basis of an assessment of the patient's quality of life. The hospital sought a court judgement that despite R's inability to give a valid refusal of treatment, it would be lawful and in his best interests to withhold cardio-pulmonary resuscitation and the administration of antibiotics. A proposed gastrostomy would be performed, however, underlining that there was no question of comprehensive refusal to treat R. Likewise, the hospital decided that it would ventilate R and provide artificial nutrition and hydration if applicable, although initially it had indicated it would not. The application made it clear that the hospital intended 'to furnish such treatment and nursing care as may from time to time be appropriate to ensure that [R] suffers the least distress and retains the greatest dignity until such time as his life comes to an end'.

At the High Court hearing, where R was represented by the Official Solicitor (who acts on behalf of incompetent patients), discussion centred on guidelines for resuscitation issued by the British Medical Association in 1993 (Revised, 1999) in a joint statement with the Royal College of Nursing. Resuscitation, originally devised to be used in a small minority of cases, is now overused, it has been argued (Hilberman et al., 1997). Although the technique can be very successful in the right context, at least in some US states it has become the default response to cardiac arrest, required unless it is explicitly refused or clearly 'futile'. Yet cardiac arrest is part of death. But was R dying?

The 1993 BMA/RCN guidelines, as used in the R

decision, did not actually say that resuscitation must always be attempted unless the patient is clearly in a terminal condition. Instead, they suggest three types of case in which it is appropriate to consider a DNR decision:

- (a) where the patient's condition indicates that effective cardio-pulmonary resuscitation (CPR) is unlikely to be successful
- (b) where CPR is not in accord with the recorded sustained wishes of the patient who is mentally competent
- (c) where successful CPR is likely to be followed by a length and quality of life which would not be acceptable to the patient.

ACTIVITY: Which, if any, of these conditions might apply to R? Note down the reasons for your answer.

Condition (a) is the most obviously clinical of the three. It focuses solely on the medical facts of the matter. Certainly R is gravely ill, but he has come through five acute admissions in the past year, so that it is difficult to say that he is definitely unlikely to survive CPR. Condition (b) cannot be met, because R is not mentally competent to record a wish. Although the consultant says that she would never terminate his care against his parents' wishes, in English law the parents of an adult have no power to accept or refuse treatment on his behalf (although at the time of writing, this was open to change after consultation on proposals for appointment of proxy decision-makers as put forward by the Law Commission (Law Commission, 1995: Lord Chancellor's Department, 1997)). (In most other European jurisdictions – for example, Greece – and in many American states, proxy decision-making on behalf of an incompetent adult is in fact possible.) The BMA guidelines merely noted that the opinions of relatives 'may be valuable' – not determining. Finally, we have condition (c), focusing on unacceptable quality of life – but again, acceptable or unacceptable to the patient. It is very hard to know whether R gets any enjoyment out of life: he seems to respond to being cuddled, and to react to pain, but that is really all we can say. Again, the

BMA guidelines did note that: 'If the patient cannot express a view, the opinion of others close to the patient may be sought regarding the patient's best interests.' But the guidelines do not say that opinion has anything more than advisory value as to what the patient would regard as reasonable quality of life. They also appear to envision a different kind of situation – where a previously competent patient, who (unlike R) had expressed definite views about good and bad quality of life, is no longer able to enunciate his or her wishes, but where the family will remember his or her preferences. (We will return to the important issue of quality of life in Section 6.)

So, strictly speaking, it is possible to make a case for arguing that none of these conditions applies to R. But that was not the opinion of the Court. Prompted by guidance from Keith Andrews as an expert witness, the Court agreed that conditions (b) and (c) were not applicable – ruling out the quality of life arguments both for and against. Only condition (a) was to be considered, that is, the likelihood rather than the desirability of successful CPR. Even in hospital settings only about 13 per cent of patients receiving CPR survive to discharge, Dr Andrews testified; in a residential home such as the one R lived in, the chances would be virtually nil. Accordingly, the case turned on the futility of treatment, rather than on quality of life. On the basis of medical futility, the Court accepted the DNR order, but not a global policy against other interventions by the consultant when, and if, a potentially life-threatening infection arose.

ACTIVITY: Stop here for a moment and try to devise a possible counter-argument to this view. What might be the pitfalls of using medical futility to decide whether or not to resuscitate?

There is quite widespread distrust of the concept of medical futility (e.g. Gillon, 1997) as excessively paternalistic. Because it purports to be a purely 'scientific' criterion, it allows the doctor to decide, rather than in consultation with the patient. It is never possible to say that, in this particular case, a

treatment will or will not be completely futile; rather, it is a question of what levels of probability are acceptable. That decision should rest with the patient, it can be argued, and not with the doctor alone. Of course, in the case of R, no consultation with the patient was possible, and Dr S's decision was accepted by the parents. But we have already seen that the parents' opinion is only advisory in English law. And it might be argued that precisely because Dr S couldn't know whether R would have thought resuscitation futile, she should have erred in favour of administration of CPR, rather than a DNR order.

One argument in favour of using medical futility as a criterion is that it is simply unavoidable. Unless we want to say that treatment should always be provided to a competent patient who requests it, or to an incompetent patient whatever the circumstances, then someone has to draw the line somewhere. That person is most likely to be the doctor (Brody, 1997).

