

PART TWELVE

THE END OF LIFE

“ *You matter because you are you, and
you matter to the end of your life.* ”

**Dame Cicely Saunders,
founder of the hospice movement**

PART TWELVE

THE END OF LIFE

When I was a child in the 1960s, sudden death amongst middle-aged adults was not uncommon. The parent of a classmate at school might die unexpectedly, usually from a heart attack or stroke. Nowadays, however, only about 15 per cent of the half a million deaths that occur every year in the UK are unexpected. The majority of us die after struggling, perhaps for years, with conditions which cannot be cured.

Today, deaths arising from the same cardiovascular disease that often killed people unexpectedly 50 years ago can be postponed for decades through inventions such as triple bypass operations and stents (which keep furred-up arteries open). Medical advances also keep alive many people with kidney disease and various types of cancer for far longer than in the past. So, many of us can expect to live for a prolonged period with a medical condition which may well kill us eventually, but not immediately.

Many people fear death, as they think it will be painful, but they are mostly mistaken. A study of 486 hospital deaths in the United States in 1908 revealed that 11 patients experienced anxiety and 90 experienced pain, but for the remaining 385, 'Death was nothing more than falling asleep'.¹ If you are in pain before you are dying, that pain is likely to remain (unless measures are taken to alleviate it), but there is nothing intrinsically painful about the process of dying.

Pain relief has of course advanced massively since the American study was conducted. What has also happened is the development of a new field of expertise called palliative care. End-of-life care is a division of palliative care – it is a multi-discipline in which nurses, doctors, social workers, chaplains, counsellors and other professionals work to maximise

physical comfort and emotional and spiritual support during the final weeks and days of life.

Palliative care is also offered to people who are not at the end of their lives but have illnesses from which they may not get better and which may give rise to troublesome symptoms, such as cancer, emphysema and heart failure. This care can be given alongside treatment designed to cure. These types of palliative care are different from end-of-life care – although plainly people who receive the first may also come to need the second.

In the first chapter of this part, I examine the sort of care and support that people who are dying as well as those who have life-limiting illnesses can expect to be offered. Britain is a world leader in palliative care – the discipline has a huge knowledge base and much of that expertise has been built up in the hospitals and hospices of the UK. Yet on the ground, provision of palliative care (including end-of-life care) is uneven.² It is therefore worth knowing what support should be provided, in case you need to prompt.

I also examine how we can exercise choice over where and how we die. Of course, some people take matters into their own hands. In the film *Venus*, an ageing actor played by Peter O'Toole ignores the ambulance sent to take him to hospital when he is gravely ill and instead takes a train to Whitstable with a teenage girl with whom he is infatuated and dies suddenly – and happily – after paddling in the cold sea.

But for people not intending or able to try to pre-empt death, important questions present themselves. Would you wish to die in your own home or somewhere else? With or without your family around you? With maximum pain relief, even if that might make you drowsy? Would you wish to know that you were dying? Would you wish others to know? 'A good death' means different things to different people.³

Pressure has built up to permit healthcare professionals to give people help to kill themselves, should they come to lack the physical ability to do so themselves. Assisted dying is unlawful in the UK. However, anybody can opt to refuse life-sustaining treatment. If they are not in a fit state to do so at the time, they can refuse it in advance, and it is well worth thinking about making an 'advance directive to refuse treatment' if you are concerned that you might be kept alive against your will. Advance directives, assisted dying and other matters which may concern us as our lives ebb towards their close are discussed in the second chapter of this part.

Part Twelve therefore examines:

- ▶ the nature of end-of-life care
- ▶ where we may be cared for when we are dying
- ▶ how to get good end-of-life care
- ▶ palliative care for illness
- ▶ medical decisions arising at the end of life
- ▶ the choices we might like to consider beforehand
- ▶ how to make our wishes known
- ▶ advance directives to refuse treatment

Chapter 40

End-of-life care

Most of us are familiar with the sort of medical and nursing expertise available to us at the beginning of life. We know less about how we should be cared for as our life moves towards its close. It is worth knowing, in case we need to ask for help. This matters not only to the person who is dying; loved ones are likely to remember the occasion for the rest of their own lives.

In this chapter I look first at the nature of end-of-life care and contrast the different places in which it may be given. I also examine palliative care for different illnesses that may eventually result in death, even though death may be months, if not years away. I go on to discuss financial matters and support for carers when someone is coming to the end of their life. This chapter therefore addresses:

- ▶ the care and support we might seek at the end of life
- ▶ the help that family and friends can give
- ▶ spiritual support
- ▶ where we might choose to spend our final weeks and days
- ▶ palliative care for certain medical conditions
- ▶ how people with dementia can best be helped
- ▶ the position of carers
- ▶ financial support during end stages

What is end-of-life care? Well, it does not aim to cure somebody but to ensure that they die as comfortably as possible, with all the relief from pain and other discomfort they desire, and with the emotional and spiritual support that they choose. It also seeks to support the person's loved ones during the dying process and afterwards.

In many cases, good, everyday nursing – no more and no less – is the end-of-life care that someone needs, and, if they wish, the company of particular friends and relatives. However, in some cases, where people are facing troublesome symptoms or finding their situation difficult to deal with psychologically, more specialist help may be needed.

The World Health Organisation has teased out the hallmark features of palliative care given at the end of someone's life. It says that palliative care:

- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- provides relief from pain and other distressing symptoms
- integrates the psychological and spiritual aspects of care
- aims to enhance quality of life
- uses a multi-disciplinary team approach to address the needs of patients and their families
- offers a support system to help patients live as actively as possible until death and to help the family cope during the patient's illness and in their own bereavement, with bereavement counselling if necessary¹

Let us look first at the sort of tools available to modern medicine to handle the physical discomfort that can arise when someone is drawing towards the end of their life.

Symptom control

As noted in the introduction to this part, many people do not experience any troublesome symptoms during the final days or hours of their lives. But if they should, what are the sorts of steps that doctors, nurses and other care-givers should be considering to reduce any distress or discomfort?²

Such symptoms overlap with several which might develop in any very frail or unwell person who is spending a lot of time in bed, such as pressure sores. Some are more common in people who have very advanced cancer than in people who are succumbing to other conditions.

Bladder and bowel problems

Constipation is common amongst all older people who are unwell: 63 per cent of elderly people in hospital have been found to be constipated, compared with 22 per cent of the same age group living at home.³ Some

people who are coming to the end of their lives may be constipated, or have continence problems, just as they might if death were not imminent. Constipation is more common in people with terminal cancer than in those dying from other causes, as opiate drugs often cause constipation, while people with cancer often have poor appetites and so do not eat much.

A doctor should assess the reasons for the condition and, unless the patient is very frail, help should be provided to use the lavatory (rather than a commode or bedpan) and to increase physical activity. The addition of fibre to the diet and plenty of fluid to drink should help, but laxatives may be needed as well. (*See also Chapter 19.*)

Insertion of a urinary catheter may be suggested for incontinence or to relieve certain symptoms, but do not give consent unless you are convinced that this is the best option for you or the person you are representing. Pads may be more comfortable. (*For a discussion of the pros and cons of using a catheter, see pages 419–23.*)

Dehydration

Some people become dehydrated but find drinking difficult and an intravenous drip uncomfortable. A subcutaneous infusion of fluid can be a relatively painless means of ensuring they receive fluid. A needle is inserted into a layer of fatty tissue under the skin, often in the stomach region or in an arm or thigh, and the fluid seeps into this tissue, where it is absorbed. A nurse could set up an infusion for somebody overnight and they might feel much better the following day. (*See page 995 for ways in which relatives can help keep the mouth and lips moist.*)

Loss of appetite, nausea and vomiting

If somebody has lost their appetite, the reason can often be addressed successfully – it may be sore gums, nausea, a dirty mouth or unappetizing food, for instance. Perhaps a different dish, a little alcohol or the sharing of a meal would make the person more likely to eat and drink?

People with very advanced cancer may be disinclined to eat. Or they may feel nauseous. In either case, the causes should be investigated and action taken accordingly. A range of drugs that treat nausea (known as anti-emetic drugs) may prove useful.

Breathlessness

Steps which can help are mentioned below in connection with specialist palliative care for emphysema (*see page 1003*). Medication to reduce anxiety may help too, as anxiety often exacerbates breathlessness.

Coughing

This can be irritating and exhausting. End-of-life care would aim to lessen and soothe it. The most obvious treatment is a simple syrup linctus; other treatment could take the form of steam inhalations or medication, such as drugs to suppress the cough reflex in the brain and bronchodilators, which keep open the bronchi (the tubes that lead into the lungs). Drugs to reduce excess sputum can also be useful (*as explained under the next sub-heading*).

Respiratory secretions

Excessive secretions are common in people with cancer, pneumonia and bronchitis; the noise known as the death rattle results from saliva secretions building up in the throat when somebody becomes too weak to cough. Secretions can be reduced through gentle suction and the use of drugs which inhibit them. A change of position often helps, such as turning the patient on their side, if they can tolerate this.

Fever

Somebody who has an infection may have a fever. Ibuprofen and paracetamol can bring this down, as can a fan, a tepid cloth applied to the forehead, drinking water or sucking small ice chips. Very cold cloths and ice bags are unhelpful as they cause shivering, which generates heat.

Pressure ulcers

These can develop if somebody has been sitting or lying for long (or sometimes short) periods (*as I explain on page 17*). Nurses should be alert to the possibility of these painful sores and take steps to prevent and treat them (*as described on pages 398–400 and 913–5*).

Pain

Pain varies greatly in its nature and also from person to person, because it is a subjective sensation. This means that the optimum dose of an analgesic has to be carefully worked out for each patient, rather than adopting a one-size-fits-all approach. A decision also has to be made about whether to maintain that dose at a constant level rather than giving doses of analgesics only when the patient experiences pain. Pain assessment tools have been developed so that particular analgesic drugs can be selected carefully and at the correct dosage, while minimising side-effects such as drowsiness.

