

A close-up photograph of several vibrant green leaves on a dark brown branch, set against a soft, out-of-focus background of more green foliage. The leaves are serrated and have prominent veins. The overall tone is peaceful and natural.

# End of life: a guide

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



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# About this booklet

This booklet explains what happens at the end of life and how to plan for it.

The booklet, which was produced together with Marie Curie Cancer Care, gives information about issues such as choosing where to be looked after, sorting out unfinished business, getting financial help, who can help if you're being cared for at home and what to expect in the last few days of life. It also includes information for your relatives and close friends who may be involved in your care, so it's helpful for them to read this booklet too. A lot of the information is for people who are being cared for at home, but even if you aren't being looked after at home, the booklet will still be useful to you and your carers.

You may find some of the issues in the booklet difficult and distressing to read, particularly if you're reading them for the first time. Getting support from other people can help. Ask your partner, a close relative or friend to read the booklet as well. You'll then be able to discuss the information together.

If you think it will be too difficult for you to read through the booklet in one go, you can use the contents list to help you dip into different sections as you feel able to do so. And don't worry about skipping some of the sections if they aren't relevant for you.

At the end of this booklet we've listed organisations that you may want to contact for help, information, or to talk about how you feel. You'll find organisations and lists of helpful publications and websites on pages 107-122. If your family or friends are helping to care for you, they may also want to read Macmillan's booklet *Caring for someone with advanced cancer* (see page 120) or visit [macmillan.org.uk/carers](https://www.macmillan.org.uk/carers) Marie Curie Cancer Care also has information for carers, visit [mariecurie.org.uk/carers](https://www.mariecurie.org.uk/carers)





# Coping with the news

This chapter includes information on:

- Your feelings
- Facing an uncertain future
- People close to you
- Talking
- Talking to children
- If you live alone

Hearing the news that you may be reaching the end of your life can be very difficult. You may be aware that your illness is progressing, but you might find it hard to believe what you're hearing, or feel that it's like a nightmare and you'll wake up and find it's not true. The initial shock and disbelief may be replaced after a few hours or days by powerful and often overwhelming emotions. These may make it difficult for you to think clearly. You're likely to need some time on your own or with your partner, a relative or close friend to deal with the news.

Some people find it easier to talk to someone outside their family. If you think this would be helpful, you can talk to your doctor or specialist nurse or call one of the support organisations at the back of this booklet. They will be able to talk things through with you.



## Your feelings

You may have many different emotions. You may feel angry because you feel more could have been done to prevent your illness. You may feel that it's very unfair that this is happening to you. You may fear what the future will bring. You may also find yourself tearful and depressed, and unsure of how to cope with all the feelings and emotions you have. Some people are stunned and resentful to see life going on as normal around them when their own world is in turmoil.

Most people have some, or all, of these emotions. But, as time passes, people generally find that the distress gets less frequent and intense.

## Facing an uncertain future

No one can be sure how long you will live and your doctors or nurses may be reluctant to give you a timescale. Even if one of your doctors has suggested that you may have months or weeks to live, perhaps because you asked them directly, it's important to remember that this is just an estimate. You may live longer or, unfortunately, you may live for less time than this.

You'll probably have good days when you feel well and positive about life, and bad days when your energy reserves are lower. Although the future may seem uncertain, for many people it's important to plan ahead and make the most of the days when you feel well. You may want to plan to do some nice things with your family and friends. There may also be important issues that you want to consider before you die. For example, deciding where you want to die, making a will or writing an Advance Decision to Refuse Treatment (see pages 23-28).

## People close to you

When you're reaching the end of your life, it doesn't mean that you have less need for love, companionship, friendship and fun. For many people, partners, family and friends become even more important and are a vital source of support and reassurance.

However, serious illness can strain relationships and many people find it difficult to know what to say. You may find that people react in unexpected ways. Some may try to deny the seriousness of the situation by being unrealistically cheerful, which can make it difficult for you to say how you feel. Other people may try to avoid you, rather than risk saying the wrong thing. Some people may avoid talking about your illness completely, while others may appear to be unsympathetic.