Whichever you believe, the R case centres on what duties doctors have to avoid imposing suffering, unless suffering has a point. It is when suffering is pointless, in the face of unacceptable burdens for little benefit, that the decision not to resuscitate appears valid. The issue is who decides what is unacceptable, and on what basis.

Acts, omissions and the doctrine of double effect

The R judgement emphasized that 'there is no question of the Court being asked to approve a course aimed at terminating life or accelerating death. The Court is concerned with circumstances in which steps should not be taken to prolong life.' The distinction here is between acts and omissions, a distinction originating in Catholic moral theology and also found in other contexts. The wording in the Anglican creed, for example, asks God to pardon believers for two separate matters: that 'we have done those things we ought not to have done' (wrongful acts) and that we have 'left undone those things we ought to have done' (wrongful omissions). In the medical

context, this Catholic tradition would hold that a decision to withhold treatment 'is not the equivalent of suicide; on the contrary, it should be considered as an acceptance of the human condition, or a wish to avoid the application of a medical procedure disproportionate to the results that can be expected' (in the words of the Vatican's 1980 Declaration on Euthanasia).

It is often difficult to distinguish between acts and omissions in practice. For example, is turning off a ventilator a positive act, or merely omitting to perform the treatment any longer? More radically, however, some philosophers, those who concentrate on the consequences of actions, do not accept the acts/omissions distinction, not even in principle. This is true of utilitarians such as James Rachels (Rachels, 1986), who argues that there is no significant moral difference between killing and letting die, and Jonathan Glover, who uses this example:

A man who will inherit a fortune when his father dies, and, with this in mind, omits to give him medicine necessary for keeping him alive, is very culpable. His culpability is such that many people would want to say that this is not a mere omission, but a positive act of withholding the medicine. Supporters of the acts and omissions doctrine who also take this view are faced with the problem of explaining where they draw the line between acts and omissions. Is consciously failing to send money to [charity] also a positive act of withholding? (Glover 1977, p. 96).

Supporters of the distinction might answer Glover's challenge by saying that the point at which to draw the line is the doctor's duty to care. It is because the son has a duty to care for the father that failing to give the medicine is wrong. (It might also be wrong to fail to give it to anyone who needed it, if we think we have a generalized 'Good Samaritan' duty to others.) In the context of a doctor's duty to care, both acts and omissions may indeed be wrongful: treating without consent would be a wrongful act, whilst failing to treat someone who had consented and who needed treatment might be a wrongful omission.

This may explain why doctors are often reluctant to rely on the distinction between acts and

omissions, why they feel a duty to treat at all costs – sometimes against relatives' wishes. This sort of scenario is illustrated by a 1995 Irish case, known for reasons of confidentiality only as 'in the matter of a ward of court'.

THE CASE OF A WARD OF COURT

The case concerned a young woman who, at the age of 22, underwent a minor gynaecological diagnostic procedure under general anaesthetic. During the procedure she suffered three cardiac arrests, resulting in serious anoxic brain damage. Doctors continued to maintain her in what they termed 'a near-persistent vegetative state' for over 20 years, feeding her first by nasogastric tube and then by gastrostomy. (She continued to breathe normally; ventilation was not required, except briefly after her cardiac arrests.) For many years she was in a rehabilitation centre, and was then transferred to a hospice, whose philosophy would not allow withdrawal of feeding tubes.

After almost 23 years her family sought an order that all artificial hydration and nutrition should cease, and that the Court should give such directions as to her care. Against public expectations, they succeeded in obtaining a Supreme Court judgement allowing treatment to be withdrawn. Non-treatment of any possible infections was also granted. With the Court's authorization, the Ward was brought home from the hospice, where volunteer nurses and doctors assisted in withdrawing the feeding tubes and caring for her until she died a week later. (They did so in contravention of guidelines from the Irish Medical Council and Irish Nursing Board, which refused, even after the Supreme Court judgement, to retreat from their insistence that 'feeding is a universal requirement in the care of human beings, and whether or not this feeding is done through tube mechanisms does not alter this moral position.')

(Irish Medical Council Guidelines of 4 August 1995)

The prayer card for the Ward's memorial mass gave two dates of death: the first in 1972, the time of the accident, and the second in 1995, when she was finally allowed to die.

Although the Supreme Court judgement eventually upheld the notion that the Ward's best interests did not require active treatment which had little chance of success, the family were angered by doctors' refusal to listen to this argument earlier – as Dolores Dooley of University College Cork makes plain.

Following a minor diagnostic procedure under anaesthetic, Ms X was left severely brain-damaged. She would, in all probability, never recover cognitive functioning, never be able to move voluntarily, and never be able to communicate by choice. The family wanted life-support therapies to be ended when the prognosis became clear.

But they were baffled and angered by the marginalization they experienced as many decisions were taken unilaterally and without consultation. They tried to ask: why resuscitate her on numerous occasions when all bodily evidence indicated she was trying to die? Why reinsert an abdominal feeding tube under anaesthetic only 6 months before her death, when their daughter had been in a 'near-persistent vegetative state' for 22 years? Why not provide the best of pain relief care (if she knew pain) and allow her dying to proceed naturally? What were the healthcare goals for this patient, and why were they not discussed with the family? What was the objective of such aggressive life-support measures? What moral imperatives were guiding these decisions?

ACTIVITY: Which of the procedures in the previous paragraph is an act, and which is an omission?