Insomnia

The first step with insomnia should be to work out the cause – such as a noisy ward, pain (*see above*) or breathlessness (*see above*) – and address it. Sleep-inducing drugs are another option.

Agitation

The cause of any agitation should be identified and addressed, if possible. Sometimes it is physical – for example, a distended bladder arising because somebody is unable to urinate. Or it may arise as a side-effect of medication, in which case the latter should be changed. At other times it is due to anxiety or emotional distress. The presence of loved ones and continuity of the staff providing care can reduce agitation arising from anxiety or emotional distress.

The administration of drugs

A fortnight before she died in 2005 in an NHS Continuing Care unit (*see page 965*), my mother, then with very advanced dementia, suddenly developed excruciating stomach pain and bleeding. This happened at a weekend and all my efforts went into finding a GP who would call. When he did, I was so relieved to have obtained some morphine that it did not occur to me to ask how it was going to be delivered. In fact, my mother struggled to swallow the tablets he prescribed and then had to endure additional distress while waiting for the next dose. Be ready to question and to press. Is morphine going to be given in a suitable form? How will its effects be monitored? What happens when they wear off? When will the dosage and method of delivery be reviewed?

Drugs can be delivered in several different ways – as tablets, in liquid form, as a skin patch, in the back passage as a suppository, intravenously, and as an infusion under the skin. It is important that they are delivered in the form in which the patient can most easily absorb them. Thus for instance, an injection or a patch would be better for somebody with severe nausea or difficulty in swallowing. Also a patch can ensure steady, continuous administration of a drug.

So too can a syringe driver. This is a device by which one or several different drugs can be given under the skin together, continuously and with the rate of delivery precisely controlled. Palliative care experts with special expertise in cancer Professor John Ellershaw and Susie Wilkinson have said: ‘A single continuous subcutaneous infusion containing up to three drugs will control the vast majority of symptoms which a dying patient is likely to experience.’⁴

If somebody is likely to develop troublesome symptoms, expect a doctor to consider giving drugs in anticipation of their appearance: clearly, inadequate medication or pain relief that is given late or not at all leaves people needlessly distressed and anxious. 'Just-in-case' anticipatory prescribing of medication to patients in their own homes ensures that if and when symptoms develop, immediate treatment is available. This can prevent hospital admissions, thus allowing patients the choice of remaining at home. However, it is important that the drugs are not actually given to the patient unless and until they need them or are highly likely to do so, as they may cause side-effects, such as drowsiness.

Individual end-of-life care plans

Although end-of-life care can consist simply of good nursing care, health-care professionals should be absolutely clear about what is needed. Perhaps a frail, elderly person has received treatment for pneumonia, but it has become clear that this will not work and they will therefore probably die. If it seems likely that death will come within days or hours, medical professionals should draw up an end-of-life care plan. This should set out how to ease any pain or other type of discomfort and provide psychological and spiritual support, and it should be drawn up in close consultation with the patient and/or their legal representatives and consultees (*see pages 782 and 789*).

These plans are intended to replace an approach developed in the late 1990s and over the following ten years called the Liverpool Care Pathway.⁵ This sought to give people who were considered to have no more than days or hours to live all-round care and support. If someone was placed on the Pathway, treatment designed to cure their illness would stop and instead steps would be taken to make them comfortable. The provision of any emotional and spiritual support they wished to receive was also a key feature.

Surveys indicated that the Pathway was well respected by professionals in the field: 89 per cent of palliative medicine consultants considered it represented best practice for dying patients and the same proportion said they would choose it for themselves if dying from a terminal illness.⁶

However, concerns were raised about the way in which the Pathway was being implemented. Establishing whether somebody is dying and what sort and dose of medication can help them is a task for specialists. Yet sometimes junior staff had to take the decision to put somebody on the Pathway, as no consultant was available. Their decision might have been incorrect.

Another concern was that untrained personnel might fail to adjust the care of someone in the light of their individual needs and wishes and changes in their physical condition. They would assume that once a patient had been placed on the Pathway there was no chance of recovery and, what is more, that food and fluid should be withheld. As a result, someone might die feeling very thirsty and/or their death might actually be caused by the withholding of fluid. Had they been given fluid, they might have lived for some time. Yet in fact there was nothing in the Pathway that said fluid should automatically be withheld, and the monitoring of a person's condition and the reviewing of their care in the light of changing circumstances were integral elements of it.

Concerns such as these were explored in a review of the Liverpool Pathway by a team led by Baroness Julia Neuberger in 2013.⁷ In the light of this team's findings, the Department of Health told health trusts in England to stop using the Pathway and instead ensure that individual end-of-life care plans were drawn up. Thereupon more than 20 organisations involved in end-of-life care came together to provide guidance for health organisations on the form these plans should take. Their recommendations were duly set out in the pithily-titled document *One Chance to Get it Right*.⁸

In the meantime, the body that draws up guidance on how particular health conditions and situations should be handled and has particular status in the health service, the National Institute for Health and Care Excellence, or NICE, had been preparing a more detailed guideline, which was published in 2015.⁹ This contains many useful recommendations.

In view of all this, here are steps you could reasonably expect people who are caring for someone who is dying to take:

1. Deciding that someone is dying

This decision should not be taken by one healthcare professional alone: it should involve people from different disciplines, who record the person's changing physical symptoms, talk to them about how they feel and also talk to those close to the patient. If doctors and nurses are uncertain whether someone is entering the last days of their life, they should seek advice from professionals with greater experience in end-of-life care.¹⁰

In other words, if you are living in a nursing home, a nurse on the staff there should not be deciding on their own that you are dying; they should consult a doctor. If together they remain uncertain, they should consult professionals with more experience and expertise.

2. Preparation of an individual plan of care

A team of professionals from various disciplines should talk to the patient and those close to them to create an individual plan of care. Refraining from a one-size-fits-all approach, they should focus on the particular circumstances and needs of the individual in front of them and their loved ones, and they should set out how the person involved should be cared for. Their plan should include the following items of information:

- the place where the person would prefer to be cared for
- the resources needed to meet this preference
- the person's views on the way in which any troublesome symptoms they develop should be managed
- the person's other goals and wishes: these might include a desire to live as normally as possible for a limited period, even if that might shorten their life; it might include a desire to end their life in a particular place and with particular people. The patient's goals and wishes may well already have been set down in an advance care plan (*see page 993–4*). If so, that plan should be borne in mind.
- needs for the person's care that are likely to arise in future
- any needs for care of the body after death¹¹

3. Giving fluid

Health and care personnel who are looking after someone who is dying should recognise that when someone is dying they may or may not need as much fluid as before. They should ensure that the person is physically comfortable and that they die with dignity. If the person wishes to drink and is able to, every help should be given to them to do so. This should be the default course of action.¹²

If somebody cannot drink in the normal way, doctors and nurses should discuss with them (or their representatives if they are unable to take the decision themselves) whether or not they should receive fluid artificially and, if so, by what means. This might be through an intravenous drip or through an infusion of fluid under the skin (*see above*).

The temporary alliance of organisations that drew up *One Chance to Get it Right*, which included the Royal College of Physicians, NICE, Marie Cure Cancer Care and the College of Health Care Chaplains stated unequivocally:

Even if it has been determined that someone may be dying, health and care staff must continue to offer them food and drink, provided eating and drinking would not harm the person. If the person wants this and needs help to eat and drink, health and care staff must provide that help.¹³

4. Monitoring and readiness to change direction

Healthcare professionals should be monitoring the patient closely and adjusting their care in the light of changing circumstances. They should always be alert to the possibility that their original conclusion that the person was dying was incorrect and be ready to give them treatment to cure their medical condition if it becomes apparent that they are not dying after all.

5. Basic principles

You may be looking after a friend or relative who is dying in your own home; you or a relative or friend may be spending their final days in a care home or a hospital. You may face a variety of different medical situations. It is impossible to predict what all these might be, but the Leadership Alliance for the Care of Dying People's report contains a short, useful set of basic principles that should underlie care planning at the end of life. The Alliance says the aim should be that all care given in the last hours and days of life in England:

- ✓ is compassionate
- ✓ is based on and tailored to the **needs, wishes and preferences of the dying person** and, as appropriate, their family and those identified as important to them
- ✓ includes regular and effective **communication** between the dying person and their family and health and care staff and between health and care staff themselves
- ✓ involves **assessment of the person's condition** whenever that condition changes and timely and appropriate responses to those changes
- ✓ **is led by a senior responsible doctor and a lead responsible nurse**, who can access support from specialist palliative care services when needed; and
- ✓ is delivered by doctors, nurses, carers and others who have high professional standards and the **skills, knowledge and experience** needed to care for dying people and their families properly (my emphases)¹⁴

Separate guidance expressing broadly similar sentiments has been published for Scotland.¹⁵

If you consider any aspect of your or your relative's care falls short of any of these principles, say so. For instance, if your relative is in a nursing home and is considered to be dying, but the home is failing to monitor their condition closely and the GP to visit sufficiently frequently, raise the matter immediately with the GP and the home's manager. Or if a care home is leaving someone who is dying on their own when they would plainly benefit from the company of someone else, ask how this can possibly be called compassionate care. If the person has said they would prefer to be alone, the home should nonetheless check frequently that there is nothing they can do to help them. Be prepared to threaten to lodge a complaint if necessary.

Telling the family what is happening

The death of a loved one remains with the living for the remainder of their lives, not least if it has been traumatic. One of the ways in which long-lasting harm can occur is through a failure on the part of doctors to communicate that somebody is close to death.

