

END OF LIFE: THE FACTS

A booklet for people in the final
stages of life, and their carers



FOREWORD



Knowing what to expect when someone nears the end of life is vitally important – both for the person who's ill and for their family and friends. Nothing can heal deep feelings of pain and loss. But having information can help us to prepare for the physical and emotional changes that we might be experiencing.

I know from personal experience it can be a time of great uncertainty and stress – much of which can be avoided by simply knowing what's going on and how and why things may change.

This booklet from Marie Curie Cancer Care and Macmillan Cancer Support aims to fill that information gap.

It's called End of Life: The Facts and provides a practical guide to the wide range of situations and issues which face many patients and carers, particularly those making the choice to stay at home.

End of life care is a sensitive subject, but I believe there is a tremendous value in feeling fully informed and involved in making decisions – big and small.

Esther Rantzen

Esther Rantzen



CONTENTS

1	Issues to consider	9
	Questions to ask	
2	Being looked after at home	15
	Who can help if you are looked after at home	
	Where to get the equipment you need	
	Where to get financial support	
	Other places where you can be looked after	
3	The last few weeks of life	29
	Emotional and mind changes	
	Coping with physical changes and symptoms	
	Complementary therapies	
	Lasting Power of Attorney, advance decisions and advance statements	
4	The last few days of life	51
	Physical care	
	Symptoms	
5	Nearing death	59
	What happens	
	Mind changes	
	Physical changes	
	Final moments of life	
6	After the death	65
	What your GP will do	
	What your funeral director will do	
	Registering the death	
	How grief might affect you	
7	National organisations that can help	75



ABOUT END OF LIFE: THE FACTS

It can be very upsetting and shocking to be told that your illness cannot be cured, and you may need help and support to cope with this news.

This booklet explains what happens at the end of life and how to plan for it. It gives information for people who would like to be looked after at home during the final stages of their life. Your relatives and close friends may also need support and advice, so some of this information has been written for them.

Both you and your carers can read this booklet. It may help you to discuss the information together after you've read it. You may find it difficult to read the booklet all at once, so you may prefer to dip into different sections when you feel able to do so. We have included a useful list of issues to consider at the beginning.

Many support services can help you cope at what may be a difficult time. We have listed their details at the end of the booklet.



CHAPTER 1

ISSUES TO CONSIDER

You can discuss the questions with your healthcare professionals.

This chapter is about some of the issues you may want to consider. We've listed some questions to help you and your carers think about how you'd like to be cared for.

You can discuss these with your healthcare professionals so that, wherever possible, they can help care for you in the way and place you'd like.

QUESTIONS TO ASK

These questions are just suggestions, so you might want to ignore any that you don't feel are relevant to you. We hope the information in this booklet will also help to answer some of your questions.

You may like to get help from a relative, close friend or support organisation.

It can be daunting to think about these issues, so you may like to get help from a relative, close friend or a support organisation (see page 75). Your healthcare professionals can also support you.

Macmillan has a booklet, *Coping with advanced cancer*, which you may also find useful. You can order a copy by calling 0808 808 00 00 or going to be.macmillan.org.uk

Information

- What information do you need about your illness to help you understand what may happen to you?

Being at home

- Do you need to think about sleeping in a different room at home to make it easier for you: for example in a room downstairs?
- Is home still the best place for you to be?
- Might it be better for you to be cared for elsewhere: for example in a family member's or friend's house or in a hospice, hospital or nursing home?

People and surroundings

Who do you
want to have
around you?

- How would you like your surroundings to be as you are dying?
- How do you want to be treated by your relatives and close friends when you are dying?
- Who do you want to have around you?
- Are there people you don't want to see or don't feel well enough to see?
- Are there any issues you'd like to sort out with particular people?
- Is there anything you want done for the people you love?
- Is there anything you want done for any pets?
- Would you like a doctor or nurse to speak to you or your relatives or close friends about any particular issues?
- Do you feel that you or your relatives or close friends would benefit from support or counselling?

Sorting things out

Is there anything that you want to do before you get too ill?

- Is there anything that you want to do before you get too ill?
- Have you made a will?
- Do you wish to create a Lasting Power of Attorney? (see page 44)
- Are there any spiritual or religious practices that you'd like to be carried out? Who do you need to ask to make sure this happens?
- Are there particular practices you'd like to have carried out at the time of your death?
- Do you want your body to be treated in a particular way once you have died?
- What funeral arrangements would you like to be made?
- Do you want to be buried or cremated?
- If you choose to be cremated, where would you like your ashes to be scattered?

Decisions about treatments

- Are there particular treatments you don't want to have?
- Do you want to write an advance decision to refuse treatment (also known as an advance directive or living will)? – see page 46.

If you are a carer

What do you need to be able to look after your relative or close friend?

- How can you take care of yourself?
- What do you need to be able to look after your relative or close friend?
- Can you get help with housework, shopping and cooking so that you have more energy to be a carer?



CHAPTER 2

BEING LOOKED AFTER AT HOME

Many people want to die at home, in their own bed, surrounded by their close family and friends. If you want to be at home, then help and support is available for you and your carers.

Looking after someone you are close to can be a time of great closeness.

Although dying is a natural process, few people have experience of looking after someone who is dying. If you are a carer, the thought of looking after someone you care for or are close to at home can be frightening. However, it can also be one of the most rewarding experiences you can have, and a time of great closeness.

This chapter gives you information about:

- Who can help if you are looked after at home
- Where to get the equipment you need
- Where to get financial support
- Other places you can be looked after

WHO CAN HELP IF YOU ARE LOOKED AFTER AT HOME

It's important that you and your carers have as much support as possible.

It's important that you and your carers have as much support as possible. Caring can be hard work, both physically and emotionally. It's not always easy to ask for help, as we often feel we should try to cope alone. However, there are many healthcare professionals who can help you and your carers.

Carers may find Macmillan's booklet *Caring for someone with advanced cancer* helpful. You can order a copy by calling 0808 808 00 00 or going to be.macmillan.org.uk

Your GP

While you are at home, your GP has overall responsibility for your care. They can help you in different ways, for example if:

- you're worried about any changes in your symptoms, they can arrange to see you either in the surgery or at home – when they assess you, they'll discuss options for treating and controlling your symptoms
- you want to talk through what may happen as you become less well
- you want to make a plan for dealing with emergencies (although this isn't often needed) so that you get the care you want
- you need nursing care – they can arrange for you to be seen by a district nurse who will help to organise this for you at home
- you need specialist care from a palliative care team (see page 18), they can arrange for you to be seen at home by a specialist palliative care nurse.

District nurses

District nurses work closely with GPs and palliative care nurses. They make visits to patients and their carers at home and can provide help with:

- giving drugs and injections, changing dressings, giving advice on pressure area care and toilet problems, such as incontinence and constipation – they will arrange visits as needed and will let you know about the services they provide
- showing your relatives how to move you and take care of your personal needs
- coordinating your care and contacting other health or social services to help look after you if they are needed.

District nurses may be able to arrange help with tasks such as washing and personal care.

District nurses often work with palliative care nurses to help support you and your carers so that you can remain at home. They may be able to arrange a nursing assistant (also called a healthcare assistant) to help with tasks such as washing and personal care.

Nurses who specialise in a specific disease

Nurses who specialise in caring for people with specific diseases or conditions, for example heart failure, renal disease or motor neurone disease (MND), are known as clinical nurse specialists (or CNSs). They work in partnership with your district nurses, hospital or community team.

Marie Curie nurses can stay in your home overnight, or for part of the day.

Marie Curie Nursing Service

The Marie Curie Nursing Service provides a team of nurses across the UK that offer practical nursing help to people with cancer or other illnesses who are nearing the end of their life. Marie Curie nurses can stay in your home overnight, or for part of the day, so that your carers can get a good night's sleep, or a break during the day.

Marie Curie nursing care is free and your district nurse will usually arrange it for you.

Hospital or community palliative care teams

Palliative care teams provide care which is specifically aimed at improving the quality of life of people and their carers who are coping with life limiting progressive illnesses, such as cancer.

Hospital palliative care teams are usually based in a hospital, and community palliative care teams are based in the community. Hospital palliative care teams can visit you if you're an inpatient or if you're attending a clinic appointment. Community palliative care teams are often linked to a hospice and can visit you at home. All palliative care teams can give you advice on pain control, coping with other symptoms, emotional support and advice on practical problems.

Palliative care teams include specialist palliative care nurses and doctors. Many teams also have, or work closely with, a social worker, counsellor, occupational therapist, physiotherapist and a spiritual care coordinator or chaplain.

Specialist palliative care nurses provide counselling and emotional support for you and your carers.

Specialist palliative care nurses are experienced in assessing and treating your symptoms and also provide counselling and emotional support for you and your carers. Most specialist palliative care nurses work closely with a wider hospital or community palliative care team, which includes doctors and other healthcare professionals.

Specialist palliative care nurses are sometimes referred to as Macmillan nurses. However many Macmillan professionals are nurses who have specialist knowledge in a particular type of cancer. You may see them when you're at clinic or in hospital.

Doctors specialising in palliative medicine give expert medical advice on managing people with advanced disease. They work closely with palliative care nurses and may visit people at home if needed.

Nurses Some community palliative care teams have nurses who can visit you at home and provide practical care such as washing, dressing and giving drugs. A specialist palliative care nurse will usually arrange care from these nurses.

Physiotherapists can help ill people to move around. They can also help with pain relief and if you have breathing problems.