We would say that resuscitation is clearly an act, and a medical procedure. Insertion of an abdominal feeding tube is likewise active medical treatment, according at least to the decision in *Airedale NHS Trust v. Bland* (1993). (In this, one of the first such cases in Europe, withdrawal of feeding tubes was authorized for a young man left in a persistent vegetative state, although basic nursing care continued to be required.) Providing pain relief is a more difficult issue, even though it is an act rather than an omission.

Suppose that the issue in R had not been resuscitation, but the administration of pain relief in such quantities as were likely to accelerate death – again, with the intention of avoiding unnecessary suffering. The final words in the R judgement

stress this: 'His parents, his doctors and the devoted and selfless care workers will continue to spare no effort to make his life as bearable and as comfortable as possible until a crisis occurs which will result in Nature taking its course and R being relieved of intolerable suffering.' Could this care rightfully include pain relief? Clearly it could; the hospital stressed that it had never sought a 'no-treatment' order, and that it intended to make R's death as comfortable and dignified as possible. But could it include pain relief at levels which might actually hasten R's death? (Of course, it is a misconception to believe that pain relief always necessarily shortens life.) That seems a different matter from letting nature take its course: it is an active step. So far, we have distinguished between not doing everything that could be done – passively accepting the inevitability of death – and actively trying to bring it about. But this example lies uncomfortably between the two. It begins to sound more like active euthanasia and less like 'letting die'.

ACTIVITY: Another concept from Catholic moral theology, the doctrine of double effect, describes this situation. In the paragraphs which follow, John Keown, a medical lawyer at Cambridge University, outlines the doctrine. Read the account through, writing down the various claims underlining the principle (Keown, 1997).

According to the principle of 'double effect' it is sometimes perfectly proper if one's conduct unintentionally has the effect of shortening, or of not lengthening, life. For example, the doctor who, with the intention of easing pain, administers morphine to a terminally ill cancer patient may foresee that this will shorten the patient's life. But the shortening of life is merely an unintended side-effect of the doctor's intention to alleviate pain, and there is a very good reason (namely the alleviation of pain) for allowing that bad side-effect to happen. He is not attacking the patient's life but the patient's pain.

Similarly, a doctor may sometimes properly withhold or withdraw treatment even though the doctor foresees that the patient's life will be shorter than it would be with the treatment. [In this view] a doctor is under no

duty to administer (and patients are fully entitled to refuse) disproportionate treatments, that is, treatments which would either offer no reasonable hope of benefit or would involve excessive burdens on the patient. Even if the doctor foresees that the patient's life will not be as long without the treatment as it would have been with it, the patient's earlier death is merely an unintended side-effect of the doctor's intention to withhold or withdraw a disproportionate treatment.

ACTIVITY: What is the weakest spot in this argument?

Perhaps one candidate is the concept of an 'unintended side-effect'. Must we take a doctor's word that the side-effect was merely foreseen and not intended? Surely there is a risk of hypocrisy here? Against that charge, it can be argued – convincingly, in our view – that if the doctor is not disappointed when the unintended side-effect fails to occur, it really is unintended. That is, if the patient's pain is relieved, and the patient does *not* die, the doctor genuinely abiding by the doctrine of double effect should be pleased rather than disappointed. He or she has truly intended the good effect and merely tolerated the possibility of the bad one.

Put in Keown's terms, the unifying factor between the withdrawal of treatment and the administration of possibly fatal pain relief is intention, rather than the action itself. In both cases the intended effect (the relief of suffering) is good. However, one might argue that is also the intention in active euthanasia. We will return to that problem in Section 4, where we discuss a case of actively assisting suicide. For now, we would like you to undertake one final activity before finishing this section.

ACTIVITY: Thinking back to the case of Mr R. in the light of the arguments you have explored thus far, do you think it would have been justifiable for Dr S to administer pain relief to R in the knowledge that his death might be accelerated? Jot down any conditions that you would want to impose on her power to do so.

In Catholic doctrine there are four conditions which must be fulfilled if a good action with a bad side-effect is to be allowed:

- (a) The action, considered by itself and independently of its effects, must not be morally wrong.
- (b) The bad effect must not be the means of producing the good effect.
- (c) The bad effect must be sincerely unintended, and merely tolerated.
- (d) There must be a proportionate reason for performing the action in spite of its bad potential consequences (Veatch, 1989).

In the case of R it seems to us that all these conditions can be met. There is nothing morally wrong with administering pain relief, in itself; indeed, it is morally good to relieve others' suffering. Death, if defined as the bad effect, is not the means of producing the good effect of pain relief, as would be the case if, say, Dr S administered a lethal dose of potassium chloride – whose only function would be to bring about R's death. We have already considered the third condition: if Dr S is not disappointed in the event that R does not die, then she genuinely does not intend his death. Finally, there is clearly a proportionate reason for performing the action, that is, the relief of suffering. All this is premised on Dr S's own feelings about the ethical acceptability of such a course.

ACTIVITY: Is it always up to the doctor's individual moral beliefs? Should doctors have the right to refuse to carry out treatments that contradict their own moral beliefs?