My father, who was coping with emphysema, fought off pneumonia about four times over the last four or five years of his life. When, just before Christmas 1974, he went into hospital with the infection that was to kill him, my family and I fully expected him to survive. Perhaps we were in denial. Certainly, no doctor had ever filled in my mother on her husband's prognosis or on the pattern that emphysema takes in its final stages (*see page 1003*). And so it was that when, on Boxing Day, we visited my father in hospital and the consultant afterwards drew me and my mother aside and told us that my father's lungs were worn out, we did not take this to mean that he was about to die. We understood that they had been worn out for several years. So, when the hospital rang us in the early hours of the next morning to say that he had just died, we were not only shocked but dismayed that we had not spent the night at his bedside. More than 40 years on, I continue to be haunted by concerns that his death was not a peaceful one and that his family was not at his side.

Doctors are not always good communicators about imminent death. If you suspect that a doctor is talking to you in euphemisms, such as 'making the patient comfortable', ask for clarification: 'Are you saying she is dying?' If you are unhappy with the place in which the doctor is talking to you about your relative's prognosis and future care, ask to move to a private space. Ask specific questions and demand answers (if you are prepared to hear them). Do not allow ignorance of impending death to

make the passing of a loved one any worse than it might otherwise be. As consultants John Ellershaw and Chris Ward point out, ‘If relatives are told clearly that the patient is dying they have the opportunity to ask questions, stay with the patient, say their goodbyes, contact relevant people and prepare themselves for the death.’¹⁶

In view of criticisms in this area, the Leadership Alliance for the Care of Dying People has explained that:

Open and honest communication between staff and the person who is dying, and those identified as important to them, including carers, is critically important to good care. Clear, understandable and **plain language** must be used ... Communication must be **regular and pro-active**, i.e. staff must actively seek to communicate ... It must be two-way, i.e. staff must listen to the views of the person and those important to them, not simply provide information. It should be conducted in a way that **maximises privacy**. Communication must be **sensitive, respectful** in pace and tone and **take account** of what the dying person and those important to them want and feel able to discuss at any particular point in time. Staff must **check the other person’s understanding** of the information that is being communicated, and **document this**.¹⁷ (my emphases)

Advance care plans

We saw when we considered individual plans for care at the very end of life that some people would already have an ‘advance care plan’. These are documents that doctors or other healthcare professionals may draw up in advance, typically a few months before it seems likely that someone will deteriorate. They seek to find out the person’s wishes ahead of time in case their ability to take decisions on the sort of care they would like becomes impaired.

The preparation of advance care plans is not mandatory, nor are patients obliged to engage with the discussions involved if they would rather not. But in the world of end-of-life care, the preparation of advance care plans is regarded as good practice. Thus the Department of Health recommends that doctors draw up these plans.¹⁸ The National Gold Standards Framework Centre for End-of-Life Care (a national organisation founded by a GP that promotes consistent and high-quality palliative care in hospitals, GP practices and care homes) says, ‘Advance care planning is the key means of improving care for people nearing the end of life and of enabling better planning and provision of care to help them live and die in the place and the manner of their choosing.’¹⁹

Patient choice should underpin advance care plans, as with other areas of medicine, so your doctor should fully involve you in drawing up yours. Indeed, the involvement of patients in planning for end-of-life care was singled out for special mention in the NHS Constitution (*see page 279*). Your doctor should ensure you have a copy of your advance care plan and that it is shared with other people likely to be involved, if you agree.²⁰ In the Medway towns in Kent, for instance, an electronic record is stored for authorised local doctors to access when needed; this is known as the My Wishes Register.

If you move into a care home to live, someone such as a nurse on the staff may ask you about your views on the way you would like to be cared for at the end of your life. If so, ask them whether they are doing so in order to prepare an advance care plan. If you are unhappy with the professional drawing up the plan, ask for someone else to do it instead or at least to be involved. The plan should range over scenarios which might arise towards the end of life and if you think the person drawing up the plan is ill-equipped to consider these, ask to speak to someone better qualified.

Advance care plans are not set in stone. They can be reviewed regularly or when circumstances change. You may well change your mind. For instance, some people say they would like to die at home but come to feel more secure in a hospital environment. Also, the extent to which your wishes are fulfilled will depend partly on whether any support you need is in place. If you go into hospital, need a lot of medical care to control pain and other symptoms and suddenly announce you wish to go home to die, you may have to cope with the fact that the health staff will find it difficult to muster the support you need immediately, and indeed some of it may be impossible to provide in your home. So, if you wish to die at home and have a serious medical condition, say so early, in time for all the necessary support to be marshalled.

Advance care plans thus provide a framework for thinking about the future. They are not legally binding documents – unlike advance directives to refuse treatment or conditions imposed in a power of attorney. *In Chapter 41, I set out some of the matters you may wish to set down in an advance care plan.*

Spiritual support

If you are a patient or relative of somebody who is edging towards the end of their life, you should not be embarrassed about asking for any spiritual support you feel you or they may need. It is an important part of the role of chaplains in hospitals (sometimes known as the Pastoral Care Team)

to provide emotional and spiritual support to people who are dying and their loved ones before and immediately after the death. Chaplains are trained to provide emotional and general spiritual support ('spiritual' is defined as anything which someone considers gives their life meaning and is certainly not confined to religion). If you think you might benefit from the help of a chaplain, you need to ask for it (*as explained on page 931*). Nursing homes do not usually have chaplains, but they ought to be able to put you in touch with local faith and humanist organisations.

Support from family and friends

Many people do not wish to be much involved in a loved one's end-of-life care, for one reason or another. They may reason that there is no point in visiting someone who is dying, as there is nothing they can do. In fact, there is usually a great deal.

Perhaps more than anything else, 'The mere presence of a familiar face raises morale, and sometimes raising morale is all you can do', retired GP Dr Justin Robbins told me in an interview in 2012.

The presence of visitors makes somebody who is coming to the end of their life also feel valued and reassured. Visitors can offer support through subtly reminding their loved one of the ways in which they are valued and the range of things they are bequeathing. I am not thinking here of money, businesses and property, but values, interests, family traditions and stories (*as discussed on page 91*). Visitors can also play music to their loved one; hearing is usually the last sense to be lost.

But there may also be practical steps that could help. For instance, some people develop a very dry mouth when they are dying. Or they may develop this beforehand – for instance if they are receiving extra oxygen to help them overcome a chest infection. Not only is a dry mouth uncomfortable, it makes talking more difficult. Helping to keep the mouth moist is a task which relatives may welcome, as it is something they can do for their loved one themselves. Steps include:

- giving regular drinks
- helping with brushing teeth
- giving regular sips of water
- giving chips of ice to suck
- giving small chunks of pineapple in juice (not syrup)
- administering water through a spray or blunt-ended syringe
- applying Vaseline or a lip salve

(I also discuss the value of visiting any patient in hospital on page 928–31.)

Where to die?

Just as pregnant women expect to be offered choice on where they will give birth, so we can expect choice to be offered at the end of our life. Our preferred place of death should be one of the questions about which our GP or another professional consults us during the preparation of our advance care plan. That said, as with pregnant women, sometimes circumstances mean patient choice is not always met.

In a general hospital

Half of deaths each year in England (nearly a quarter of a million) occur in hospital, many of these in general hospitals. Any large, general hospital is likely to have a palliative care team which includes palliative care consultants and specialist palliative care nurses, who should have up-to-the-minute knowledge of the latest techniques and drugs. The team is also likely also to include a social worker, who should offer a range of practical advice and help, including information on state benefits. Expertise may be brought in, such as the hospital psychiatric team, whose clinical psychologists or psychotherapists could be asked to give emotional and psychological support (*see pages 316–7*). Chaplains, too, may be consulted (*page 931*).

A survey by the Royal College of Physicians with the Marie Curie Palliative Care Institute in Liverpool found there had been steady improvement in the care of dying people in general hospitals in England between 2013 and 2015.²¹ In three-quarters of cases in the hospitals studied, staff had undertaken a holistic assessment of patients' needs to draw up an individual plan of care, and (while drinking is not always desirable as explained above), 39 per cent of patients were drinking during their last 24 hours of life while 45 per cent were being helped to drink. The hospitals were also trying to improve care further, with 63 per cent of them training their medical staff in relevant communication skills. Room for improvement remained – in particular, fewer than 40 per cent of the hospitals could provide specialist palliative care staff at weekends.

Whatever the quality of care, hospitals remain large buildings, and inevitably have some institutional feel. And although they usually have professionals who specialise in palliative care, the focus of an acute or a general hospital is on carrying out investigations and giving treatments that aim to cure. Perhaps because of this, it is not always easy to persuade hospital doctors to switch to palliative care when it is clear that their patient is not going to get better. Researchers interviewed 29 cancer and

palliative nurse specialists from five hospitals about end-of-life care in an acute hospital in 2006. Several of the nurses involved reported that it was often difficult to persuade doctors to stop giving curative treatment and start end-of-life care. Some of the doctors in question felt that palliative care equated to giving up on a patient. Others were disinclined to embark on what might be difficult discussions with patients and their relatives about end-of-life matters, and so carried on treating the patient, even though recovery was very unlikely. As a result, patients did not receive end-of-life care or, if a decision was made to give it to them instead of continuing to try to cure the condition, by then it was too late.²² Clearly this study involved only a small number of people, but it is worth bearing its findings in mind. You may need to engage in some straight talking with your doctor and prompt them to summon palliative care expertise if the treatment to cure you or your relative seems to be on a hiding to nothing.

In a hospice

The size, nature and ethos of hospices differ from those of general hospitals. Usually far smaller in size and purpose-built, the focus of hospices is on giving people who are not going to get better as high a quality of life as possible and supporting their relatives during the dying process and afterwards. Of the 220 complaints about end-of-life care that the Parliamentary and Health Service Ombudsman examined for the period 2011–2014, virtually none involved care within a hospice.²³

The people who pass away in hospices tend to be those whose final weeks or days call for especially sophisticated care. Admission in that final period can come as a great relief to both patient and family: they may have been struggling to cope at home, but in the hospice they know that all the help they may need is at the end of a call bell.