Social workers or care managers can give you information about any benefits you may be able to claim.

Social workers/care managers can organise help with housework, shopping and cooking, or a personal care assistant to help with tasks such as washing and dressing. If you can afford it, you may be asked to pay towards the cost of this help, but in some circumstances it may be funded for you. Social workers or care managers can also give you information about any benefits you may be able to claim, such as attendance allowance or disability living allowance (see page 22). They may also be able to provide more advanced counselling and emotional support for you and your carers.

Occupational therapists can visit your home to assess whether specialist equipment would help you move around and be able to do as much for yourself as possible (see page 21).

Counsellors are trained to help people in all types of situations. Seeing a counsellor can help people to understand and express their feelings, and cope better with their situation.

Spiritual care coordinators or chaplains offer spiritual care and support.

Your district nurse, specialist nurse or GP can tell you how to access these healthcare professionals and about the specific types of help and support available in your area.

WHERE TO GET THE EQUIPMENT YOU NEED

Your district nurse or occupational therapist can organise equipment to help you manage at home.

Your district nurse or occupational therapist can organise equipment to help you manage at home.

Your district nurse can arrange for you to have:

- a commode, urinal, bedpans or incontinence sheets
- a special mattress or shaped pillows
- a hoist or sling
- a special bed.

Your occupational therapist can supply:

- an adjustable bed
- a wheelchair, walking frame or ramp
- small gadgets, such as two-handled mugs or special cutlery
- grab-rails for your bath.

Your occupational therapist can also give you information about stair lifts.

If you haven't seen an occupational therapist, but need some equipment which they usually supply, ask your district nurse, GP or community palliative care team to arrange for one to visit your home.

Many shops and organisations also sell or hire aids and equipment. The Red Cross (see page 87) hires out equipment such as commodes and wheelchairs. You can also buy items such as incontinence pads and urinals from most large chemists.

WHERE TO GET FINANCIAL SUPPORT

Financial help is available from a number of sources and can sometimes be accessed at short notice.

Illness nearly always involves unexpected expenses and this can cause extra worry at a time when you least need it. Help is available from a number of sources and can sometimes be accessed at short notice.

Benefits

If you'd like to find out more about any benefits you may be entitled to, the Benefits Agency has two booklets (IB1 and SD1), which outline social security benefits. You can get a copy from your local Citizens Advice Bureau where staff can advise you about the benefits you can claim. You can find their contact details in the phone book and you'll usually need to make an appointment. You can also get information from the Benefit Enquiry Line on freephone 0800 882200 or the Department for Work and Pensions website at dwp.gov.uk

You may qualify for Disability Living Allowance if you are under 65 or for Attendance Allowance if you are 65 and over. Your local social security office can send you claim forms. There is a fast-track claim for people who may not live longer than six months. People claiming under this 'special rule' need to get their doctor to complete a form for either benefit. Your district nurse or palliative care nurse specialist can tell you more about these, and whether you can apply for them.

You may be entitled to get direct payments from your local authority.

Direct payments If you've been assessed as needing social services, such as help with practical care at home, you may be entitled to get direct payments from your local authority. This means that you're given payments to organise social services yourself, rather than local social services organising and paying for them for you. You can get information about direct payments from the Department of Health website at dh.gov.uk or from your local authority.

Other financial help

You may also be able to claim grants from other organisations or charities. Macmillan Cancer Support gives grants and benefits advice to people with cancer – call the Macmillan Support Line on 0808 808 00 00. You can also order the booklet *Help with the cost of cancer* at be.macmillan.org.uk or by calling 0808 808 00 00.

Your union or professional organisation, if you belong to one, may be able to give you financial help or advice. For example, actors, bank employees, doctors, musicians, nurses, printers, social workers, members of the armed forces and teachers all have special funds which help with cash grants and sometimes holidays. Details are listed in *A Guide to Grants for Individuals in Need*, which is available in public libraries (see page 90). It also gives details of all trusts and organisations that provide financial support.

People who have been told their cancer can't be cured and who need to gain some money quickly may benefit from a viatical settlement. This means that an independent financial company buys an existing life insurance or endowment policy from a terminally ill person. Care must be taken before selling an insurance policy, and we recommend that you always seek advice from an independent financial adviser.

Prescriptions

In England,
people with
cancer can
get free
prescriptions.

In England, people with cancer can get free prescriptions. If you are undergoing treatment for cancer and the effects of cancer treatment, you can apply for an exemption certificate by collecting a FP92A form from your GP surgery or oncology clinic. Prescriptions in Wales and Northern Ireland are also free and they will be free in Scotland by 2011.

In many areas of the country you can arrange for your GP or a local pharmacist to collect and deliver your repeat prescriptions to your home.

OTHER PLACES WHERE YOU CAN BE LOOKED AFTER

Although your wish may be to die at home, there may be a time when this changes.

Although your wish may be to die at home, there may be a time when this changes. You may decide that you'd be more comfortable in hospital or in a hospice, where trained staff can help your carers look after you, and relieve pain and other symptoms if needed.

If you're a carer, it's important that you don't feel guilty if you encourage the person you're caring for to die in a hospice, hospital or nursing home. If you have to make this decision to move them at a late stage, this shouldn't be seen as a failure, but rather because you want to make sure that your loved one gets the expert care they need.

Hospital or hospice

If you decide to go into hospital or a hospice, you and your carers may feel anxious that you might not be able to come home again. However, it's quite usual for someone to go into hospital or a hospice for a short time, so that symptoms can be closely monitored and brought under control. Then, if you and your family wish, you can return home.

Hospices are smaller and quieter than hospitals and often work at a much gentler pace.

Hospices specialise in controlling pain and other symptoms.

They are smaller and quieter than hospitals, and often work at a much gentler pace. Many have sitting rooms, a coffee shop and accommodation for relatives or close friends.

Accommodation and care in a hospice is always free of charge. Sometimes there's a waiting list, but urgent admissions can often be organised within a couple of days. Many hospices also have day centres for people living at home.

If you're not sure about the idea of hospital or hospice care, you can ask to visit the hospital or hospice before making a decision. You can then discuss any concerns with the staff.

If you decide that you'd like to be cared for in a hospice when you reach the final stages of your life, your GP or specialist palliative care nurse can arrange this.

Nursing homes are another place where you can be cared for, either for a short time or longer-term.

Nursing homes

Nursing homes are another place where you can be cared for either for a short time or longer-term. Your GP, district nurse, palliative care team or social worker can arrange this for you. Availability of care varies from one area to another and may take some time to organise. Private nursing homes charge fees for their services, but you may be entitled to NHS-funded nursing care or to fully-funded continuing healthcare. A team of health and social care professionals can carry out an assessment to decide whether you're entitled to funding.

It's a good idea to get information and advice from a social worker. You can get a list and details of local registered care homes and nursing homes from your local social services department or your area health authority. You can get information about finding a nursing home, and all the issues to consider on the Nursing Home Fees Agency (NHFA)'s website nhfa.co.uk or through the NHFA Care Advice line on 0800 99 88 33.



CHAPTER 3

THE LAST FEW WEEKS OF LIFE

During the last few weeks of life, you may experience a number of emotional and physical changes and symptoms. We have outlined these here, together with ways of dealing with them.

Being prepared for what may happen can make the situation a little easier to cope with.

Although these changes and symptoms are normal for someone in the last few weeks of their life, they can be upsetting for both you and the people around you. Being prepared for what may happen can make the situation a little easier to cope with. If you'd like support as you read this chapter, or if you'd like to talk through these issues in more detail, you can contact one of the healthcare professionals looking after you or one of the organisations listed on pages 75–89. You could also call the Macmillan Support Line on 0808 808 00 00.

This chapter gives you information about:

- Emotional and mind changes
- Coping with physical changes and symptoms
- Complementary therapies
- Advance decisions to refuse treatment and advance statements

We have included information for relatives and friends on page 49.

EMOTIONAL AND MIND CHANGES

Sometimes it's very difficult to talk to the people close to you and you may want to talk to someone outside of your situation.

As people go into the last few weeks of their life they often have a lot of different emotions. These can include worry, anxiety, panic, anger, resentment, sadness and depression. Their feelings and emotions may change very quickly. It's natural to be worried or anxious when you're facing death and it can help to talk about this with your carers. You may also feel the loss of your health and worry about the loss of your role in your family or with friends. Sometimes it's very difficult to talk to the people close to you and you may want to talk to someone outside of your situation.

If you have a specialist nurse, they can talk to you about your feelings. This can help you understand and deal with your situation. Some people prefer to talk to a person they don't know, such as trained counsellor. If you'd like to see a trained counsellor, your GP can refer you. Many support organisations (see pages 75–89) can also help and some have helplines you can call. Talking to a religious or spiritual adviser can also help to reduce your fear and anxiety, even if you've not attended religious services or had contact with spiritual leaders in the past.

Many people become withdrawn. For some people this may be due to depression and your doctor or nurse can suggest ways of dealing with this. However, as you become more ill it's common to feel that you are losing interest in the things and the people around you, even close family. This is a natural part of gradually withdrawing from the world.

Although it may not feel as though you're doing much, just being there and listening can be very supportive.

If you are a carer, it may be upsetting if your relative or friend seems uninterested in you. It may feel as though they are giving up when you want them to stay alive. However, withdrawal is a natural aspect of dying. They may seem angry or very anxious and it's important to really listen to what they're saying and acknowledge their feelings. Although it may not feel as though you're doing much, just being there and listening can be very supportive.