Although the answer to this question might obviously seem 'yes', you might also like to consider the opposite point of view: that patients can be harmed if doctors exercise their rights of conscience. In an American case, Beverley Requena, a competent woman of 55 who was on a ventilator in a church-affiliated hospital, decided to refuse tube feeding (Miles et al., 1989). This contradicted the hospital's ethical code, but hospital management offered to transfer her to another institution

which would honour her refusal. Ms Requena refused the transfer; in all other respects she was happy with the care she was receiving in the church-affiliated hospital, and it was there that she wanted to die. The hospital brought a suit to force Ms Requena to transfer, but failed in court. There the judge directed the hospital to reconsider its beliefs in a more flexible manner. The case of Beverley Requena makes a good link to the next section of this chapter, in that it concerns a legally competent patient.

In this section, as in Section 1, we have looked at ethical issues in the care of patients who cannot express a preference in their own end-of-life decisions. In the next section we move on to the competent patient. How comprehensive is the duty to relieve suffering there?

ACTIVITY: Make a list of the key points raised by this section.

Section 3: Refusal of treatment and advance directives

In the previous two sections we looked at the goals of medicine in the care of dying patients who are not competent to choose or refuse treatment. There, the clinician's main concern was to avoid imposing unnecessary suffering, in the best interests of the patient. But what happens when doctors also have to take into account the views of patients? Here and in Section 4 we move on to cases of competent patients – although in both these cases the patient's competence was borderline, for reasons of mental illness. In Section 3 we consider the UK case of Mr C, a long-term mental patient who was allowed to refuse amputation of a gangrenous leg; in Section 4, we look at the Dutch case of Dr Chabot, who assisted the suicide

of a clinically depressed but otherwise healthy woman.

Even if healing and/or the relief of suffering are taken to be the unquestionable goals of medicine, that does not justify the doctor's imposing his or her goals and values on those of the competent patient. Treating patients without their informed consent, even in the name of their best interests, is an unacceptable invasion of personal integrity, in this argument about what is ethically right and wrong – and that is also the legal position in most European jurisdictions. Even at the end of life, or at the risk of death, a competent adult patient has an absolute right to refuse treatment, as Ron Berghmans explains.

A well-considered refusal of treatment ought to be respected, even if the physician takes the view that treatment is beneficial to the patient. The reasons for respecting competent refusals of treatment are twofold. The first reason is that non-consensual intervention where a person has decision-making capacity invades the integrity of the person involved. The second is that competent persons ought to be considered the best judges of their own interests. Only the competent person himself can assess the benefits, burdens and harms of treatment, in view of his or her wishes, goals and values. So, if a person refuses treatment because he or she does not value treatment in his or her personal life, then such a refusal ought to be respected, even if this might result in an earlier death. Although healing is an ideal in medical practice, other goals and values can and do operate as constraints on medical actions serving this ideal (Berghmans, 1997a).

But what does Berghmans mean by 'a well-considered refusal of treatment'? Might one argue that refusing treatment which is medically advisable is automatically ill-considered? That this kind of reasoning does occur in practice has been extensively documented (e.g. Roth et al., 1977; Faulder, 1985; Culver and Gert, 1982) and, in the case of young people under 18, it has actually been upheld in law (*Re R* [1991]). The argument here is that refusal should carry a heavier 'tariff' than consent to treatment, because it goes against medical opinion. But that is different from saying that a refusal can never be 'well considered', even

if it flies in the face of medical opinion. As another court ruled in an earlier decision, 'the patient is entitled to reject [medical] advice for reasons which are rational, or irrational, or for no reason' (*Sidaway v. Bethlem RHG*, 1985).

We will now look briefly at a case which illustrates the criteria for competence. (This case is considered at greater length in the mental health chapter.)

THE CASE OF MR C

Mr C, aged 68, had been detained in a secure mental hospital for 30 years as a paranoid schizophrenic. His delusions included the belief that his doctors were torturers, whilst he himself was a world-famous specialist in the treatment of diseased limbs. When his own foot became infected, he therefore hid his condition from medical personnel until it had actually become gangrenous. His doctors believed that unless his foot was amputated, he stood an 80 to 85 per cent chance of dying.

Mr C, however, refused to consent to the amputation, saying that he would rather die intact than survive with only one foot. He sought reassurances from the hospital that his foot would not be amputated without his consent if he slipped into a coma. The health authority in charge of the hospital refused to give an undertaking not to amputate his foot without his consent. Mr C then sought a High Court order to prevent amputation if he became unconscious.

ACTIVITY: Do you think Mr C was competent to refuse consent to treatment? Jot down the principal reasons why, or why not.

As Mr C's solicitor, Lucy Scott-Montcrieff, explained:

The issue at the heart of all of this was whether or not Mr C had the capacity to refuse the treatment that was being offered to him. Mental illness doesn't of itself mean that a person doesn't have capacity; you could have capacity for some things and not other things. We had to establish whether Mr C could understand and

retain the information about the advantages and disadvantages of amputation and the advantages and disadvantages of not having amputation. The surgeon who'd been treating Mr C gave evidence; what he said was that he believed that Mr C did have capacity, because Mr C's views about capacity fitted in a very normal sort of way with the views of other elderly people with vascular disease who got gangrene more or less at the end of their lives. They didn't want to spend their last few years either coping with an amputation or possibly coping with repeated amputation as the vascular system fails all round the body. So the order was made that the hospital trust shouldn't amputate his foot without his permission (BBC, 1995).

In the event, Mr C survived, and his case made legal history in the UK for two reasons which are very important to the wider concerns of this chapter. Firstly, it established a clear set of criteria for competence.