Patients may also stay in a hospice building well before the last weeks of their life while undergoing treatment to manage difficult symptoms; once they stabilise, they return home, or perhaps go to a care home, where their care is overseen by GPs. Whether patients are staying at a hospice or attending only for the day, psychological and spiritual support is an integral element of what the hospice offers, as for instance at St Catherine's Hospice in West Sussex.

St Catherine's Hospice is housed in an attractive, one- and two-storey, brick-and-tile building with ample car parking a few minutes' walk from the centre of Crawley. You enter through glass doors leading into the reception area, which opens onto to a large atrium occupying the centre of the complex. This is well-lit – indeed, the whole building seems flooded with natural light.

From the atrium, four wings radiate like wide spokes of a wheel. Two of these are bedroom wings and they look out onto the gardens that encircle much of the building and in which patients and their visitors can sit at tables with parasols, amongst well-tended plants. These wings provide accommodation for a total of 18 in-patients in two four-bed bays and single rooms.

The widest arm leading off the atrium contains a coffee shop, which leads into a large and welcoming conservatory, which gives onto the garden. Next to this, and also looking onto the garden, is a space for day-patients' communal activities. The fourth arm is smaller and contains the kitchen and an office. Other offices and meeting rooms for staff are housed in a separate building close by.

The 'quiet room' also leads off the atrium. It contains sofas, books, CDs and an open outer door, which faces Mecca. Gina Starnes, the patient services director, told me, 'Here you can kick off your shoes and curl up on the sofa with a book. Patients can sleep in here, if they wish.'

The quiet room can also be used for family meetings, including weddings and christenings, for meetings between family and staff, and for remembering. There are candles and a memories book. 'Mum, I miss you', reads Starnes explaining, 'The place where somebody died is important – people like to return'.

Visiting in hospices tends to be more flexible than in hospitals, with more support for visitors. At St Catherine's, visitors have the use of their own kitchen, which includes a microwave, so they can heat meals round the clock. There are two rooms for overnight accommodation and 'Staff will always make visitors tea and toast at night', according to Starnes. Visitors can bring in pets; once a goat was brought in to visit a farmer.

In hospitals too, there may, of course, be empathy and support for visitors, but the chances of finding these in a hospice are probably greater. In some ways, comparison between the two types of institution is unfair: hospitals have a far lower ratio of staff to

patients than hospices; also, hospices tend to be relatively small, with their own garden, kitchen, café and spaces for patients and their visitors to use.

‘Day hospice’ is another element of support which hospices usually offer. Somebody who has been diagnosed with leukaemia, say, might attend day hospice one day each week at which, in company with other people with life-limiting illnesses, they might do craftwork or some other activity, enjoy a talk or another form of entertainment, have a lunch cooked on the premises with a drink beforehand, and chat to other attenders. Should they need medical advice, this can also be provided while they are on the premises. Day hospice at St Catherine’s is ‘a time out for attenders’, says Gina Starnes: ‘There’s quite a nice, jovial environment. Crucially, they talk together – they get great strength from being with people in a similar situation. So it’s not purely social and it’s not purely medical.’

In fact, as in the majority of hospices, most of the work at St Catherine’s is carried out by staff in the community. It provides support to 500 families each year in their homes. There, nurses offer training and advice to family carers and also hands-on care, often taking over from a family carer, who can then go shopping or enjoy a good night’s sleep. They work in close touch with other professionals based on the ground, such as GPs and district nurses.²⁴

Where no local hospice exists, national hospice services such as Sue Ryder Care and Marie Curie Care and Support through Terminal Illness provide a similar service. As with most local hospices, they provide help mainly through a peripatetic team of nurses who minister to people day and night in their own homes, usually as a planned service rather than an emergency one, and with care in their own hospice buildings for a limited number of patients. (Macmillan nurses tend to provide specialist advice rather than hands-on care.)

Patients are referred to hospices through their GP, district nurse or hospital consultant. Hospices are regulated and inspected by the Care Quality Commission in England, Healthcare Improvement Scotland, the Healthcare Inspectorate Wales and the Regulation and Quality Improvement Authority in Northern Ireland. The national standards or guidance that set out what is expected from hospices, as well as inspection reports on individual facilities, are available from these organisations.

Information about hospice and palliative care services throughout the UK is also available from the voluntary organisations Dying Matters (see page 1023) and Hospice UK; the latter publishes an annual *Hospice and Palliative Care Directory* covering the UK and Ireland.

In a community hospital

In fact, many people die not in hospices or general hospitals but in community hospitals and care homes. The advantage of community hospitals (defined on page 902) is that they tend to be situated closer to where patients and their circle of friends and family live than district hospitals and hospices. Also, they are smaller than general hospitals and tend to have a more homely feel. Of course community hospitals vary across the country, but they can provide a congenial environment for somebody who needs care in the final weeks of life (longer than the time for most hospice in-patients). Thus, for example, in a survey involving six community hospitals in 2007, all 51 bereaved carers were positive about the care their loved ones had received in these hospitals.²⁵ The carers particularly appreciated the location of the hospital (close to their homes), the availability of parking, the pleasant environment and the support that they themselves received from the staff.

In a care home

A care home can also be an agreeable place in which to spend one's final weeks. It is likely to have a more intimate atmosphere than a general hospital, with staff knowing how the resident is faring and recognising relatives when they visit (though these are broad generalisations and may not apply in a large home that relies heavily on agency staff).

Some older people die in care homes because they have been living in them for a while and deteriorate. Other people die in care (usually nursing) homes after being transferred to them following a spell in hospital, because they are too incapacitated to return to their own home. Some people are moved from hospices to care homes if their condition stabilises. In both cases these will probably be nursing homes – in other words, care homes with a registered nurse on duty all the time (as explained in the *Glossary*). All told, more than one fifth of people aged over 65 die in care homes.

If you are considering entering a care home at the end of your life, do check that it could look after you well and that you would feel at home there.²⁶ The Scottish Partnership for Palliative Care has considered how care homes should provide end-of-life care, and wherever you live in the UK, it is worth getting hold of the booklet that distils its conclusions.

Although you could not press that the ‘good practice statements’ it lists should be met outside Scotland, it gives a useful sense of what you could reasonably expect:

- nursing homes should have at least one nurse on the staff who has a degree-level qualification which contains modules in palliative care
- care staff have or are working towards a qualification in palliative care, such as a Scottish Vocational Qualification in Social Services and Healthcare at level 3 (*see page 514*)
- provision will be made for relatives or friends to be accommodated overnight in the home so that they can be with a resident at the end of life, if that is their and the resident’s wish
- there will be one member of staff who can provide spiritual support, for example by saying a prayer with a resident or reading a text
- staff will assist residents in seeking help to settle any outstanding affairs, including legal ones
- if a resident who is approaching the end of life does not want to eat or drink as much as before, staff will know the importance of offering small amounts of tasty food and drink, and these will be available at all times during the day or night
- staff will help residents keep their mouth clean, fresh and comfortable²⁷

The amount of training in specialist end-of-life care that care home staff receive varies greatly. The Gold Standards Framework Centre in End-of-Life Care provides training to care facilities. By 2015, it had given special accreditation in end-of-life care to more than 500 care homes (a small proportion of the total number of homes). The Framework publishes a list of accredited homes on its website, together with a search facility for finding one in any particular area.²⁸ A good home will have this accreditation or be ensuring that a high proportion of its staff are taking courses in palliative care. It will also welcome links with a local hospice, many of which offer training in care homes. Thus in 2010 Highland Hospice reported to a conference that it was training staff in more than 40 care homes on best practice in end-of-life care and also providing helplines so that homes could obtain advice from hospice staff.²⁹

Good care homes will do whatever they can to care for residents who become very unwell, helped by visiting doctors, district nurses and other

health professionals. Some residents fear that if they are facing death, a care home manager may say that the home can no longer look after them so they must relocate to hospital or to another home. If the reason given is that particular equipment is needed, such as an intravenous drip or an additional supply of oxygen, how do you know whether the manager is behaving reasonably? The Scottish Partnership for Palliative Care says that equipment which can be deployed outside hospital includes a drip stand, oxygen provision, pressure-relieving mattresses, a portable nebuliser and a nasal-gastric feeding pump.³⁰ Plainly, it is important to check that the staff in the care home know how to operate the equipment.

It is also worth asking a nursing home about its approach to the deaths of residents if you are considering moving in. How does it help other residents to cope with the death of one of their number? Does it welcome back loved ones who wish to retain a link with the home? Does it encourage them to visit residents with whom their loved one was close?

At home

Many people say they would prefer to die at home. Others do not wish to do so, citing the frailty of family care-givers and fear of leaving behind sad memories in their homes.³¹ Although dying at home can seem ideal, many people change their mind and opt to die in hospital as their condition deteriorates.³²

It is important to talk to your doctor early on, particularly if you wish to die in your own home or in a care home, so that there is time for support arrangements to be put in place, such as training for a family carer and support from a hospice. Although most people would prefer to die at home, Professor Keri Thomas, a GP with a special interest in palliative care who pioneered the development of the Gold Standards Framework, believes the main reasons why many people end up going into hospital in their final days despite their wish to do otherwise include breakdown in the provision of homecare services and other support for family carers, such as night-sitters.³³ Doctors know that they should be planning ahead in this area; the General Medical Council has told them:

As treatment and care towards the end of life are delivered by multi-disciplinary teams often working across local health, social care and voluntary sector services, you must plan ahead as much as possible to ensure timely access to safe, effective care and continuity in its delivery to meet the patient's needs.³⁴

Palliative care

End-of-life care is not the only type of palliative care. Palliative care can also be given over days, weeks, months or years to people who have been diagnosed with an incurable, progressive condition such as cancer, chronic heart or lung disease, motor neurone disease or multiple sclerosis. Treatment aimed to cure can be given alongside palliative care – as well as treatment for other ailments, such as toothache. In this case, palliative care would seek to manage any pain or other troublesome physical symptoms and also to support the person in the round, providing any psychological and spiritual care they might wish to receive and enabling them to live as active a life as they wished. At the beginning, the focus would be on active therapies to enable them to maintain and improve their physical and mental capabilities.