COPING WITH PHYSICAL CHANGES AND SYMPTOMS

The physical changes and symptoms that occur vary with the type of illness a person has. Here, we describe physical changes that generally happen in the last few weeks of life and the specific changes that may occur with some types of cancer.

As someone becomes more ill, their medicines may be reviewed by their doctor or specialist nurse, and some may be stopped if they are no longer needed. If someone has symptoms such as pain, feeling sick or breathlessness, the doctor or specialist nurse may prescribe new medicines to control them. Medicines can be changed and tailored to what is needed. Complementary therapies may improve quality of life and well-being, and can also sometimes help to reduce symptoms (see page 43).

If you feel tired,
it's important to
pace yourself.

Tiredness and lack of energy

It's usual to gradually lose energy and not be able to do things for yourself. Tiredness and weakness can make it harder for you to concentrate or take part fully in what is going on around you. If you feel tired, it's important to pace yourself and save your energy for the things which matter to you and which you enjoy. Just do as much as you feel like.

You may need to rest a lot during the day, either in a chair or in bed. If you're not moving around much you may get sore areas, for example on your bottom or heels. Your district nurse can organise equipment, such as a pressure-relieving cushion for your chair or a mattress for your bed, to prevent soreness. You can also help by changing your position as often as you can.

Sleep disturbance

Some people find they can't sleep well at night. This can be particularly hard to cope with if it continues. There may be many reasons why sleeping at night can be difficult. These include:

- some drugs, such as steroids, which can keep you awake
- psychological factors, such as anxiety and depression, or perhaps a fear of dying in the night
- symptoms which are not controlled, such as pain, breathlessness or incontinence
- other factors, such as light, noise and sleeping during the day.

Tell your doctor or nurse if you're not sleeping well.

It's important to tell your doctor or nurse if you're not sleeping well. Once the causes of your sleeplessness are known, your sleep can often be improved. Let your doctor or nurse know if you have any specific anxieties or symptoms, such as pain, breathlessness or incontinence, that are affecting your sleep. For example, if pain is causing sleeplessness this can be controlled by adjusting your dose of painkillers at night time – your specialist nurse can advise you about this.

Here are some simple ways to help you sleep:

- If your mattress is uncomfortable, ask your nurse for advice on a more comfortable one.
- Try to reduce light and noise at night.
- Have a hot drink before going to bed, but avoid caffeine and alcohol at night time.
- Keep your bedroom for sleeping. If you wake during the night, go to another room in the house. If you need to sleep during the day, go to your bed and sleep.
- If you wake at night, don't toss and turn. Get up and go to another room. Have a hot drink if you like. When you feel sleepy, go back to bed again.
- Avoid using any screen, such as a TV screen or computer screen, for one hour before going to bed.
- Keep a 'worry' book so that if you wake at night you can write down the things you are worried about. You can then work through your list of worries during the day and get support and advice from your carers or your doctor or nurse.
- Try using relaxation techniques at night – you may find it helpful to use a relaxation tape or listen to some soothing music.
- If you find touch and massage helpful, you could ask your carer to give your hands or feet a gentle massage.

Not everyone gets pain, but if you do there are effective ways of controlling it.

Pain

Not everyone gets pain, but if you do it can be reassuring to know there are effective ways of controlling it. If you have pain, it's important to let your doctor or specialist palliative care nurse know exactly where your pain is, how it feels, and how it affects you so they can treat it effectively.

Painkillers

Everyone feels pain differently and there are several types of painkillers for different types of pain. They include:

- simple painkillers, such as paracetamol and codeine
- anti-inflammatory drugs like ibuprofen
- painkillers for nerve pain, such as gabapentin, pregabalin and amitriptyline
- strong painkillers, such as morphine, oxycodone, fentanyl and diamorphine.

Painkillers are usually given as tablets, liquid medicines, or patches stuck to the skin. If you are unable to swallow or are being sick, your nurse or doctor can give you painkillers such as morphine, diamorphine and oxycodone as an injection or by using a syringe driver (see next page).

Syringe driver

This is a small portable pump set up by your nurse or doctor.

A syringe containing enough drug(s)* for 24 hours is attached to the pump. The pump delivers a continuous dose of the drug(s) from the syringe through a small needle or tube that is inserted just under the skin of your tummy (abdomen) or arm. Your nurses will change the syringe each day or when needed.

*Painkillers, anti-sickness, anti-anxiety and several other medicines can be given by a syringe driver.

The 'right' dose is the dose that gets rid of your pain.

Many people worry that their pain will worsen as they near the end of their life and they'll need to take increasing doses of strong painkillers such as morphine. It's important to remember that there's no such thing as a 'right dose' of morphine. The 'right' dose is the dose that gets rid of your pain.

Side effects of painkillers

Painkillers containing codeine and strong painkillers have three common side effects: drowsiness, sickness and constipation. Drowsiness usually wears off after a few days, so you should be pain-free and still alert enough to do all that you want to do. If you feel sick, anti-sickness medicines can help, and this usually settles gradually over a few days. Constipation is such a common side effect that everyone taking strong painkillers usually needs to take a laxative regularly. Your doctor, nurse or pharmacist can advise you about this.

Pain control organisations can give you information about pain relief (see page 88).

Other ways of controlling pain

In addition to painkillers, there are a number of other ways to control pain. These include:

- finding a comfortable position to sit or lie in
- using warmth or cold on the area of pain
- using relaxation
- trying to distract attention from the pain, for example by playing music you enjoy
- Transcutaneous Electrical Nerve Stimulation (TENS) and acupuncture, which are more specialised ways of controlling pain (your doctor or specialist nurse will tell you if these are suitable for you).

You may also know of methods that have helped you control your pain in the past.

You may find
Macmillan
Cancer Support's
booklet
Controlling
cancer pain
useful.

You may find Macmillan Cancer Support's booklet Controlling cancer pain useful. You can order a copy by calling 0808 808 00 00 or going to be.macmillan.org.uk

Feeling sick and vomiting

Your illness, or your medicines, may make you feel or be sick. If this happens, your doctor can prescribe anti-sickness drugs which usually control sickness effectively. These may be taken as tablets, but if you can't swallow tablets, they can also be given as suppositories which are inserted into your back passage, as injections or by a syringe driver (see page 35).

There are various ways to try to reduce sickness:

- if you've been given anti-sickness medicines, take them regularly to prevent the sickness from coming back
- have warm or cold food, as this doesn't smell as strong as hot food
- eat dry foods, such as crackers
- have ginger as root, tea, ginger beer or ginger biscuits
- sip fizzy drinks
- eat little and often.

Gradually you'll find that your appetite reduces due to your illness, or the medicines you're taking.

Weight loss and loss of appetite

You may lose weight even if you're eating well and this can be upsetting. Gradually you'll find that your appetite reduces due to your illness, or the medicines you're taking. It's also common to be put off eating by the sight and smell of food.

Medicines, such as steroids, can sometimes help to boost your appetite. Small frequent meals, consisting of your favourite foods, are likely to be most tempting. You may be able to boost your appetite by:

- making your food look attractive
- having a glass of sherry, brandy or your favourite alcoholic drink about 30 minutes before eating (remember that the effects of alcohol may increase if you're ill or taking particular medicines, so it's best to check this with your doctor)
- having snacks handy to nibble
- drinking nourishing drinks
- eating slowly.

It's important not to force yourself to eat and it's okay if you don't.

However, as you near the end of your life, your metabolism slows down and your body no longer needs food as it cannot digest it so well or absorb the nutrients from it. At this stage, it's important not to force yourself to eat and it's okay if you don't.

As a carer you might feel anxious or upset because your relative or friend no longer wants or enjoys food. Although this can be hard to accept, it's important that you don't try to force them to eat. You may want to try giving them drinks they like instead.

Constipation

Many people find that it's easier to get constipated because they aren't moving around or eating and drinking as much. There are also a number of medicines, such as strong painkillers, that can cause constipation. If you are constipated, let your doctor or nurse know so they can prescribe laxatives. It may also help to drink as much fluid as possible, and add high-fibre foods to your diet, such as fruit and vegetables, brown rice, bread or pasta if you're able to eat them.

You may have swollen legs and ankles if you're not able to move around much.

Fluid build-up (oedema)

Some people have a build-up of fluid in a part of their body. This is known as oedema. You may have swollen legs and ankles if you're not able to move around much. Water tablets (diuretics) can sometimes help. If the fluid build-up is in your legs and ankles, your doctor may prescribe special pressure stockings to help reduce this. Using a footstool to keep your feet up when sitting can also help, as can gently exercising your legs.

A nurse or physiotherapist can show you some exercises to do. It may be harder to move around if your legs are swollen and this can be frustrating. It may help to talk to your carers about how you feel. Your nurses can help you find ways of moving around.

Change in appearance

You may find it upsetting if your appearance has changed, for example if you've lost or put on weight. It can help to talk through your feelings with your carers or your nurses. They may be able to find ways to help you look and feel better.

Infection

If you're not moving around much and aren't eating or drinking well, you may be more at risk of infection, such as a chest or urine infection. Let your doctor know immediately if you develop a high temperature or start to feel shivery, shaky or unwell. They'll probably prescribe antibiotics to treat the infection.

Breathlessness

Some people will feel breathless. There may be many reasons for this, such as cancer in the lung, chronic lung problems, general weakness, fluid inside the lung (pulmonary oedema), fluid around the lungs (pleural effusion) or anaemia (low red blood cell count).