- (a) Capacity to comprehend and retain information about the proposed treatment. Mr C was found to have this capacity, in part because it was shown that, in other aspects of everyday prudence, such as budgeting, he was able to take 'sensible' decisions. Further, it was held that what mattered was the narrowly construed ability to comprehend and retain information about this particular decision, on a functional basis, not capacity in some general sense. Given the general presumption of competence in adults, the doctors had to establish that Mr C did not possess this capacity; the court held that this had not been proved.
- (b) Belief in the validity of the information (see also *Re MB*, 1997). It might be thought questionable whether Mr C really believed what the doctors told him; after all, he thought they were torturers. Perhaps he also believed, in his delusions about his own medical 'stardom', that he knew better than the hospital physicians. Nevertheless, the court held that Mr C also met this criterion.
- (c) Ability to weigh up the information so as to arrive at a choice. Mr C had balanced the risks and benefits differently from the doctors, but that did not invalidate his decision, particu-

larly because an expert witness had testified that many other elderly people came to the same conclusion.

Secondly, the C case concerned the validity of advance directives, sometimes called living wills: statements made while a patient is competent, concerning what forms of treatment he or she would wish to refuse in the event of becoming incompetent, e.g. through coma or persistent vegetative state (Law Commission, 1995; Lord Chancellor's Department, 1997). (Because the general purpose of advance directives is to specify treatment which would not be considered acceptable, they are also sometimes known as 'advance refusals'.) They can be either written or oral, Mr C's was a witnessed verbal refusal. Advance directives illustrate in practical form the distinction introduced in the previous section between acts and omissions. They rest on the legal and ethical distinction between acting to do everything which could be done to relieve suffering – regardless of what the patient wants – and respecting the patient's right to request that certain forms of treatment should be omitted.

In the UK, at the time of writing (early 2000), it has been emphasized that '*certain forms of advance statement already have full effect at common law*' (Lord Chancellor's Department, 1997, p. 23). The conditions are that an advance refusal must be 'clearly established' and 'applicable in the circumstances'. In that case the refusal is as binding as that of a competent, conscious adult. 'An advance refusal made with capacity simply survives any supervening incapacity.' (Law Commission, 1995). However, because there was no statutory provision at the time of writing – although a consultation document was laying the grounds for such legislation – it was still necessary to go to court in order to establish the validity of an advance directive, as Mr C had to do. None the less, advance directives are generally recognized as an important part of patient choice and autonomy. Although they no longer apply only to terminal conditions, as they did when first introduced in the United States during the late 1970s, they may be particularly important in planning a treat-

ment programme for dying people. In the US there are both ‘information directives’ which specify what treatments are not acceptable to the patient and ‘proxy directives’ which authorize another individual to make the decision.

Advance directives also illustrate the difference between acts and omissions in another sense. They cannot direct the clinician to undertake acts against his or her clinical judgement: only to refrain from treatment which the patient finds unacceptable. Resource limitations will also determine what an advance directive can specify. Someone dying of kidney failure cannot obtain dialysis or a kidney transplant merely by taking out an advance directive demanding it. English case law has held that there is no specific liability on the Secretary of State to provide any particular level of health care (*ex parte Hincks*, 1980). Furthermore, an advance directive cannot direct what is unlawful. Thus in the UK at present, no one can take out an advance directive requesting euthanasia or assisted suicide. The position in the Netherlands is different in relation to euthanasia, as we shall see in the next section.

ACTIVITY: Take a few moments to write down the key points raised by this section.

Section 4. Euthanasia and physician-assisted suicide

Can euthanasia and physician-assisted suicide ever be a rightful part of the goals of medicine? Can it ever be ethical to inflict death in the name of avoiding suffering? Or is this a violation of the moral integrity of medicine (Singer and Siegler, 1990; Pellegrino, 1992; Momeyer, 1995)? Can ‘the best interests of the patient’ extend to ceasing to exist, or is that logically impossible? Is trust in the medical profession so radically undermined if

doctors are allowed to kill that we ought to rule out euthanasia and physician-assisted suicide altogether? Or does the possibility of euthanasia and of assisted suicide where suffering is intractable actually meet what patients want?

This section will explore these questions in the context of practice in the Netherlands, where euthanasia and assisted suicide are prohibited by the Penal Code but may lawfully be performed if the doctor follows certain guidelines laid down by the courts and the medical profession. Those guidelines, and Dutch public opinion about euthanasia and physician-assisted suicide, were severely tested in a case involving a doctor who assisted the suicide of an otherwise healthy woman who was deeply depressed over the deaths of her two sons: the case of Dr Boudewyn Chabot (Berghmans, 1997a). Dr Chabot felt that he would be letting his patient down, and increasing her suffering, if he failed to grant her request for assisted suicide. His deep commitment to his patient – which no one questioned – led him to feel that assisting her suicide was indeed part of his medical duty, and of the goals of medicine as he construed them.

Chabot’s critics, however, denied that he would be failing in his duty to the patient if he refused her request. It was also argued that the Chabot case dramatically illustrated the ‘slippery slope’ argument against euthanasia and physician-assisted suicide: that once introduced, it allows physicians to ‘kill off’ patients who are not terminally ill, and indeed not even ill at all. At most, Dr Chabot’s patient was mentally ill, clinically depressed; but should such a request from a mentally ill patient be respected? This relates back to the C case, which you examined in the previous section, and to the criteria for competence.