When my father was suffering from emphysema in the early 1970s, he had to face the difficulties of walking and climbing stairs, the anxiety of not being able to catch his breath and the psychological challenge of increasing immobility pretty well unaided by the health service. Little in the way of equipment, drugs or even suggestions to cope with his condition was offered. Now, however, somebody with emphysema should expect palliative care, probably including a range of drugs, the administration of extra oxygen, and instruction, perhaps by a respiratory specialist nurse, on how to breathe in order to lessen the severity of the symptoms. Techniques can include breathing through pursed lips, leaning forward while sitting and supporting the upper arms on a table, and sitting near an open window or in front of a fan, so that a flow of cold air passes onto the face.³⁵ Relaxation techniques can also help control breathlessness: in one study, patients were less breathless and more able to do everyday activities after they had been taught breathing exercises, relaxation and coping strategies in three to six weekly sessions by a specialist nurse.³⁶ These sorts of techniques have the potential to much improve the quality of life of people with chronic lung disease.

But although considerable palliative care expertise exists, it is not always offered, particularly if the illness is not cancer. For instance, the Scottish Partnership for Palliative Care has pointed out that people with chronic heart failure often have limited access to palliative care. It says that it should be introduced at the early stages of the disease, ‘gradually and seamlessly, overlapping and complementing active treatment’.³⁷

The Department of Health has drawn attention to the need for doctors to ensure that palliative care is provided for a wide range of terminal conditions.³⁸ If you have not been offered specialist palliative care, raise the matter with your GP.

Cancer, chronic lung diseases, heart failure and motor neurone disease all typically follow different trajectories in their final stages. People with terminal cancer tend to go downhill suddenly and have particular needs for care during the last fortnight of life. In contrast, people suffering from heart or lung failure tend to show a continuous gradual decline over two to five years. This is punctuated by sudden problems which often require emergency hospital admission but from which they recover; in one of these, death usually seems sudden. On the other hand, people who are very frail and have dementia go downhill gradually and may recover a little along the way.

Dying with dementia

Dementia itself can cause death: as brain cells are progressively damaged, the heart, lungs and other organ systems of the body come to lose the direction they need. Eventually, damage to the brain is so serious that parts of the body start to shut down. This can take a very long time. Often the immediate cause of the death of someone with dementia is another illness such as pneumonia or cancer which they develop on top of their dementia and which their dementia may – or may not – have predisposed them to develop. All told, one in three people over 65 die with some degree of dementia.

Dementia can make coping with any illness more difficult, whether it is one of the ailments that afflicts us throughout life such as the common cold and toothache, or a serious illness which kills. If someone with dementia cannot put into words how they feel, they will be unable to convey the nature and extent of their symptoms or the impact of treatment. Ascertaining the level of pain and its location is therefore difficult, as is determining the presence and severity of other symptoms, such as nausea or constipation.

Yet alleviating distressing symptoms is all the more important because people with advanced dementia will be unable to help themselves cope with discomfort by deliberately distracting themselves with new thoughts or a diverting activity. Nor will they be in a position to put their immediate situation in the context of happier times or deeply held beliefs. So their response to pain, anxiety and so on is essentially unmediated, just as it is for an infant.

If your relative has dementia, it is therefore important to ensure that they have all the end-of-life care that might be beneficial. In the past, people with dementia have often received less attention to their palliative care needs than other people. A study in 2002 and 2003 of older people dying on an acute medical ward of a London hospital found that those

with dementia were less likely to be referred to palliative care teams (9 per cent of them as opposed to 25 per cent of people without dementia) or to be prescribed palliative care drugs (28 versus 51 per cent).³⁹ In recent years, there has been growing recognition of the special attention that should be paid to the care of people with dementia who are dying. For instance, the Select Committee of the House of Commons on Health has urged parity of access to end-of-life care for people with dementia and those dying of physical health conditions.⁴⁰

Talk to your loved one's GP or hospital consultant beforehand about how palliative care will be provided. Consider whether you should press their GP to seek advice on how to act: the average GP sees only about 20 patients a year who die, so may not have much experience of providing palliative care to somebody with dementia. You may wish to suggest that your relative should receive end-of-life care in a local hospice if they have or are likely to have symptoms which would be difficult to manage in the environment in which they are living. However, this factor has to be weighed against the reality that it is often better to keep people with dementia in an environment with which they are familiar, if possible.

Anybody treating a person with dementia should be taking steps to work out how they are going to comprehend the nature and severity of any symptoms and the effect of any treatment. Cards with simple questions such as 'Do you have a pain?' can be helpful (*see page 263*). Expect doctors and nurses to consult with relatives so that they fully understand any pre-existing conditions which might cause pain or other symptoms.

For people with advanced dementia, health and care staff should look for clues to any discomfort. These might take the form of:

- body language
- facial movements and expression
- moaning or muttering
- poor sleep
- agitation
- loss of appetite
- the extent to which somebody can be consoled⁴¹

Caring for loved ones

Some close friends or family members wish to care for loved ones who can no longer look after themselves and are in the final stages of a life-limiting illness and/or dying. Others do not. The state cannot force somebody –

including a spouse – to do this: the ultimate legal responsibility to care for adults who cannot look after themselves rests with the state.

If you are prepared to provide practical help, make sure that:

- ✓ social services gives you an assessment of any needs you may have for practical help to support you. The result of this carer's assessment (*see page 621*) might include help with housework and the provision of personal care for the person for whom you are caring. Some carers do not wish to help with personal care themselves, lest that should undermine their relationship with the person involved. No assumptions should be made about the type or level of support carers will provide (*see page 626–7*).
- ✓ your GP practice enters your name on any register of carers it holds. Everybody in the practice, not just your doctor, should know you are a carer. So, for instance, you could mention your status when booking consultations and expect receptionists to appreciate any difficulties you may encounter in attending surgery at particular times, most obviously if you are caring for someone who cannot be left alone.
- ✓ your GP practice or other health professionals give you all the training you need. Many cared-for people need help to get out of their chair and to transfer between chairs, to lavatory seats and so on. You cannot learn how to provide assistance from a book: the way you help the person for whom you are caring to move will depend on their physical condition and yours, as well as your relative weights. Expect instruction, perhaps from a district or practice nurse. If helping the person to move would threaten your own health, demand a hoist or other lifting equipment. Such equipment should be provided free under the NHS if you and they are assessed as needing it (*see page 279–80*).
- ✓ you are given any respite support you need, through somebody else caring for your loved one. If your loved one has troublesome symptoms which keep them awake at night, you will have your work cut out simply staying the course. You may be able to obtain respite from peripatetic hospice nurses, for example.
- ✓ you receive advice on state benefits for you and your loved one. For example, you might be entitled to Carer's Allowance (*see page 844–6*).

Financial support during end stages

Anybody who has a progressive illness and is not expected to live for more than six months as a result of that disease is entitled to be fast-tracked to the higher rate of Attendance Allowance. *As explained on page 835*, Attendance Allowance is a benefit granted on grounds of disability or illness to people aged 65 and over; it is not means-tested. Under this special provision for Attendance Allowance for people who are terminally ill, applicants simply have to produce a form from their doctor or consultant which describes their medical condition and explains that they are terminally ill. Awards under these 'claims under the special rules' are usually made for a fixed period of three years; they can be withdrawn by the Department for Work and Pensions if somebody's condition or prognosis improves so they are no longer considered to be 'terminally ill'. A claim under special rules may be made by somebody other than the person involved and without their knowledge or say-so.

There is also a fast-tracking provision for receipt of the equivalents of Attendance Allowance for people below the age of 65 – Disability Living Allowance and the Personal Independence Payment (*see page 840–4*).

NHS Continuing Care is a different sort of funding which can be given to people who are terminally ill. It covers both their healthcare costs and the costs of providing the practical help they need, and can be provided in a hospital, hospice, care home, the person's own home or that of a friend or family member. People who are deteriorating rapidly and are expected to die fairly soon can be fast-tracked to NHS Continuing Healthcare so that the support can be provided very quickly. This can enable them to leave hospital and die in their own home, if that is their wish. (*I discuss this funding for people who are dying on page 961.*)

End of life care

- * Dying is not intrinsically painful or distressing.
- * Palliative care enables any troublesome symptoms which may arise to be managed and provides emotional and spiritual support to the patient and their friends and family.
- * If you have only hours or days to live, expect health professionals to have drawn up an end-of-life plan for your care and to review it frequently.
- * If you wish to know, ask a doctor to clarify whether they are telling you that you or a loved one are dying.
- * Relatives and friends can do much to provide moral support when someone is dying and also perform practical tasks such as helping to keep the mouth moist.
- * Chaplains can be helpful sounding boards and comforters; religion need not be mentioned.
- * If you wish to return home from hospital to die and will need care, give your GP or hospital plenty of notice so that equipment and services can be put in place before you arrive.
- * A third of people over 65 die with dementia. They need special understanding and support.
- * People who have only weeks or months to live can be fast-tracked for Attendance Allowance, Disability Living Allowance, the Personal Independence Payment and NHS Continuing Healthcare.