Breathlessness can be very frightening but there are various ways of treating it.

Breathlessness can be very frightening but there are various ways of treating it, depending on the cause. It's important to let your doctors and nurses know if you are breathless so they can help you as soon as possible.

Nurses can show you and your carers the best positions for you to sit or stand to ease your breathing. You can also be taught how to breathe more effectively, how to pace your activity and how to save your energy. Anxiety is very common in patients with breathlessness and this can make your breathing feel even more difficult. Your nurse can teach you ways to relax, so that you feel less anxious and breathless.

There are several medicines that can be used for breathlessness, such as a very low dose of morphine. Your GP can also arrange an oxygen supply for you at home if you need this.

If breathlessness is caused by a build-up of fluid around your lungs (pleural effusion), the fluid can be drained off. If it's caused by anaemia (a low red blood cell count), then your doctor may arrange for you to have a blood transfusion (see next page).

Macmillan's booklet Managing breathlessness has information about living with breathlessness and learning how to cope with it. You can order a copy by calling 0808 808 00 00 or going to be.macmillan.org.uk

Cough and wheezing

You may have a cough or feel wheezy and this can be upsetting. Your GP can prescribe medicines to help with these symptoms. Sitting as upright as possible while supported on pillows can reduce a cough and help you breathe more easily.

Anaemia (low red blood cell levels)

Anaemia can make you very tired and breathless. If you're anaemic, your doctor or nurse may recommend that you have a blood transfusion. You will usually have this as a day patient in a hospital or hospice but in some areas it may be possible to have it done at home.

A blood transfusion may help you feel better very quickly and can be repeated.

A blood transfusion may help you feel better very quickly and can be repeated if it's needed and has helped you before.

With some types of cancer, fluid may sometimes build up in the tummy.

Bladder problems

If you have problems emptying your bladder or cannot control it, a thin, flexible tube (catheter) can be put into your bladder to drain the urine. Having a catheter saves you from the discomfort of trying to use a bedpan or bottle if you can't get out of bed.

Swollen tummy (ascites)

With some types of cancer, fluid may sometimes build up in the tummy (abdomen) so that it becomes swollen, tight and uncomfortable. This is known as ascites. It can sometimes be relieved by medicines or by inserting a tube into the abdomen to drain off the extra fluid. This is done under local anaesthetic and can be repeated if needed. It may also be managed by taking water tablets (known as diuretics), which your GP or specialist palliative care nurse will discuss with you.

High calcium levels (hypercalcaemia)

People with some types of cancer may have high calcium levels. This can make you feel drowsy or sick and can cause confusion, constipation and may make pain more difficult to cope with. If you develop these symptoms, let your district nurse or doctor know so they can take a blood test to check your calcium levels. If your calcium level is high, a few days of treatment in hospital or a hospice with medicine (bisphosphonates) given through a drip will help to bring your calcium levels down.

COMPLEMENTARY THERAPIES

Although complementary therapies cannot cure illnesses, they often help to control symptoms and help people feel better. They can be used alone or in combination with medicines.

Complementary therapies include:

- acupuncture
- homeopathy
- relaxation techniques
- hypnotherapy
- meditation
- visualisation
- aromatherapy
- reflexology
- Reiki.

You might like to try some complementary therapies, such as meditation or visualisation, to reduce anxiety. Other therapies, such as gentle massage, can be carried out by your carers and can help them to support you. The organisations on page 89 can give you further information.

Many hospices and hospitals offer free complementary therapies to carers.

Physical contact and touch can be powerful ways of supporting people who are faced with uncertainty, fear or pain, whether emotional or physical. Touching someone gently can show how much you care about them. Many hospices and hospitals offer free complementary therapies to carers. You can ask your nurse what therapies are available in your local area.

Macmillan has a booklet Cancer and complementary therapies, with more information.

LASTING POWER OF ATTORNEY, ADVANCE DECISIONS AND ADVANCE STATEMENTS

You may need to make important choices in the later stages of your illness. Usually you can talk about your healthcare with the doctors and nurses looking after you. However, there may come a time when you can't make decisions or communicate easily.

The Mental Capacity Act (2005) aims to protect people who cannot make a decision for themselves.

The Mental Capacity Act (2005) applies to people aged 16 and over in England and Wales. It aims to protect people who cannot make a decision for themselves. This means that a person can plan ahead for a time when they may not be able to make decisions on their own behalf. It makes it clear who can make decisions in which situations, and how they should do this. There are many parts to this act, including sections on lasting power of attorney and advance decisions. The Adults with Incapacity Act (2000) relates to people in Scotland.

Lasting Power of Attorney (LPA)

A Lasting Power of Attorney (LPA) is where you put in writing the name of someone you trust to manage your financial, legal or health affairs, or make decisions on your behalf in the future if you are no longer able to do so. An LPA must be made while you're able to understand what it is and what it means for you. It's only valid in England and Wales. See page 45 for information about Scotland and Northern Ireland.

The personal welfare LPA only allows your attorney to make decisions about your care and treatment.

The personal welfare LPA only allows your attorney to make decisions about your care and treatment. They can't make any decisions about your property and affairs, such as your finances. These can be made by a property and financial affairs LPA.

There is a fee to register an LPA. If you're receiving certain benefits, or have a low income, you may be exempt from paying the registration fee or only have to pay part of it.

You can get more information about registering an LPA from a social worker at the hospital, The Office of the Public Guardian or organisations such as Age UK (see page 81).

If you're unable to make a decision about your medical treatment and have no family or friends to represent your views, the medical staff are required to appoint an Independent Mental Capacity Advocate (IMCA) to represent your interests.

Scotland In Scotland the Welfare Power of Attorney (WPA) is a legal document that appoints one or more people to make decisions on your behalf about your care and treatment, should you become incapable. The WPA has to be registered and there may be a fee to do this. You can get more information about WPAs from a social worker at the hospital, The Office of the Public Guardian (Scotland) and organisations such as Age Scotland (see page 81).

Northern Ireland In Northern Ireland it's not yet possible to appoint other people to make decisions about your care and treatment on your behalf. New legislation is being considered by The Department of Health, Social Services and Public Safety and is expected in 2011.

Normally you will talk to your doctor about how you'd like to be treated and which treatments you don't want to have.

Advance decisions to refuse treatment and advance statements

Normally you will talk to your doctor about how you'd like to be treated and which treatments you don't want to have. Some people write down their choices in advance so that, if they become unable to discuss things with their doctors or make any decisions, the doctors will still know what their wishes are.

Instructions about the treatments you do or don't want are called advance statements and advance decisions. They are sometimes known as living wills.

- An advance statement is a general statement of your views and wishes. It can indicate the treatment you'd prefer and can include non-medical things, such as your food likes and dislikes, or religious beliefs. An advance statement is not legally binding, but your doctors should take it into account when deciding what is best for you.
- An advance decision to refuse treatment is simply a decision to refuse treatment. For example, you may decide that if your condition suddenly worsens and your breathing stops, you don't want people to try to bring you round (resuscitate you). Or, that if you are very ill and have an infection, you don't want to be given antibiotics. In England and Wales, an advance decision is legally binding under the Mental Capacity Act (2005), and must be respected by your doctors. In Scotland an advance decision is known as an advance directive.

Advance statements and decisions to refuse treatment can also let your family know your wishes, so that they too can do what you would want.

An advance decision to refuse treatment is legally binding but you can change your mind and rewrite it at any time.

An advance statement can include who you'd like to be consulted about your care, if you're unable to make those decisions yourself. If you want to give these people the power to make decisions on your behalf you'll need to create a Lasting Power of Attorney or LPA (see pages 44–45). The LPA can include your advance statement so that the people named in the LPA take your wishes into account when deciding what is best for you.

An advance decision to refuse treatment must indicate exactly what treatment you want to refuse and in which situation. Demands to be given treatments or interventions cannot be included in an advance decision to refuse treatment. It can only be made by someone aged 18 or over (16 in Scotland) who has the mental capacity to make the decision. You can change your mind and rewrite it at any time. A copy of your advance decision to refuse treatment can be kept in your medical and nursing notes. It's also helpful to provide your GP with a copy, as well as your local out-of-hours service.

In Northern Ireland, there is currently no legislation covering the use of advance statements, living wills or advance decisions to refuse treatment.

You can get information about advance statements and decisions to refuse treatment from a social worker or from some of the organisations listed on pages 75–89, such as Age UK. You may find it helpful to read the leaflet *Planning for your future care: A guide*, which has been produced by The NHS National End of Life Care Programme. You can ask for a copy from your GP or at your local hospital information centre. The leaflet is also available on the Department of Health's Care Networks website dhcarenetworks.org.uk

It's important to discuss your wishes with a medical professional, such as your GP or consultant, and with your nurse, family and friends. Remember that your family and friends may see things differently to you. For example, they may treasure every minute of your life, even though you

It's good to have an honest and open discussion with your family and friends in advance, so that they understand your wishes.

may be in a coma or unable to respond to them.

If possible, it's good to have an honest and open discussion with them in advance, so that they understand your wishes. It can be difficult to discuss these issues and you may want support from someone who knows you and who you can trust. You can also talk to some of the organisations on pages 75–89.

Macmillan Cancer Support has a fact sheet called An advance decision to refuse treatment (living will), which you may find useful. Call 0808 808 00 00 to order a copy.