In this section we concentrate on a further extract from Ron Berghmans’s article on ‘Physician-assisted suicide in the case of mental suffering’, which you began reading in Section 1. This part of the paper concerns the Chabot case explicitly, but it also sets that case in the wider context of euthanasia and physician-assisted suicide in Dutch practice. Before you begin, you should note the difference between the two:

- In physician-assisted suicide, the doctor provides the means and guidance, e.g. a prescription for a lethal dose of medicine, and counselling on doses and methods. Although the physician may be present at the end, he or she does not perform the final act: the patient does.
- In voluntary euthanasia, a physician administers a drug injection or other agent at the patient's request, thereby performing the final act that results in the patient's death (Berghmans, 1997a). Euthanasia is more common than physician-assisted suicide: about 2.4 per cent of deaths in a recent Dutch research project resulted from euthanasia, against 0.3 per cent from physician-assisted suicide. In 0.7 per cent of cases, life was ended without the explicit, concurrent request of the patient, even though in the Netherlands euthanasia is defined as voluntary euthanasia (Van der Maas et al., 1996). In many of these cases the patient was comatose or otherwise incapable of making a request. The Dutch Rummelink Commission of 1992 estimated that up to 1000 instances of euthanasia every year were unasked for, and that some of these included competent patients. This is a frightening statistic, and, if accurate, a powerful argument against euthanasia; but it is not our principal concern here. Rather, we proceed from the assumption, *in arguendo*, that euthanasia is valid when requested by a competent patient; but we test that argument to the utmost by looking at a particularly troubling case.

Now continue with your reading of Berghman's paper.

Physician-assisted suicide in the case of mental suffering

Ron Berghmans

The debate concerning physician-assisted suicide and euthanasia is broadening: along with patients suffering from terminal illness, other groups of

patients are also being considered as potential candidates for assistance in dying. One of these groups is the mentally ill. I will concentrate on the case of physician-assisted suicide for the mentally ill, offering some background to the debate concerning the practice of assisted suicide and euthanasia in the Netherlands, and presenting opinion as it is developing in the Dutch context.

Although the point is sometimes misunderstood by foreign commentators, physician-assisted suicide and euthanasia remain criminal offences in the Netherlands. Assisting in the suicide of a person, which includes providing the means for someone to take his life, is a crime under Article 294 of the Penal Code. This article also applies to physicians acting on the request of a patient (Gevers, 1995).

The legal acceptability of euthanasia and assisted suicide is based on recognition on a case-to-case basis of the physician's defence of necessity (*force majeure*). To have this defence accepted, the doctor performing euthanasia or assisting with suicide must act according to the five following criteria, as set down by the Royal Dutch Medical Association:

- (a) There must be a voluntary, competent and enduring request on the part of the patient.
- (b) The patient's request must be based on full information.
- (c) The patient must be in a situation of intolerable and hopeless suffering.
- (d) All acceptable treatment alternatives must have been attempted.
- (e) The physician must consult an independent colleague before performing euthanasia or assisting with suicide.

ACTIVITY: Which of these criteria would be the easiest to fulfil, in your opinion, and which would be the most problematic?

We rated criterion (e) as the least problematic, and the easiest to prove or disprove in practice. (After you have read the case of Dr Chabot below, you might want to return to this list: you will see that his case hinged on this factor.) The other four

criteria all seemed problematic to us for different reasons.

- (a) How do we judge whether the doctor's influence lessens the voluntariness of the action? What about patients who are unable to give a voluntary consent, because they are in a coma? We have already seen that there are instances of euthanasia being performed on such patients in the Netherlands.
- (b) Full information is almost never available: no one can say for certain how long the patient will have to suffer. It is largely in B-grade films that doctors give a definite estimate such as 'You only have six months to live'.
- (c) The same caveat applies to 'hopeless'. The palliative care movement would deny that any suffering is 'hopeless'; palliation can almost always be achieved. Does 'hopeless' refer to the possibility of cure or of good palliative care?
- (d) 'No acceptable treatment alternatives' begs the question, insofar as the existence of euthanasia itself contaminates this decision. If it weren't available, the patient couldn't rule out all other alternatives.

These requirements were developed in the context of persons suffering from a terminal, or at least fatal or incurable, disease, such as patients with advanced cancer (Gevers, 1995). In the 1980s and 1990s, through a series of court decisions, reports and opinions from bodies such as the Dutch Society of Psychiatrists, the Royal Dutch Society of Medicine, the Inspectorate for Mental Health, and the Dutch Association for Voluntary Euthanasia, attention was extended to the issue of physician-assisted suicide for psychiatric patients. Lower courts took the view that, in exceptional circumstances, assisting a mentally ill person to commit suicide might be acceptable practice.

A landmark in this respect has been the so-called Chabot case (Griffiths, 1995). The defendant was a psychiatrist named Boudewyn Chabot, who in September 1991 supplied to Mrs Boomsma, at her request, lethal drugs which she consumed in

the presence of the defendant, her GP, and a friend. She died half an hour later.

Mrs Boomsma was 50 years old; she had married at 22, but from the beginning the marriage was unhappy. In 1986 her eldest son committed suicide. From that time on her marital problems grew worse and her husband more violent; her wish to die began to take shape, but she said that she remained alive only to care for her younger son. In 1988 she left her husband, taking her younger son with her. In 1990 her son was admitted to hospital in connection with a traffic accident, and was found to be suffering from cancer, from which he died in May 1991. That same evening Mrs Boomsma attempted suicide with drugs she had put by, but did not die. She then approached the Dutch Association for Voluntary Euthanasia, which put her in touch with Dr Chabot.