Final decision-making

At any stage in our life, doctors may have to decide whether to prevent our death by offering us life-saving treatment. This might involve stopping bleeding from a wound, providing antibiotics to fight a potentially fatal infection or resuscitating us after a heart attack. In normal circumstances, we do not have a right to receive any medical treatment, but a doctor should offer it to us so long as it would not be futile.

Decisions on whether to give potentially life-prolonging treatment are more complex when someone is very unwell and/or very old. The fragility and perhaps frailty of their body may mean that the steps involved to save their life are less likely to work. Also, the measures involved might cause more distress than in a younger, fitter person.

Take ventricular defibrillation. Familiar from hospital TV dramas, this involves giving a massive electric shock to restart a heart which has stopped beating, thereby saving life. However, the procedure is traumatic. The patient has to be placed on a hard surface and intravenous tubes have to be inserted to give them drugs. The paddles through which the current passes may burn the skin. The procedure can cause bruising, and frail patients may suffer fractures of the ribs or breastbone. Patients may come round afterwards with soreness around the throat, as a plastic tube airway is usually inserted into the windpipe to provide more effective ventilation of the lungs. Pain can be treated and bruises fade, but if there has been an interruption in blood flow to the brain despite the procedure, the patient may wake up permanently brain-damaged.

Advanced dementia is often the reason why decisions over whether or not to administer life-prolonging interventions can be very difficult. A radio programme in 2014 discussed the case of a woman who had had a pacemaker inserted to make her heart beat at the normal rate.¹ Years later,

she developed dementia and the question arose whether the batteries in her pacemaker should be replaced when they wore out. Neither her dementia nor any other condition was threatening to kill her within a year, yet without a working pacemaker she would be likely to die at some stage in the not too distant future. Replacement of pacemaker batteries usually involves a simple medical procedure with a local anaesthetic, but this woman would not have been able to understand that she should lie still, so would have had to be brought into hospital against her will, restrained, given a general anaesthetic, woken up from that and then prevented, over several weeks, from tampering with the wound. In the event, her doctors, taking into account the views of her attorneys, decided it was not in her best interests to replace the batteries. When they did run out, her pulse slowed, then her heartbeat, and she died, at the age of 93.

But in many cases, lay people are unaware that treatment could be given that would avert death. For example, an elderly person in the advanced stages of a serious lung disease starts going blue in the face and slipping in and out of consciousness. An onlooker might assume nothing can be done. In fact, this condition is the result of a dramatic rise in blood carbon dioxide, which can often be treated by measuring the amount of gases in the blood and then adjusting the concentration of oxygen. The machine that performs this (which can be taken home) allows breathing to be effective even at night, when it naturally becomes shallower. A ventilator might also be needed.

While publicity tends to focus on people's efforts to ensure they would not be given life-saving treatment against their will, it is important to be aware of the desire of others to remain alive for as long as possible, even though they might be at death's door and appear to others to have a very low quality of life.

How can we ensure that the decisions made about offering or withholding life-saving interventions are those we would wish, particularly if we are not in a fit state at the time to grant or withhold our consent?

In this chapter, I set out:

- ▶ the rules governing the behaviour of doctors in end-of-life decision-making
- ▶ how patients can secure the medical treatment they would like
- ▶ advance directives to refuse treatment
- ▶ non-medical end-of-life choices
- ▶ where you could set down your wishes

Compulsory rules for doctors at the end of life

The General Medical Council, which regulates what doctors can do in the interests of the general public (*page 305*), has issued guidance on how doctors should take decisions on whether or not to offer life-prolonging treatment to patients who are likely to die within the following 12 months.² This guidance is available free on the internet and it is worth getting hold of a copy. It applies throughout the UK. Any serious or persistent failure to follow it which comes to the attention of the GMC puts the registration of the doctor involved at risk.

In normal circumstances, doctors should offer treatment to patients likely to die within 12 months without hesitation, unless it plainly will not work. But where somebody is likely to die soon, they can decide to withhold it. The GMC has said: ‘Decisions concerning potentially life-prolonging treatment must not be motivated by a desire to bring about the patient’s death, and must start from a presumption in favour of prolonging life’. However, ‘There is no absolute obligation to prolong life irrespective of the consequences for the patient, and irrespective of the patient’s views, if they are known or can be found’.³

The GMC sets out a two-stage process for doctors considering whether to offer life-prolonging treatment to somebody likely to die within 12 months. They should consider, ‘Which investigations or treatments are clinically appropriate and likely to result in overall benefit for the patient’ and also take into account ‘the patient’s views and understanding of their condition’.⁴

1. Weighing up whether treatment would benefit a patient

In deciding whether treatment is clinically appropriate and likely to result in overall benefit to a patient, doctors would be expected to ask themselves:

- Would this treatment actually work in terms of saving this person’s life?
- If it did, would the effect last or would the treatment have to be repeated soon afterwards?
- What is the nature of the pain and the other downsides the treatment would be likely to inflict on the patient?
- What sort of quality of life would the patient enjoy once any short-term effects of the treatment had worn off?

Let us take the example of ventricular fibrillation again. Suppose a healthy young person suffers a cardiac arrest after a routine operation. In

this case, a doctor will have a fairly high chance of restarting the heart. However, the situation is different when a patient is very sick. People suffering from major illnesses such as heart or lung disease or cancer are much less likely to have their heart restarted successfully, and the chance is lower still if they are also very old. In these instances, if the heart were restarted, an arrest might happen again within minutes, and yet again if the heart were restarted once more.

But of course this has to be set against the fact that the patient might go on to survive and return to the life they had been living before this episode, even though that life might involve much illness and disability.

How is a doctor supposed to evaluate the quality of life a patient might enjoy once the short-term effects of the life-saving treatment have subsided? That is very difficult – none of us can assess the quality of life of another human being, as Professor Sam Ahmedzai, who led the Royal College of Physicians' audit of end-of-life care in hospitals in 2016, explained to me:

Doctors cannot and should not try to estimate the quality of life of another person. They can't even reliably estimate how much pain a patient is having; they frequently underestimate pain. They underestimate nearly all symptoms. And they underestimate psychological problems. Routinely when we do a direct head-to-head comparison with what the patient says about quality of life on a questionnaire or interview with what the doctor says, we find the doctor has underestimated. Of course the more training a doctor has, the better he or she gets it; the longer the doctor knows the person, the better they get it. So a GP who had had training in communication skills would be very good at knowing whether a patient would want artificial resuscitation or not. But how often do doctors in a hospital or hospice or nursing home even think of ringing up the GP to ask whether such and such a person would want resuscitation?⁵

Just how wrong any of us can be in our estimation of the quality of life of another individual has been demonstrated by Ian Basnett, a doctor who was paralysed in all four limbs after a sports accident. He has pointed out that:

Research on the attitudes of accident and emergency doctors found that only a fifth imagined they would be glad to be alive if they were quadriplegic, whereas over 90 per cent of people with quadriplegia reported they were glad to be alive.⁶

In view of these uncertainties, the GMC has told doctors:

You must be careful not to rely on your personal views about a patient's quality of life and to avoid making judgments based on poorly informed or unfounded assumptions about the healthcare needs of particular groups, such as older people and those with disabilities.⁷

2. The patient's view

The second general area that a doctor must consider is the view of the patient. Usually, before doctors can give any treatment, they must obtain the consent of the patient. However, if emergency treatment is needed to save somebody's life, a doctor can proceed without the patient's consent.

Normally fit people can usually weigh up the pros and cons of receiving treatment, state their view and thus give or withhold consent for any treatment offered by a doctor. But some people may not be in a mentally fit state to do that. Their mental powers might be impaired, either because they are suffering from a condition such as dementia or because those powers are affected temporarily by illness: as we saw earlier (*on page 30*), elderly people are more likely to become confused than younger people if they are unwell. These impairments will clearly affect a person's mental capacity, or their ability to take a decision at the time it needs to be taken or to communicate their views, even through blinking.

In accordance with the principles of the mental capacity legislation (*explained on pages 770–4*), the GMC has told doctors that they, 'Must work on the presumption that every adult patient has the capacity to make decisions about their care and treatment'.⁸ If there is a chance that the patient may lack capacity, doctors, 'Must provide the patient with all appropriate help and support to maximise their ability to understand, retain, use or weigh up the information needed to make that decision or communicate their wishes'.⁹

If a doctor concludes that their patient lacks the mental capacity to come to a decision about whether to receive life-prolonging treatment, then they should explain the options to somebody the patient has appointed to speak on their behalf, most obviously through a personal welfare attorneyship (*see page 751*). If such a person has been appointed and has been given the power to refuse life-prolonging treatment, they can act as the patient's proxy in granting or withholding consent for any treatment offered.

The other set of circumstances in which a doctor would refrain from giving treatment they would otherwise offer involves an advance directive to refuse treatment (ADRT). If one of these has been signed by the patient and it is valid and relevant to the circumstances, a doctor would

not give the treatment in question, even if the patient would die without it. (*ADRTs are discussed on pages 1017–20.*)

If there is no legal proxy and no advance directive in place, the doctor must consult certain individuals associated with the patient, before coming to a final decision, if it is reasonable and practical to do so. (*These people are listed on page 782 and 789.*) Their views are fed into the decision-making process and the doctor must bear them in mind but does not have to go along with them: it is ultimately up to the doctor to consider what is in the best interests of their patient.

‘Do not resuscitate’ notices

In most situations in which decisions have to be made on whether to give or withhold life-sustaining treatment, there is some time in which the patient and/or other people can be consulted. But with ventricular defibrillation, time is of the essence. Once the heart stops beating and fresh blood therefore fails to reach the brain, the patient loses consciousness within a matter of seconds. Within minutes, brain cells start to die. Within about four minutes, irreversible brain damage is likely to occur. After a further two or three minutes, the brain will fail to respond to electrical stimuli and the patient will then be judged to be clinically dead.