Assisted dying or voluntary euthanasia

Currently, under UK law, any action that speeds up a person's death is illegal. Although your doctor and nurses can make sure you have enough painkillers to keep you comfortable, it's illegal for them to give you more than you need with the intention of ending your life more quickly.

INFORMATION FOR RELATIVES AND FRIENDS

Caring can be physically and emotionally hard work. If you've been looking after your partner, relative or friend for some time, you may start to feel drained. It's also common to have a lot of intense emotions, including anger or resentment, towards the person you're looking after. If you feel like this, it's important to tell your GP or nurse so they can help you deal with these emotions.

You may find that you have very little time for yourself, which can be frustrating and this may make you feel trapped or claustrophobic.

It's important to look after yourself, so think about making arrangements for someone to come in regularly so that you can have some time to yourself, even if it's only for a few hours a week. If there isn't a relative or friend who can help, you can contact the carers' organisations on pages 83–84.

When you get time off, try to relax. It's tempting to spend the break clearing up the house or doing the washing, but doing something you enjoy can help to revive your energy. Having some support and help can allow you to regain your previous role of being a partner, friend, son or daughter. You can also spend time just sitting with and talking to the person you are caring for.

Doing something
you enjoy can
help to revive
your energy.



CHAPTER 4

THE LAST FEW DAYS OF LIFE

Each person's experience will be different in their last few days of life.

This chapter is about the emotional and physical changes that a person may have in their last few days of life. Each person's experience will be different, so it's difficult to predict exactly what will happen or how quickly the changes will occur.

Usually you will gradually become very weak and have very little energy, and you may:

- find it difficult to move around and need help getting from your bed to a chair
- need to spend most or all of the day in bed
- lose interest in eating and have no appetite because your body can't digest food at this stage and doesn't need it
- sleep a lot and feel drowsy when you are awake
- feel disorientated and unsure whether you are dreaming
- dream about people who are not there or that you knew in the past – your mind may bring up old memories
- lose interest in your surroundings and even your close family.

This chapter gives you information about:

- Physical care
- Symptoms

We have included information for relatives and friends on pages 54–57.

PHYSICAL CARE

It may be strange for you to have to accept so much help from your carers.

During the last few days of your life, the people looking after you will need to give you a lot of physical care. It may be strange for you to have to accept so much help from your carers but it can also be a time when you become very close emotionally. If your carers need help to wash and bathe you, your district or specialist nurse can arrange this. They can also show your carers how to lift and move you safely.

As your mouth often becomes dry, it will need to be moistened regularly. Your district nurse can get mouth care sticks (like big cotton buds) and show your carers how to use them. They can also apply lip balm to keep your lips moist.

To prevent your skin from getting sore, it's important that your carers moisturise it and help you change your position regularly. Your nurses can advise your carers on how to make sure you're in a comfortable position when you're unable to move yourself. You can use various pressure care aids to help keep you comfortable including cushions for chairs, mattresses for beds and special beds with pressure-relieving mattresses. Your district nurse can assess what you need and arrange these for you.

There may be a lot of time when you don't need to have anything done and you can just lie quietly and have your relatives or friends sitting with you. This can be a very intimate and special time. You can let them know whether you'd like to talk, have a quiet time or listen to music that you like. You can also let them know if you need some time completely on your own.

SYMPTOMS

Some medicines may no longer be necessary and may be stopped.

If your symptoms change, your medicines may need to be changed. Some medicines may no longer be necessary and may be stopped. If you develop new symptoms, new medicines may be started.

If you have problems swallowing, it's possible to give all the medicines that you're most likely to need either by injection, by patches stuck on to the skin, by suppository or by using a syringe driver (see page 35).

Let your doctor or specialist nurse know if your relative or friend seems to be in pain.

INFORMATION FOR RELATIVES AND FRIENDS

This part of the chapter is written for relatives and friends, but you may find it helpful to read it together.

Pain

Your relative or friend may seem to be in pain: they may be restless, grimace (screw up their face) or move as if they're in distress. They may sweat and have a fast heartbeat and breathing rate. If this happens, the dose of their painkillers may need to be increased. Let your doctor or specialist nurse know so they can advise you about this and can check for other causes of these changes, such as an infection.

Breathing changes

If your relative or friend seems to have problems breathing, a number of medicines can be given to help. Their nurse or GP can also arrange for oxygen to be given to them at home. Their breathing may be noisy due to fluid collecting in their breathing passages. Although this can be distressing for relatives and friends, the person won't usually seem distressed themselves.

Restless moving, shouting, agitation, twitching or jerking of the body

Sometimes people have symptoms of restlessness, agitation, confusion, shouting or twitching. These symptoms are often known as terminal restlessness. The main cause is usually due to chemical changes that are happening in the body and the build-up of waste chemicals (toxins). These chemicals affect the brain and nerves and cause the restlessness. Terminal restlessness can often be well controlled with different medicines, such as sedatives which can be given by injection or by a syringe driver.

Sometimes pain, constipation, infection or medicines can also cause these symptoms. Once these are treated, the symptoms settle. If a person is restless due to emotional distress, they may gain comfort from a close friend, trusted health professional, or spiritual or religious leader.

If a person is restless due to emotional distress, they may gain comfort from a close friend.

You can talk to the district nurse and they can get you aids to help.

Incontinence

As someone gets closer to death, they may lose control over their bowel and bladder. You can talk to the district nurse about this, and they can get you aids to help, such as bed covers and pads. Men can have a sheath put over the penis to collect urine and drain it into a catheter bag. Sometimes it may be more comfortable for the person to have a tube (catheter) put into the bladder to drain away the urine. Your district nurse may be able to help organise a laundry service if you need it.

Urine retention

Sometimes urine can't drain out of the bladder, and so the person cannot pass urine. This causes severe abdominal pain, and their tummy (abdomen) will feel very hard and bloated. If this happens, it's important to contact your doctor or nurse and ask them to come urgently. They can put a catheter into the bladder to drain the urine and relieve the pain.

It's important to do whatever you both feel is right and most helpful.

Religious and spiritual needs

Your relative or friend may want to have particular practices carried out, or prayers read, as they are dying. It's important to do whatever you both feel is right and most helpful. Keep a note of anyone you need to contact in this situation.

Help and support

If you're worried at any time that your relative or friend seems to be distressed or have uncomfortable symptoms, you can contact the GP, district nurse or specialist nurse for advice and reassurance. You'll be given numbers for contacting these teams out of hours should you need them.



CHAPTER 5

NEARING DEATH

Although death is a normal process, it's natural to worry about what will happen.

The thought of death nearing can be very frightening. Although death is a normal process, it's natural to worry about what will happen. You may want to have a religious or spiritual adviser present and may want to carry out particular religious practices. It's important to do whatever you feel is right at this time.

This chapter gives you information about:

- What happens
- Mind changes
- Physical changes
- Final moments of life

We have included information for relatives and friends on pages 61–63.

WHAT HAPPENS

For many people, dying is very peaceful.

For many people, dying is very peaceful. You will usually slip slowly into unconsciousness and find that it's difficult to wake up.

Generally, people eventually become completely unconscious: they cannot be woken at all, but may still be able to hear and be aware of the people around them. Some people have phases where they are awake and can talk, and then slip back into unconsciousness.

If anything happens that worries your carers during this time, for example, if you have pain or other symptoms that are difficult to control, your carers can contact your district nurse, specialist nurse or GP. They can give you medicines to control your symptoms, either as an injection or through a syringe driver. They can also discuss any concerns that you or your carers have and reassure you.

You may want to read Macmillan Cancer Support's booklet *Dying with cancer*, which has further information. Call 0808 808 00 00 to order a copy.

Even if your relative or friend is unable to respond, they may still be able to hear you.

INFORMATION FOR RELATIVES AND FRIENDS

Even if your relative or friend is unable to respond, they may still be able to hear you and they may still know you are there. So it can help to speak to them and let them know what you're doing, especially if you're giving them medicines or moving them. This may feel strange as they cannot respond, but it can be comforting for both of you. There may be times where not much needs to be done and you can just sit with them and be close to them. You may need to move them regularly to keep them comfortable.

It's fine to call your GP or specialist nurse to let them know what is happening and to ask for advice.

MIND CHANGES

If your relative or friend is drifting in and out of consciousness, they may not seem to recognise you or the other people around them. You may find this distressing. They may also talk to people who they knew in the past, or who died long ago, probably because they are thinking of these people. If they seem panicky or agitated, sedatives may be given through a syringe driver. Terminal restlessness may occur, as described on page 55.

As your relative or friend gets closer to death, their breathing pattern will probably change.

PHYSICAL CHANGES

Your relative or friend will not usually feel thirsty at this stage but their mouth may be dry and need to be moistened. If they feel sick, anti-sickness medicines can be given by the syringe driver or as a suppository.

Skin and sensation changes

In the last few hours, your relative's or friend's hands, feet and the rest of their skin may feel very cold and possibly moist. Sometimes the skin changes colour and becomes slightly more blue, grey or white. Their skin may also be very sensitive to touch, so if you move them be very gentle and tell them what you're doing.

Several layers of light, warm clothing and bedding can help to keep them at a comfortable temperature.

Breathing

As your relative or friend gets closer to death, their breathing pattern will probably change. Their breathing may become irregular, with longer gaps between the breaths. It may also become very noisy, due to a build-up of fluid in their air passages as they are lying flat. This may be distressing for you and any other people around, but it isn't usually distressing for the person who is dying.

If fluid does build up in the air passages, drugs can be given by injection to reduce the build-up of further secretions. Sometimes these drugs are given in a syringe driver.