Mrs Boomsma was diagnosed as suffering from an adjustment disorder, consisting of a depressed mood, without psychotic signs, in the context of a complicated bereavement process. Although her condition was in principle treatable, treatment would probably have been protracted and the chance of success small. But she rejected therapy, despite Dr Chabot's best efforts to persuade her. He became convinced that she was experiencing intense, long-term psychic suffering which was unbearable for her, and which held out no prospect of improvement. Her request for assistance with suicide in his opinion was well considered. In letters and discussion with him, she presented the reasons for her decision clearly and consistently, showing that she understood her situation and the consequences of her decision. In his judgement, her rejection of therapy was also well considered. Chabot consulted seven experts. None of them believed that there was any realistic chance of success, given Mrs Boomsma's clear refusal of treatment.

In its ruling of 21 June 1994, the Dutch Supreme Court used the Chabot case to clarify a number of important issues in the euthanasia debate. First, it held that assistance with suicide was justified in the case of a patient whose

suffering is not somatic, and who is not in the terminal phase of an illness – but only if the physician has acted ‘with the utmost carefulness’. The court took the view that what matters is the seriousness of the patient’s suffering, not its source.

Secondly, the court stated that it was incorrect, as a general legal proposition, to claim that a psychiatric patient’s request for assistance with suicide cannot be voluntary. A person’s wish to die can be based on an autonomous judgement, even in the presence of mental illness.

ACTIVITY: How does this judgement compare with the C case we considered earlier?

The basic proposition appears similar on the surface: both courts agree that mental illness does not in itself bar a patient from making a valid medical decision. If you believe that killing is different from letting die, however, the Chabot case is more serious: Dr Chabot was being asked not to refrain from doing everything which could be done, but to actively assist Mrs B in her suicide – an act rather than an omission. There is also considerable doubt about whether Mrs B actually was mentally ill, or simply grief-stricken – whereas there is no doubt that C was the victim of gross psychotic delusions. Finally, in English mental health law a patient is allowed to refuse treatment for a physical disorder, but not treatment for mental disorder. The C case is consistent with that principle. Mrs Boomsma, however, had rejected treatment designed to mitigate her depression, that is, treatment concerning her mental health. It is certainly arguable that, if she was adjudged mentally ill, she should have been forcibly treated by anti-depressant medication. If she was not mentally ill, but rather deeply bereaved and yet sane, there were no medical grounds for assisting her suicide.

The Supreme Court also took the view that a patient’s condition cannot be considered hopeless if he or she freely rejects a meaningful treatment option. In such a case, assisted suicide is not justified. The difficult question is what counts as a

meaningful option. The court followed the viewpoint of a committee of the Dutch Royal College of Medicine, which laid down the following three conditions:

- the patient’s condition can be alleviated if proper treatment is given, on current medical opinion
- alleviation is possible within a reasonable time period
- the relationship of benefits to burdens of treatment should be proportionate.

Finally, the Supreme Court took the view that an independent expert must be consulted on all relevant aspects of the case, and must himself examine the patient before assistance with suicide can be given. This was the respect in which Chabot was adjudged to have failed. The seven experts whom he consulted had not themselves examined the patient. Therefore Chabot was convicted by the Court, although he was given a suspended sentence. After the Supreme Court decision, Chabot was also cautioned by the Dutch Medical Council, which took the view that he should have considered treating his patient with anti-depressants, even if she refused consent.

ACTIVITY: The implication of the Dutch Medical Council ruling is that most psychiatrists would have treated Mrs Boomsma with anti-depressants, and that Dr Chabot’s decision was aberrant practice. But how often do such cases arise? If they are rare, how can we know what is typical practice? – and how useful is the Chabot case for ‘ordinary practice’? How common do you think such cases are?

Two large-scale research projects into the practice of medical decision-making at the end of life have provided reliable data on the types of decisions being made, the motives of physicians, and other characteristics of Dutch practice on euthanasia and assisted suicide (Van der Maas et al., 1991, 1996). Another project, conducted in 1996, after the Supreme Court ruling in the Chabot case, also gives insight into the incidence of physician-assisted death in psychiatric practice (Groenewoud et al., 1997). Explicit requests for physician-

assisted suicide are not uncommon in psychiatric practice, but these requests are rarely granted. On the basis of Groenewoud's data, we can estimate that physician-assisted suicide in psychiatric practice occurs two to five times per year in the Netherlands. The total incidence of explicit requests for physician-assisted suicide by psychiatric patients was estimated to be about 320 annually. Most of the psychiatric patients who received suicide assistance suffered from both a mental disorder and a serious physical illness (unlike Mrs Boomsma, who was physically well). The most frequently mentioned reasons for assisting in suicide were that the patient's suffering was unbearable or hopeless, and that all previous treatment had failed. Two-thirds of Dutch psychiatrists surveyed consider assisted suicide in mental illness to be acceptable, and 46 per cent could envisage a case in which they themselves would be prepared to assist the patient in suicide.

After the Supreme Court's ruling in the Chabot case, the Dutch Society of Psychiatrists established a committee to advise on guidelines for dealing with requests for assisted suicide by patients who suffer from mental illness. The committee began from the following premises:

- A request for assistance in suicide in someone with mental illness ought to be assumed to be a request for help. The presumption should be that suicidal wishes are a sign of psychopathology, in the first instance, requiring suicide prevention, not suicide assistance.