Artificial resuscitation, in which somebody manually gives heart compressions and breathes into the patient’s mouth, can, if successful, restore partial flow of oxygenated blood to the heart and brain, thus keeping them alive. This extends the window of opportunity for successful ventricular defibrillation without permanent brain damage.

As these steps must be taken immediately in the event of a cardiac arrest, an instruction is usually drawn up ahead of time if there is any doubt about whether the treatment should be offered. This is in the form of a ‘Do not resuscitate’ or ‘Do not attempt cardio-pulmonary resuscitation’ notice. It is kept in the patient’s medical records and on a hospital ward you may well see a drawer labelled ‘DNAR’ or ‘DNACPR’ at the nurses’ station. The instructions ‘DNAR’ are entered into a patient’s notes by a doctor (usually a consultant), and it is only a doctor who can alter or rescind them. However, the patient or their representatives should be consulted before such an instruction is drawn up.

It is important to check your DNAR status, just in case it says you should be resuscitated when you would rather not be – or, conversely, that artificial resuscitation would not be attempted when you would prefer that every effort should be made to keep you alive. As noted (*on page 281*), we all have a legal right to see our medical records, and representatives such as attorneys can also access them.

If you are unhappy with an instruction on resuscitation in your medical notes, go and see your GP or, if in hospital, ask to speak to a member of the medical staff (preferably a consultant or registrar) or, if none is available, a senior nurse. Ask for the instruction to be changed. If you are concerned about someone else, such as a close relative, ask on what grounds the decision was made. Was it the result of a conversation with the patient, and if so, when did this conversation take place? If there has been no recorded conversation, you are in a good position to challenge the decision. Speak to the consultant or a representative of the consultant such as a senior registrar, either of whom should have enough authority to agree that the DNAR order should be rescinded.

Of course, the consultant may say they consider the order should remain in force, as it is judged to be in the patient's best interests. Legally, doctors have a duty of care to the patient, not to the family, so if they maintain that the decision is in the patient's best interests, they can still act on it, regardless of what the relatives think (unless they are attorneys whose powers specifically include the right to refuse life-prolonging treatment). All a relative can do is to lodge a formal objection through the hospital complaints system. Go to the hospital trust's medical director to speed things up, because delay can (literally) be fatal.

If you are neither the patient nor have legal authority to speak up for them, probably your best card to play in seeking to overturn an instruction is that you consider, in view of your knowledge of the patient, it would run contrary to their wishes, views and beliefs.

Institutions such as hospices and care homes are not allowed to adopt blanket policies which deny all their residents certain types of treatment, so they cannot automatically write 'DNAR' on the notes of every patient or resident. Each case must be considered on its merits. But it is, of course, well worth the patient checking that they have not been made subject to any blanket policy, just in case.

People with chronic heart failure may have devices implanted which give an electric shock to stimulate the heart if the beat becomes irregular; these are implantable defibrillators. However, at the end of life they can cause a more prolonged, uncomfortable death. If you are in this position, discuss with your doctor the possible deactivation of your defibrillator.

What patients can do to influence end-of-life decision-making

As we have seen, we can only give or withhold our consent for treatment that is offered. At the end of life, we may not be in a fit state to do this.

What many people fear is that they will be given treatment, such as artificial resuscitation which they would have turned down had they been compos mentis.

A specific tool has been devised for this eventuality, to which I will turn in a moment. First, it is worth saying that a welfare attorney can be invaluable. If you grant one or more people the proxy power to take decisions on your behalf should you come to lose the ability to make or convey them (or in Scotland also to remember or act on decisions), you should stand a good chance of getting what you want. You can grant your welfare attorney the right to refuse consent for treatment, even if refusal would be likely to result in your death. If a particular treatment were being offered that could save your life, your attorney would consider what your best interests would be, bearing in mind your wishes and views; this might result in their refusing consent for life-saving treatment on your behalf.

The form in which one grants power of welfare attorney contains a section called ‘statement of wishes’. Many people seem to ignore this, but it provides the opportunity to set down the various ways in which you would like to be treated, should you become mentally incompetent, perhaps as a result of brain injury or dementia, or unable to convey your wishes and feelings, perhaps after a major stroke. Your attorney or attorneys should take these wishes into account whenever they are acting or taking decisions in your best interests. You can put down pretty well whatever you like. It could include medical and nursing matters, but also, for instance, whom you would welcome as a visitor should you become very ill and whether you would like a piece of music to be played if you were dying. (*I discuss welfare attorneyships in Chapter 31.*)

Health (and social care) professionals in England and Wales have a legal duty to consult certain people associated with a patient should they be unable to speak up for themselves or lack the mental capacity to take the decision in question. These include any welfare attorney, but also any deputy (*see Chapter 32*), unpaid carer, anyone ‘interested in the welfare’ of the person involved and ‘anyone named by the person as someone to be consulted on the matter in question or on matters of that kind’.¹⁰ These people may – or may not be – the person’s next-of-kin. (*I explain these requirements on consultation on pages 782–92.*)

It is well worth nominating one or more people in that final category: they could be an old school or work friend, for instance. Being such a consultee usually involves a one-off contribution only and so should not

be an onerous responsibility; acting as a welfare attorney sometimes can be.

Whoever represents you, make sure that they know your views beforehand, and that doctors, nurses, care home managers and anybody else who might be present at the time have clear information on the status of these people and their contact details. If you secure people whom you trust to take part in medical decision-making, you stand a better chance of securing the treatment you wish.

Advance directives to refuse treatment and living wills

Whether or not you nominate welfare attorneys or other people to be consulted in healthcare decision-making, you may wish to make an ‘advance directive to refuse treatment’ (ADRT). This provides a means for patients to refuse a particular medical treatment if they lack the mental capacity to grant or withhold consent at the time, perhaps because they are too ill or under anaesthetic or have serious brain impairment. Formerly known as the similar ‘living will’, an ADRT is usually used in the case of treatment that could save a patient’s life. The authorisation involves only the withholding of consent for specified types of treatment – it does not give doctors, or anybody else, any other power over someone’s treatment. An ADRT is legally binding; if one has been made and it is valid and applicable to the circumstances, doctors are required to follow it, even if death will probably result.¹¹

An ADRT cannot be couched in general terms – it must specify the treatment or treatments the person wishes to refuse. You might wish to decline artificial resuscitation, for example, should your heart stop beating; or the use of a machine to enable you to continue to breathe; or antibiotics in the event of an infection; or kidney dialysis; or a blood transfusion; or artificial feeding, perhaps through a tube. If you have a particular medical condition, there may be other forms of treatment that could prolong your life that you would wish to refuse. Discuss with your doctor the circumstances in which an advance directive might be relevant and the treatment that might be offered before you complete it. Your doctor will be able to explain the implications of refusing treatment. For instance, you might consider saying you refuse the offer of (potentially lifesaving) thrombolytic drugs should you suffer a major stroke (*see page 351*). But you might find that the stroke did not kill you but left you paralysed down one side of your body – an effect that the drugs might well have reversed. In other words, in some situations refusing a particular treatment in all circumstances may cause additional distress.

Two further conditions must be met for an ADRT to be valid:

- ✓ the person involved must have mental capacity when they sign the form (in other words, they must be mentally capable of making the decision and understanding the implications of it; *see page 774 or the Glossary for a fuller explanation of the meaning of mental capacity*)
- ✓ the ADRT must include a statement that the instructions in the directive are to apply even if the person's life is at risk

An ADRT made verbally is valid, but to refuse treatment necessary to sustain life, the decision must be in writing, and witnessed, and expressly state that it applies even if the person's life is at risk.

If an advance decision to refuse treatment is not valid or is not applicable to the circumstances in question, doctors do not necessarily ignore it. They must decide whether or not to give treatment based on what they consider is in the patient's best interests (*as outlined on page 773*). As part of this process, they must consider even an invalid ADRT if they have reasonable grounds to believe that it is a true expression of the patient's wishes.¹²

Unlike the lasting power of attorney, no standard form has been published by the Office of the Public Guardian for use as an ADRT. However, the voluntary organisation Compassion in Dying publishes 'Helpful Questions to Consider when Making an Advance Decision' as part of its Advance Decision Pack, available free on its website or by post, including in large-print form. Macmillan Cancer Support also publishes suggested clauses for an ADRT and explanatory notes.

Do remember to include in your ADRT an instruction about continuing steps to keep you alive specific to your situation, such as the replacement of pacemaker batteries. (*I mention the sort of circumstances in which this decision could arise on pages 1009–10.*)

It is clearly important to make sure that your ADRT is flagged up in your medical notes and that any relevant health professionals with whom you come into contact, from a paramedic to a locum doctor, know of its existence. An ADRT could form an important part of an advance care plan (*see page 993*).

Clearly, there is no need to involve anybody else such as a relative in making an ADRT, as is necessary with powers of attorney. However, do make sure that any welfare attorney, relatives and other people who will be consulted if you are not in a position to consent to medical treatment have a copy of your ADRT or know where to find one. According to research at the University of Nottingham in 2014, almost half the people who had made an ADRT had not shared this information with other

people.¹³ If you fear treatment which might be given in a hurry, wear some highly visible instruction on your person.

You can withdraw or alter your advance decision at any time and neither the withdrawal nor the alteration need be in writing. However, you must have the mental capacity to do so. If you do not, a proposed rescinding or alteration would be invalid.

It is important to review your ADRT regularly. The life-or-death circumstances you think you might face could change over time. Advances in medical science could alter the picture radically. You might change your views about the circumstances in which you would find life intolerable.

If somebody has specifically granted a welfare attorney the power to give (or withhold) consent for the same life-sustaining treatment decisions *after* making an ADRT, the latter becomes invalid. But if an advance directive is made after conferring welfare power of attorney and at a time when the person still possesses the mental capacity to do so, the advance directive overrules the power in the attorneyship.