FINAL MOMENTS OF LIFE

For most people, their final moments are very peaceful. Their breathing may become even slower and more irregular with very long pauses between each breath. Their tummy (abdominal) muscles may take over control of the breathing from the chest muscles, so that their tummy rises and falls with each breath.

Often, the person's body will relax completely and they may look very peaceful.

Finally, they will stop breathing altogether. This may seem to take a long time for some people. For others it will only be a few minutes. Sometimes it can be difficult to pinpoint the exact moment of death. Often, the person's body will relax completely and they may look very peaceful. Some people feel they can sense when the person has died.

In some cultures, there is a belief that the person's consciousness (mind or soul) stays around the body for some time after death. Other people feel that the consciousness moves on quickly to another place. Some people believe that life just ends and nothing is left of the person's mind or consciousness.



CHAPTER 6

AFTER THE DEATH

You may have
lots of
overwhelming
emotions.

The death of someone close to you is a very significant event in a person's life and everyone reacts differently. You may feel shocked and numb, as though you cannot believe that it has happened. You may have lots of overwhelming emotions, such as feeling extremely upset and angry. Many people find they also feel very relieved that their relative or friend can now be at peace.

Most cultures and religions have processes or rituals that they carry out at the time of death. It's important for you to do what you feel is right. There may be some things that you need to do. However, you don't usually need to do anything straight away, so you don't have to feel rushed. You can just sit with your relative's or friend's body for a while. Many people like to sit and talk or hold hands, and see their relative or friend at peace, especially if the last few hours or days were a strain. You may want to have someone there to support you. It may help to ask them to contact other people to let them know, if you don't feel up to telling them. A spiritual or religious adviser can also support you and carry out any processes or rituals that are important to you and your relative or friend.

This chapter gives you information about:

- What your GP will do
- What your funeral director will do
- Planning a funeral and burial or a cremation
- Registering the death
- How grief might affect you

WHAT YOUR GP WILL DO

You will need to tell your relative's or friend's GP about their death within a few hours.

You will need to tell your relative's or friend's GP about their death within a few hours. The GP or a community nurse will come as soon as possible to verify the death. If your GP comes, they will verify the death and give you a medical certificate for the cause of death with a form called Notice to informant, which tells you how to register the death. If a community nurse comes, or you have to call an out-of-hours doctor, they can verify the death but you may need to get the death certificate from your GP the following day.

The doctor who certifies the death has a legal responsibility to inform the coroner if a post-mortem is needed. However, a post-mortem isn't usually necessary if the death was expected except in some cases, such as mesothelioma, where the cancer is caused by occupational exposure to asbestos.

A post-mortem will usually take a few days to arrange if needed, after which you'll get a medical death certificate. This can help to give exact information about the cause of death. You will need to wait until your doctor has decided whether a post-mortem is needed before you set a date for the funeral or alternative service.

When you have the medical death certificate, you need to take this to the local registrar's office to register the death (see pages 69–70).

WHAT YOUR FUNERAL DIRECTOR WILL DO

Once you've had the death verified by a nurse or doctor, you can contact the funeral director (undertaker). They provide a 24-hour service and can advise you on what to do. Details of funeral directors are in your local phone book or on the internet. You can also get information from the National Association of Funeral Directors on page 87. When you contact the funeral director, they will come as soon as you want them to.

You can visit the chapel of rest to be with your relative's or friend's body if you'd like to.

You can let the funeral director know if you'd like them to help you look after your relative's or friend's body at home until the funeral, or whether you would like it to be taken to the funeral director's chapel of rest. You can visit the chapel of rest to be with your relative's or friend's body if you'd like to.

Caring for the body

The funeral director will take care of your relative's or friend's body and will wash them. This process is different for different religions and cultures but usually involves carefully washing and drying the body, closing the eyelids, and making sure their mouth is supported while closed. The person's hair is tidied and sometimes washed. The funeral director will also ask if you'd like them to be dressed in any specific clothes, such as a favourite outfit.

If you'd like to help the funeral directors wash and dress your relative or friend, let them know as soon as possible so they can arrange this.

Embaling

Some people want to be embalmed. In this process, the body is disinfected and treated with chemicals to help preserve it. Blood is drained out of the body and replaced with embalming fluid. This is carried out at the funeral directors.

PLANNING A FUNERAL AND BURIAL OR A CREMATION

Funerals and memorials allow relatives and friends to pay their respects to the person who has died. It's a way of acknowledging their death and saying goodbye.

You can make all the arrangements for the funeral and burial yourself if you'd like to. However, most people prefer to have the help of the funeral director. Your GP will need to know if you're planning a cremation so they can complete the relevant paperwork.

Before making any funeral arrangements, it's important to consider several issues:

- What were the wishes of the dead person?
- Have they expressed their wishes in a will?
- What are your wishes?

A funeral, religious or spiritual service can be held wherever you wish.

Some people have strong religious beliefs or views about how they'd like their funeral to be carried out. Other people have no religious or spiritual beliefs and may have a non-religious or humanist funeral. It's not necessary for a religious leader to conduct a funeral or memorial service. Your funeral directors or the registrar can give you information about non-religious services if you prefer. A funeral, religious or

spiritual service can be held wherever you wish, for example, in the person's home or in their favourite place.

After the memorial service, the person's body is cremated or buried.

Cremation takes place in a designated crematorium. The ashes of the person are given in a container to the next of kin. You may have discussed with your loved one what they wanted to do with their ashes and you can carry out these wishes when you are ready.

Burial is usually in a churchyard or other designated burial place. It's also possible for people to be buried in other places, such as a garden.

There are books with helpful advice and information on page 90.

REGISTERING THE DEATH

You need to take the medical death certificate to the registrar's office in the area where the death occurred.

You need to take the medical death certificate – and birth and marriage certificates – to the registrar's office in the area where the death occurred. This needs to be done within five days (eight days in Scotland).

Some registrars' offices have an appointment system, so check before you go. You can find the number of your local registrar's office listed under Registration of births, deaths and marriages in the business section of your local phone book and it may also be on the envelope containing the death certificate. If you're not able to go yourself, another person can act as an 'informant' and register the death for you.

Before you attend the registrar's office, it's helpful to think about how many copies of the death certificate you might need. You can buy 'certified copies' for a small charge at the time of registration. These are duplicate original certified copies of entry and not photocopies. You'll usually need one certified copy for each life insurance policy or similar which you need to claim.

At the registrar's office, the registrar will enter details of the death in the register.

At the registrar's office, the registrar will enter details of the death in the register and give you a certificate of burial or cremation, also known as a green form. You need to give this to the funeral director. The registrar will also give you a certificate of registration of death form (BD8) if this is needed for social security purposes.

Information

Your district or palliative care nurse can give you information about what to do when someone dies. The Consumers' Association publishes *What to do When Someone Dies*, which is available in most public libraries (see page 90).

HOW GRIEF MIGHT AFFECT YOU

The feeling of missing the person can be overwhelming.

Emotional effects

The death of a partner, relative or close friend is an extremely difficult situation to face and you may feel very upset, anxious and distressed. Immediately after the death, and for some time afterwards, you may feel numb and find it hard to believe that the person is dead. It's common to feel angry that they have died. This anger may be directed at the person themselves for leaving you, or at other people, such as family members or health professionals, for not being able to save them from dying.

The feeling of missing the person can be overwhelming. Many people continue to 'see' or 'hear' the person who has died, and have a strong sense of their presence. For example, some people walk into a room and have an experience of 'seeing' the person sitting in their favourite armchair. Other people have vivid dreams in which they see the dead person as fit and well. These are perfectly normal experiences, although they can be shocking and upsetting.

If you'd like support at this time, you can contact your GP, specialist nurse, or a counselling service – see pages 84–86. Cruse is a specific counselling service for people who have been bereaved and you can call them on 0844 477 9400.

When someone close to you has died, it's common to have physical symptoms for some time afterwards.

Physical effects

When someone close to you has died, it's common to have physical symptoms for some time afterwards. These can be frightening and some people say the symptoms are so strong that they worry they are seriously ill themselves.

However, physical reactions are normal and can include headaches, dizziness, a dry mouth, feeling weak, tightness in the chest and throat, breathlessness and feeling sick. You may be aware that your symptoms are similar to those of your relative or friend who has just died. If any of these symptoms persist you should let your GP know.

Practical help

Immediately after the death, while you are probably feeling numb, you may need plenty of practical help to do important tasks such as registering the death, arranging the funeral and coping with visitors. You may also need to spend some time on your own, coming to terms with what has happened.

After the funeral

The period of time after the funeral, when everyone has gone home and you are expected to pick up the threads of your own life, can be the hardest. It's a good idea to try not to do too much too soon. You may need time to get used to your loss and the changes this has brought about. It's important to take time to look after yourself.

Don't be afraid to show your emotions during the grieving process.

Don't be afraid to show your emotions during the grieving process – it's perfectly natural to cry when you're thinking and talking about your loved one, and this can help you feel better. Some cultures have specific practices to follow, which can help to mark each phase of the bereavement process after a person's death.

You may find the book, *What to do When Someone Dies* (see page 90) helpful. It has practical advice on what to do when someone dies, and sections on: registering the death; death in hospital; the coroner; registration; burial; cremation; funerals; non-religious funerals; grief; probate; pensions; property; organ donation; and body donation for research.



CHAPTER 7

NATIONAL ORGANISATIONS THAT CAN HELP

We've listed organisations that may be able to help you.