ACTIVITY: Compare this premise with the argument made below by two medically trained practising psychoanalysts from Italy, Raffaele Bracalenti and Emilio Mordini:

A request for suicide assistance from a terminally ill patient should always be considered a reflection of bad practice. There is something wrong with the diagnostic or therapeutic process which has led to such a strong refusal to carry on with life (Bracalenti and Mordini, 1997).

Bracalenti and Mordini do not confine their statement to patients with mental illness: that is a key

difference from the Dutch guidelines. However, in both cases clinicians are advised to make a *prima facie* assumption against honouring a request for suicide. But the Dutch psychiatrists' association goes on to state that:

- Suicidality should not *a priori* be considered as a psychopathological phenomenon. Although many death wishes in mentally ill people have a temporary, transitory character, in exceptional cases a request for suicide assistance may be the result of a careful weighing process, and may be enduring.
- In exceptional cases, physician-assisted suicide may be responsible practice, but it can *never be* a general duty. Individual psychiatrists have no moral or legal obligation to practise assisted suicide, although they do have a duty to deal responsibly and carefully with every request for suicide assistance.

ACTIVITY: What does this imply about goals of medicine? Think back to the original premise with which this chapter began, that the principal goal of medical care at the end of life is the relief of suffering. Throughout this section we have been testing that premise to the utmost, by asking whether it is a duty in cases of hopeless and unbearable suffering to relieve that suffering by assisting the patient to die. On this alternative view, relieving suffering by assisting suicide is not part of the *telos* of medicine; rather, the proper goal is to deal carefully and responsibly with any request for suicide, and thereby to take the patient and her suffering seriously.

There is no duty to kill implied in the relief of suffering, nor in the patient's right to die. As the American bioethicist Daniel Callahan succinctly puts it, 'Your right to die doesn't imply my duty to kill'.

The Chabot case illustrates the 'slippery slope' problem about euthanasia and physician-assisted suicide, in that it seems unlikely that this was the sort of case envisioned when the current guidelines were first established (Keown, 1995a, 1997). Have the Dutch gone too far? Within the Netherlands, the Chabot case occasioned widespread doubts to that effect. Outside the country, some commentators even surmised the Chabot

cases demonstrated that euthanasia and physician-assisted suicide risk becoming a kind of social control and medical abuse (Bracalenti and Mordini, 1997). If there was no medical problem in Mrs Boomsma's case, this argument runs, it becomes clear that Chabot's action instantiates social rather than medical judgements. If we look at a hypothetical case of a healthy 50-year-old Indian woman who 'requests' *suttee* on her bereavement, surely we would think this an instance of dreadful social pressure, not a free choice.

Terminal illness, however, had never been a requirement in the Dutch system, and it can certainly be argued that mental suffering is no less unendurable than physical pain. Although mental illness may undermine autonomy and competence – thereby casting the request for euthanasia from a mentally ill person into doubts about validity – it does not automatically make the decision to refuse treatment invalid, as we saw in the C case.

On the other hand, by focusing on the doctor's duties rather than the patient's competence, it becomes irrelevant as to whether Mrs B's illness was mental or physical. As one of his critics pointed out at the Dutch Medical Association hearing, if Mrs B was mentally well enough to make a valid request for physician-assisted suicide, Dr Chabot, as a psychiatrist, should not have been acting in the first place. (Although he also viewed himself as her friend, he would have had no access to the lethal drugs if he were acting merely in his private capacity.) If Mrs B was mentally ill, Dr Chabot's duty was to cure her mental illness rather than assist her suicide. In fact Dr Chabot recognized that Mrs B was not mentally ill; the 'illness' from which she suffered was intractable grief. But that takes us back to the question of whether euthanasia was intended as a 'remedy' for human tragedy. Surely not – and if not, then this case shows that the Dutch have indeed slid too far down the slope.

A different sort of argument against euthanasia and physician-assisted suicide draws attention to the regrettable practical consequences of focusing

on its legalisation, rather than pressing for improvements in palliative care. This view, typical of the hospice movement, asserts that proponents of euthanasia and assisted suicide encourage the widespread public misapprehension that nothing can be done about suffering at the end of life except to end it by death. This is pernicious, they argue, and indeed ethically wrong. In the next section we will look at an example of good palliative care and dialogue with the patient. The purpose of this example is twofold: to provide an ordinary case from everyday hospice practice, in contrast to the highly dramatic and unusual case of Dr Chabot, and to show how doctors may respond to what their patients want without feeling, as Dr Chabot did, that he would be letting his patient down if he did not assist her suicide.

ACTIVITY: Take a few moments to list the key points from this section.

Section 5: Ethics at the end of life: a case

We began this chapter on ethical issues at the end of life with a consideration of the *telos* of medicine and of the role of the physician in situations where it seemed clear that 'healing' was no longer possible. In the introductory section we made the tentative hypothesis that the *telos* of medicine under these circumstances might perhaps best be characterized as something like the 'alleviation of suffering'. As you have worked your way through the various sections of the chapter since then, we have asked you to consider whether this is in fact an adequate expression of the ethical dimensions of decision-making in palliative care. Together, we have explored what the ethical and practical implications of this conceptualization might be through the consideration of a range of 'hard cases'.