Ultimate authority in the field of ADRTs is wielded by the Court of Protection, which can rule on whether an ADRT exists, is valid and is applicable to a particular form of treatment. Deputies may not refuse life-sustaining treatment: if such a question arises, the matter must be referred to the Court of Protection.

The **Scottish** legislation does not include provision for an advance decision to refuse treatment along the lines discussed above. However, according to Scottish law, when health professionals are deciding what if any treatment to give somebody who cannot consent, they should take account of the patient's past and present wishes.¹⁴

The Mental Capacity (**Northern Ireland**) Act 2016 gives advance directives to refuse treatment statutory recognition. It says (at Section 11) that someone who gives treatment to a patient contrary to their wishes as expressed in an advance statement does not have an exemption from liability. This would mean that a doctor who gave someone life-saving treatment when they had expressly said in an ADRT that they wished to refuse it would be breaking the law. The Act says that to be valid in these circumstances an advance statement must have been made by someone who had the mental capacity to make the decision, and that they would make the decision to refuse treatment in the current circumstances were they able to do so. In other words, the person must not have done anything since making their statement that contravenes it and they would not have changed their decision had they known more about their current circumstances. If they conferred the power to refuse life-sustaining

treatment onto an attorney after making an ADRT, that step would also be likely to invalidate the advance decision. *As noted on page 728*, no commencement date on which the Mental Capacity (Northern Ireland) Act 2016 would come into force had been agreed at the time of writing. However, many of the Act's provisions are reflected in common law and so might well be upheld before the Act comes into force.

Fudging and transparency

Plainly, an advance directive to refuse treatment enables somebody to refuse a particular treatment that a doctor offers. But what it does not do is to enable the patient or their loved ones to ensure that a doctor offers that treatment, still less to know that it exists.

In the past doctors may have taken it upon themselves to play God. They looked at a patient, perhaps with at an advanced stage of an incurable illness, considered their quality of life to be poor and decided against offering to provide a treatment that might extend their life; if the patient was unaware that the treatment might be provided, they were not in a position to ask why it was not being offered.

Nowadays, doctors are supposed to consult patients about all the decisions they take about their care, including those at the end of their lives. But do they still retain an instinct not to consult, a sense that their superior knowledge in the medical field trumps all other considerations? We do not know. However, in a large-scale study in 2003 involving six European countries, a large proportion of end-of-life decisions were taken with doctors consulting neither the patient nor their relatives – more than half of such decisions in Italy and Sweden.¹⁵ The decisions frequently involved doctors deciding either not to treat on the one hand or to administer medication to alleviate symptoms while appreciating that the hastening of death was a possible side-effect on the other.

Decisions towards and at the end of life can be complex. Interventions can give some people extra time that they value; for other people, they can result in great suffering, both for them and their loved ones. But if you are concerned that decisions are being taken without your being consulted, ask: does a treatment exist for the condition? Could it be tried? What would be the likely drawbacks?

The area where the absence of transparency in end-of-life care has probably been most prevalent in the past has been dealing with thirst. Plainly, if a patient who is too unwell to raise a cup to their lips is not given help to drink, they will die. But whether or not the provision of fluid should be viewed as a form of medical treatment has been debated. In the past it was seen as good nursing practice, but not necessarily a

matter with which doctors should concern themselves. However, as we have seen (*on page 912*), it is now firmly viewed as a matter on which doctors and nurses have real responsibility. Furthermore, any withdrawal or withholding of fluid or omission of help with drinking when someone seems to be dying should only happen if an active decision has been taken that this would be in that person's best interests: it should never be automatic (*see page 773*). This decision should involve the patient or their representatives and any other people who ought to be consulted (*see pages 782, 789 and 791*).

In the past it seems likely that withholding fluid by omitting to provide someone very ill with the help they needed to drink was used to end life and perhaps also to fudge end-of-life decision-making. In a case of which I became aware, a frail woman in her late eighties who was suffering from advanced dementia and living in a healthcare facility developed pneumonia. A doctor was called, who duly prescribed antibiotics. A week later, when the manager of the facility returned from leave, she expressed amazement to a daughter who was visiting that her mother had survived the infection. One key difference between this case and others is likely to have been that, during the manager's absence, the woman's daughter and other members of her family had been sitting at her bedside for long periods, helping her to drink.

A matron of a nursing home told a colleague of mine in 2001 that a large proportion of residents in nursing homes die from dehydration. Whether or not this is true, it is easy to see how it would happen if it were. A resident becomes ill and a doctor provides treatment for the illness, thus avoiding any discussion with relatives about whether treatment should be given. But for one reason or another, the manager of the care home refrains from providing the necessary staff time to help the enfeebled resident to drink and therefore stay alive. In other words, allowing a person to die of thirst provides a convenient means of ducking a difficult decision.

Whether or not this situation still exists remains unknown, save anecdotally. But help to drink remains different from other life-sustaining measures such as dialysis or resuscitation in that it takes effort over a period. If someone has a fever and therefore needs more fluid than usual, it takes a lot of sips to keep them hydrated. Relatives will need to check that adequate help is being given or give it themselves (making sure it can be done safely without fluid accidentally entering the lungs), if they wish to do all they can to aid recovery.

Assisted dying

Many people fear the long-term disability and illness they may face and are keen to shorten any suffering by ensuring they are given any help they need to die if they should come to lack the physical ability to kill themselves. Dementia is feared in particular, so much so that Terry Pratchett (who had a rare form of early-onset Alzheimer's) declared in 2010 that, 'People are frightened about the future. ... Suddenly we find a growing interest in assisted dying. Fear is the spur, fear of hell before death.'¹⁶

Assisted dying can take two forms. In assisted suicide, which Pratchett (who died in 2015) supported but did not in the event use, somebody is given the help they request to die, although they must be able to perform a deliberate act to deliver it, such as raising the cup containing poison or pressing a button or lever. They must also have the mental ability to understand what they are doing.

In an act of euthanasia, somebody deliberately kills a person who is unable to ask for help to die. The killing must be for the benefit of the person whose life is to be ended; it can involve a deliberate act or omitting to give somebody the help they need to remain alive. Plainly someone who cannot make the decision to end their own life, such as someone with advanced dementia, could not benefit from assisted suicide, but they could benefit from euthanasia, were it to become legal.

Both forms of assisted dying are currently unlawful throughout the UK. Strenuous efforts are regularly made to change this. Equally strenuous efforts are made to retain the existing legal situation.

Britons who opt for assisted suicide may choose to travel to countries such as Switzerland, where the practice is lawful. However, they are usually too unwell to get themselves there, so must find at least one person to help them. They must then consider whether that person might later face prosecution in the UK and also how they will deal with such practical matters as the disposal of the body. If the person who accompanies them is a loved one, everyone must consider how the bereaved will deal emotionally with the whole experience.

Who will look after the goldfish?

As they approach the end of their lives, many people worry about what will happen to their pets, whether they will see a particular person before they die, and what form their funeral will take.

They may also be concerned about unfinished business. Adela Austin, a psychotherapist with many years' experience, emphasised to me in an interview in 2016 the importance of trying to make peace with those close to us with whom we have unresolved difficulties. If it is not possible

to do this in person, writing a letter can also be helpful. Austin believes such action can enable someone who is dying to develop greater peace of mind and gain a sense of completion and well-being. This benefits not only the person at the end of their life, but also those they will leave behind.

As well as considering whether there are particular people with whom you wish to try to make up, here are some questions you might like to address (*others are mentioned in the context of advance care plans on pages 993–4*):

- ✓ whom you would like to be told of your death or that you are dying
- ✓ whether you wish your organs to be donated or your body used in medical training
- ✓ what kind of funeral you would like
- ✓ where you would like to be buried or your ashes placed
- ✓ to which organisations, if any, you would like mourners to send donations
- ✓ whether you would like a seat or other facility donated in your memory and if so, where (*see page 674*)
- ✓ whether your will expresses your current wishes
- ✓ what should happen to anyone for whom you are caring
- ✓ what should happen to your pets

Talk to your loved ones as frankly as possible about your final wishes. The one certainty is that at some point it will be too late. A voluntary organisation called Dying Matters, which has a local presence in many places as well as a national one, seeks to get us all talking more openly about death, dying and bereavement, using a powerful video on its website called *I Didn't Want That*. 'Death cafés', which have sprung up in several towns, involve occasional discussions about such matters in which an organiser facilitates debate over tea and cake.

Some of the most challenging end-of-life decisions that can arise involve what to tell loved ones about their or our own end. If you know your mother is dying but she does not, and she asks you about her prognosis, what do you say? Have a look at the website at healthtalk.org.uk (*see page 327*). It features video testimonies from people and carers facing illnesses and medical situations, including the end of life.

Final decision-making

- * Doctors must consider the extent to which any life-saving intervention for someone likely to die within 12 months would result in overall benefit to the patient.
- * In doing this, they must take into account the patient's views and understanding of their condition.
- * Check that any 'Do not attempt resuscitation' instructions in your medical notes conform to your wishes.
- * Make an advance directive to refuse treatment (ADRT) if you fear being given life-saving treatment that you would rather forego.
- * Specify in your ADRT the treatment or treatments you wish to refuse.
- * Review your ADRT regularly.
- * Make sure your ADRT will be seen by healthcare personnel, not least in an emergency.
- * Fluid should only be withheld or withdrawn if that seems the best course for that particular person. It should never be withheld simply because the person does not seem to have long to live.
- * If you are contemplating assisted suicide, consider carefully the likely practical and emotional implications for relatives or friends who help you travel to a country where this step is legal.
- * Make your wishes known about where you wish to die and what should happen after your death.