These are divided into the following sections:

- How Macmillan Cancer Support can help you
- How Marie Curie Cancer Care can help you
- Useful organisations
- Carers' organisations
- Counselling, bereavement and emotional support
- Practical and financial support
- Pain control organisations
- Complementary therapy organisations
- Useful books and leaflets

HOW MACMILLAN CANCER SUPPORT CAN HELP YOU

Macmillan Cancer Support
89 Albert Embankment,
London SE1 7UQ
General enquiries
020 7840 7840

Questions about living with cancer?
Call free on 0808 808 00 00
(Mon–Fri, 9am–8pm)
Alternatively, visit macmillan.org.uk

Hard of hearing?
Use textphone 0808 808 0121,
or Text Relay.

Non English speaker?
Interpreters available.

Macmillan Cancer Support improves the lives of people affected by cancer. We are a source of support: providing practical, medical, emotional and financial help. We are a force for change: listening to people affected by cancer and working together to improve cancer care locally and nationally.

We have a wide range of services and activities that might be of help and interest.

Clear, reliable information

We provide expert, up-to-date information about cancer – the different types, tests and treatments, and living with the condition.

We can help you by phone, email, via our website and publications, or in person.

And our information is free to all – people with cancer, families and friends, as well as professionals.

Just call and speak to one of our cancer support specialists. Or visit one of our information and support centres – based in hospitals, libraries and mobile centres – and speak with someone face-to-face.

Need out-of-hours support? Our phone service is open Monday–Friday, 9am–8pm. At any time of day, you can find a lot of information on our website, macmillan.org.uk, or join our online community at macmillan.org.uk/community For medical attention out of hours, please contact your GP for their out-of-hours service.

The following organisations can offer immediate information and support:

NHS Direct 0845 4647
www.nhsdirect.nhs.uk

NHS Scotland
 0845 24 24 24
www.nhs24.com

Samaritans 0845 790 9090
www.samaritans.org.uk

Someone to talk to

When you, or someone close to you, has cancer, it can be difficult sometimes to talk about how you're feeling. You can call our cancer support specialists to talk about how you feel and what's worrying you.

Alternatively, we can help you find support in your local area, so you can speak face-to-face with people who understand what you're going through.

Professional help

Our Macmillan nurses, doctors and other health and social care professionals offer expert treatment and care. They help individuals and families deal with cancer from diagnosis onwards, until people decide they no longer need this help. You can ask your GP, hospital consultant, district nurse or hospital ward sister if there are any Macmillan professionals available in your area, or call us.

Support for each other

No one knows more about the impact cancer has on a person's life than those who have been affected by the disease themselves. That's why we help to bring people with cancer and carers together in their communities and online. You can find out about people affected by cancer who meet in your area to support each other by calling us or by visiting macmillan.org.uk/selfhelpandsupport

You can also share your experiences, ask questions and get support from others by heading to our online community at macmillan.org.uk/community

Financial and work-related support

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills.

If you've been affected in this way, we can help. All you need to do is call our helpline and one of our specialists will tell you about the benefits and other financial help you may be entitled to.

Legacies

For free, general advice on writing a will, Macmillan's Legacy team is here to help. Our booklet, *Family. Friends. Macmillan?* has useful information about making or updating your will. We also have a Macmillan legacy adviser in your area who would be happy to call or visit for a confidential chat.

To find out more, call us on 0800 107 4448, visit macmillan.org.uk/legacies or email leavealegacy@macmillan.org.uk

Get involved

There are many ways that you, your friends or family can get involved with Macmillan and help other people affected by cancer.

Use your experience to speak out

Share your experiences – online, in the media, with each other. Or use your experience to improve cancer care – join Macmillan Cancer Voices and get involved in opportunities that can make a real difference to people's lives.

Campaign with us

Join one of our campaigns – help us fight discrimination, tackle inequalities and get a better deal for people affected by cancer.

Give your time

Become a volunteer – give a bit of your time and energy to make a difference to others, and meet new friends at the same time.

Fundraise

Raise some money – host a coffee morning, hold a street collection or organise your own sponsored event.

Donate

Give some money – whether you give a one-off donation, set up a direct debit, donate through payroll giving or leave a legacy, we'll use every penny to help support people affected by cancer.

Find out more about all these opportunities on
be.macmillan.org.uk

HOW MARIE CURIE CANCER CARE CAN HELP YOU

Marie Curie Cancer Care
89 Albert Embankment
London SE1 7TP
General enquiries
0800 716 146 (free call)

Marie Curie Cancer Care is a UK charity dedicated to the care of people with cancer and other life-limiting illnesses.

We have more than 2,000 Marie Curie Nurses and Healthcare Assistants across the UK, providing end of life care for patients at home and support for their families. Our services are always free for patients and families.

There are nine Marie Curie Hospices across the UK offering specialist care for inpatients along with day services. The hospices are in Belfast, Bradford, Edinburgh, Glasgow, Hampstead (London), Liverpool, Newcastle, Penarth (Cardiff), and Solihull.

Talk to your district nurse or GP to see if they think you could benefit from Marie Curie's services.

Visit Marie Curie's website for film guides featuring practical demonstrations focusing on personal care and everyday living. As well as films you'll find our website mariecurie.org.uk is packed with information for people with cancer and other life-limiting illnesses and their families.

Support Marie Curie Cancer Care

Our services are free to patients and families but we rely on the generous support of the public to continue our work.

There are many ways you can support Marie Curie Cancer Care, from making a donation or leaving a gift in your will, through to taking part in an event or helping out with street collections during our Great Daffodil Appeal each March. Visit our website mariecurie.org.uk to find out more or phone 0800 716 146 (free call).

USEFUL ORGANISATIONS

Age UK

207–221 Pentonville Road,
London N1 9UZ
Advice Line 0800 169 6565
(Daily, 8am–7pm)
Email contact@ageuk.org.uk
or from the website
www.ageuk.org.uk
Age UK combines Age Concern and Help the Aged. If you are an older person and you need information or advice on anything from health to housing, call its free national information line. Age UK also publishes impartial and informative fact sheets and advice guides.

Age Cymru

Ty John Pathy,
Units 13/14 Neptune Court,
Vanguard Way, Cardiff CF24 5PJ
Tel 0800 169 6565
Email enquiries@agecymru.org.uk

Age Northern Ireland

3 Lower Crescent, Belfast BT7 1NR
Tel 0808 808 7575
Email
info@ageconcernhelptheagedni.org

Age Scotland

Causewayside House, 160
Causewayside, Edinburgh EH9 1PR
Tel 0845 125 9732
Email enquiries@ageconcernandhelptheagedscotland.org.uk

British Heart Foundation

Greater London House,
180 Hampstead Road,
London NW1 7AW
Tel 020 7554 0000
Email internet@bhf.org.uk
Heart Helpline 0300 330 3311
(Mon–Fri, 9am–6pm)
www.bhf.org.uk
The largest independent funder of heart research in the UK. As well as playing an important role in funding education, reaching the public and health professionals, it also provides life-saving cardiac equipment and support for rehabilitation and patient care. Its Health Information series, which covers a range of heart and health-related topics, can be ordered or downloaded from its website.

British Lung Foundation

73–75 Goswell Road, London EC1V 7ER

Tel 020 7688 5555

Helpline 08458 50 50 20

www.lunguk.org

Supports people affected by lung disease, helping them understand their condition. Provides comprehensive and clear information on paper, online and over the telephone.

Citizens Advice Bureau

Find contact details for your local office in the phone book

or at citizensadvice.org.uk

Find advice for the UK online, in a range of languages, at adviceguide.org.uk

Citizens Advice Bureaus provide free, confidential, independent advice on a variety of issues including financial, legal, housing and employment.

Citizens Advice Scotland

www.cas.org.uk

Help the Hospices

Hospice House, 34–44 Britannia Street,
London WC1X 9JG

Tel 020 7520 8200

Fax 020 7278 1021

Email info@helpthehospices.org.uk

www.helpthehospices.org.uk

A charity providing a wide range of information relevant to living with advanced illness. Compiles a directory of hospice services, as well as practical booklets. These are all available free on its website.

NHS Direct

Tel 0845 4647

www.nhsdirect.nhs.uk

NHS health information service for England, covering all aspects of health, illness and treatments.

NHS 24 in Scotland

Tel 08454 242424

www.nhs24.com

Office of the Public Guardian

PO Box 15118, Birmingham B16 6GX

Tel 0845 330 2900 (Mon–Fri,

9am–5pm, Weds, 10am–5pm)

Fax 020 7664 7551

Email [customerservices@](mailto:customerservices@publicguardian.gsi.gov.uk)

publicguardian.gsi.gov.uk

www.publicguardian.gov.uk

Supports and promotes decision-making for those who lack capacity or would like to plan for their future, within the framework of the Mental Capacity Act (2005).

CARERS' ORGANISATIONS

Carers UK

20 Great Dover Street, London SE1 4LX

Tel 020 7378 4999

Carers line 0808 808 7777

(Weds and Thurs, 10am–12pm and 2–4pm)

Email info@carersuk.org

www.carersuk.org

Offers information and support to carers. Can put people in contact with support groups for carers in their area. Has national offices for Scotland, Wales and Northern Ireland:

Carers Scotland

The Cottage, 21 Pearce Street,

Glasgow G51 3UT

Tel 0141 445 3070

Email info@carerscotland.org

www.carerscotland.org

Carers Wales

River House, Ynsbridge Court,
Gwaelod-y-Garth, Cardiff CF15 9SS
Tel 029 2081 1370
Email info@carerswales.org
www.carerswales.org

Carers Northern Ireland

58 Howard Street, Belfast BT1 6PJ
Tel 028 9043 9843
Email info@carersni.org
www.carersni.org

COUNSELLING, BEREAVEMENT AND EMOTIONAL SUPPORT

British Association for
Counselling and Psychotherapy
(BACP)

BACP House, 15 St John's Business
Park, Lutterworth,
Leicestershire LE17 4HB
Tel 01455 883300

Email enquiries@bacp.co.uk
www.bacp.co.uk

Aims to promote the awareness and
availability of counselling, and to
signpost people to appropriate
services. Has a database on its
website where you can search for
a qualified counsellor.

Childhood Bereavement Network

8 Wakley Street, London EC1V 7QE
Tel 020 7843 6309

Email cbn@ncb.org.uk
www.childhoodbereavementnetwork.org.uk

A national, multi-professional group of
organisations and individuals working
with bereaved children and young
people. Has an online directory, which
you can search for local services.

Compassionate Friends

53 North Street, Bristol BS3 1EN

Tel 0845 120 3785

Helpline 0845 123 2304

(Open every day of the year,

10am–4pm and 7–10pm)

Helpline email helpline@tcf.org.uk

www.tcf.org.uk

A befriending service for the families of children who have died. The helpline is always answered by a bereaved parent who is there to listen when you need someone to talk to.

Cruse Bereavement Care

PO Box 800, Richmond,

Surrey TW9 1RG

Helpline 0844 477 9400

(Mon–Fri, 9.30am–5pm)

Helpline email helpline@cruse.org.uk

Young person's freephone helpline

0808 808 1677

Young person's helpline email

info@rd4u.org.uk

www.crusebereavementcare.org.uk

Provides bereavement counselling, information and support to anyone who has been bereaved. Has a network of branches across the UK.

National Association of Widows

3rd Floor, 48 Queens Road,

Coventry CV1 3EH

Tel 0845 838 2261

Email info@nawidows.org.uk

www.nawidows.org.uk

A self-help organisation offering comfort and friendship to women who have lost a partner through bereavement.

Ruby Care Foundation

PO Box 21, Llandysul, Wales SA39 9WA

Email info@rubycare.org

www.rubycare.org

An international educational charity dedicated to the care of the terminally ill, companionship of the dying, and support and counselling for the bereaved.

Samaritans

Chris, PO Box 9090, Stirling FK8 2SA

Tel 08457 90 90 90

Email jo@samaritans.org

www.samaritans.org.uk

Provides 24-hour confidential, non-judgemental and emotional support for people experiencing feelings of distress or despair, including those which could lead to suicide. The service is provided by phone, email or letter.

The WAY Foundation

Suite 35, St Loyes House,

20 St Loyes Street, Bedford MK40 1ZL

Tel 0870 011 3450

Email info@wayfoundation.org.uk

www.wayfoundation.org.uk

Provides a social and support network to help young widows and widowers, up to the age of 50, rebuild their lives after the death of a partner. Members' children are also included.

Winston's Wish

Westmoreland House,

80–86 Bath Road, Cheltenham,

Gloucestershire GL53 7JT

General enquiries 01242 515157

Tel 08452 03 04 05

Email info@winstonswish.org.uk

www.winstonswish.org.uk

Helps bereaved children and young people rebuild their lives after a family death. Offers practical support and guidance to families, professionals and anyone concerned about a grieving child.

PRACTICAL AND FINANCIAL SUPPORT

British Red Cross

44 Moorfields, London EC2Y 9AL

Tel 0844 871 11 11

Email information@redcross.org.uk

www.redcross.org.uk

Offers a number of services for people with a disability, including a medical equipment and a transport loan service.

National Association of Funeral Directors (NAFD)

Helpline 0845 230 1343

www.nafd.org.uk

Monitors standards of funeral directors in the UK and gives help and advice on what to do in the event of a death. Also advises on arranging funerals and has information on what you should expect from a funeral director.

Natural Death Centre

In The Hill House, Watley Lane,

Twyford, Winchester SO21 1QX

Tel 0871 288 2098

Email contact@naturaldeath.org.uk

www.naturaldeath.org.uk

Aims to support those dying at home and their carers, and to help people arrange inexpensive, family-organised, and environmentally-friendly funerals.

PAIN CONTROL ORGANISATIONS

The British Pain Society

3rd Floor, Churchill House, 35 Red Lion

Square, London WC1R 4SG

Tel 020 7269 7840

Email info@britishpainsociety.org

www.britishpainsociety.org

Gives information on pain, and pain management clinics.

Pain Relief Foundation

Clinical Sciences Centre, University

Hospital Aintree, Lower Lane,

Liverpool L9 7AL

Tel 0151 529 5820

Email

secretary@painrelieffoundation.org.uk

www.painrelieffoundation.org.uk

Can send information packs about pain. Send an SAE and £1, or download the pack for free from its website.

Pain Concern

1 Civic Square, Tranent EH33 1LH

Tel 01875 614537

Listening ear helpline 0844 499 4676

Email info@painconcern.org.uk

www.painconcern.org.uk

Gives information about pain control and supports people with pain, and their carers. Has a listening ear helpline, which gives an opportunity to talk to another person with pain. Has pain management leaflets.

COMPLEMENTARY THERAPY ORGANISATIONS

British Complementary Medicine Association

PO Box 5122, Bournemouth BH8 0WG

Tel 0845 345 5977

Email info@bcma.co.uk

www.bcma.co.uk

Can send a list of complementary medicine practitioners who belong to complementary therapy organisations.
Cannot advise which therapies to use.

British Holistic Medical Association (BHMA)

PO Box 371, Bridgwater,

Somerset TA6 9BG

Tel 01278 722 000

Email admin@bhma.org

www.bhma.org

Can send details of members, a self-help tape list and a quarterly magazine called Holistic Health.

Institute for

Complementary Medicine

Can-Mezzanine, 32–36 Loman

Street, London SE1 0EH

Tel 0207 922 7980

Email info@icnm.org.uk

www.i-c-m.org.uk

Can send information on local complementary therapists. Aims to increase the quality of health by ensuring the best possible natural treatments are available.

USEFUL BOOKS AND LEAFLETS

What to do after a death in England and Wales

Department of Work and
Pensions, 2009, Free

A guide to what you must do and the help you can get when someone in your family dies. Available online at www.dwp.gov.uk/docs/dwp1027.pdf You can get a copy, along with advice on benefits for widows or widowers, from your local JobCentre Plus or post office.

What to do after a death in Scotland: practical advice for times of bereavement

The Scottish Government,
9th edition, 2009, Free

This booklet applies to Scotland only and gives information about some of the things that need to be done when someone dies. It's available online at www.scotland.gov.uk/Resource/Doc/277028/0083194.pdf

What to do when someone dies

Paul Harris (editor)

Which? Books, 2000

Gives straightforward and simple information about dealing with the formalities after someone has died. The book covers the law and practice in England and Wales and highlights the important differences that apply in Scotland.

A Guide to Grants for Individuals in Need 2009/10

Directory of Social Change,
11th edition, 2009

A directory of a wide range of charities and trusts that provide financial assistance to people in need. A copy will be kept in most public libraries.

This booklet has been revised and edited by Macmillan Cancer Support's information development nurses, the editorial team and Terry Priestman, Consultant Clinical Oncologist.

With thanks to: Dr Leslie Allsopp, Consultant in Palliative Medicine, Marie Curie Cancer Care; Linda Bailey, Community Nurse Specialist, Marie Curie Cancer Care; Jean Gordon, Clinical Service Manager, Marie Curie Cancer Care; Theresa Mann, Palliative Care Clinical Nurse Specialist; Pauline McCulloch, Palliative Care Clinical Nurse Specialist; Dr Karon Ornel, Staff Grade Physician in Palliative Medicine, Marie Curie Cancer Care; and the people affected by cancer who reviewed this edition.

References

Twycross R, et al. Symptom Management in Advanced Cancer. 4th edition. 2009. Palliativedrugs.com Ltd.

Hanks G, et al. Oxford Textbook of Palliative Medicine. 4th edition. 2010. Oxford University Press.

Advanced Decisions, Advanced Statements and Living Wills. October 2007. Age Concern.

End of Life Strategy – Promoting high quality care for adults at the end of life. July 2008. Department of Health.

Supportive and palliative care for people with cancer. Part A and part B. March 2004. National Institute for Health and Clinical Excellence (NICE).

Questions about living with cancer?

Call the Macmillan Support Line free on 0808 808 00 00

(Monday-Friday 9am-8pm).

Alternatively, visit macmillan.org.uk

Hard of hearing?

Use textphone 0808 808 0121, or Text Relay.

Non-English speaker? Interpreters available.

WE ARE MACMILLAN. CANCER SUPPORT

Macmillan Cancer Support, registered charity in England and Wales (261017),
Scotland (SC039907) and the Isle of Man (604).

For more information about Marie Curie including how to get a
Marie Curie Nurse call 0800 716 146 or visit mariecurie.org.uk



Marie Curie, registered charity in England
and Wales (207994) and Scotland (SC038731).

© Macmillan Cancer Support and Marie Curie Cancer Care, 2011.
3rd edition MAC12149



This paper is recycled – please recycle

Next planned review in 2013