Your partner, children or close friends may irritate you by being overprotective or trying to 'wrap you in cotton wool'. Sometimes, close family and lifelong friends may feel like strangers, just at the time when you need them most.

Sometimes, partners try to protect each other from the truth by denying it, even though both are aware of what's happening. Talking openly with each other about your feelings can help support both of you through sadness, anxiety and uncertainty. You may find that your relationship becomes stronger as you face the challenge of your illness together.

It's important to keep your relationship as normal as possible. So if you've always been close and talked a lot, try to continue to do this. When words fail you or don't seem enough, a hug or holding hands can be very comforting. If you've always argued a lot, don't feel that you must try to change this. There are bound to be times when you don't get on well. If you argue, having short breaks from each other can help you think more calmly and recharge your emotional energy.

Remember that everyone will be shocked by the news. Your family and friends are also dealing with powerful emotions, and may need help and support to deal with them. People's initial reactions don't necessarily reflect their true feelings. Macmillan's cancer support specialists on **0808 808 00 00** can provide advice and support for your family and friends.

Many people who are reaching the end of their lives find that their relationships improve as they, and the people close to them, realise what's really important. You may become much closer to some people. Your illness can also be an opportunity for you and others to get back in touch, or resolve past arguments or bad feelings.

## Talking

People who have cancer or another serious illness sometimes feel that a lot of responsibility rests with them. They may feel that they are the one who has to be strong. They have to start the difficult conversations and help other people face the illness, even though they are the one who is ill.

If you're unwell or feeling low, it can be very difficult to do this. But if you're able to talk openly about how you feel, your family and friends will probably be relieved and able to respond. They will learn how best they can help you and what you'd like from them.

You can choose the people who you want to talk to and who you feel will be able to support you. You only need to share as much as you want to, and at a time when you feel ready.

Sometimes talking to someone outside your own close circle, such as a counsellor or one of the support organisations listed on pages 113-117, can be helpful.

Macmillan has a booklet called *Talking about your cancer*, which you may find helpful (see page 120).

## Talking to children

There's no easy way to talk to children or grandchildren about the fact that you're very ill and nearing the end of your life. It's often best to be as open with them as you can, and give information appropriate to their age.

Children can be very aware of things happening around them. Even if you don't say anything, they will usually sense that something is wrong. They may become frightened and their fears can sometimes be worse than the reality. If they are then told that everything is fine, they may find it hard to trust you. Children can also feel that they are somehow to blame for your illness, so it's important to reassure them that it's not their fault.

How and what you choose to tell them depends on their age and how much they can understand. Macmillan and the Marie Curie Palliative Care Institute Liverpool both produce information that you may find helpful. This includes:

- *Saying goodbye* - a series of leaflets for children and teenagers (Marie Curie)
- *Supporting toddlers and pre-school children when a parent or close relative is dying* (Marie Curie)
- *Talking to children when an adult has cancer* (Macmillan)
- *Talking to children when someone is dying* (Marie Curie).

To find out how to get copies of this information, see pages 120-121.

## If you live alone

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It may be very hard to keep positive and be optimistic if you live alone. Even though you may value your independence, being ill can make you feel very lonely.

It's okay to ask for help. People who care about you will want to help in any way they can. Some people will find it difficult to talk, but may be happy to help in more practical ways, such as doing your shopping or helping with your garden. Other people may be able to keep you company, listen to you and share your worries and fears.

Your GP, district or community nurse will also be able to tell you what help and support is available from health, social care and voluntary organisations (see pages 113-119).



## Chapter 2

# Issues to consider

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This chapter is about some of the issues you may want to consider as you near the end of your life.



We've listed some questions to help you and your carers think about things you'd like to sort out and how you'd like to be cared for.

We hope that the information in this booklet will help answer some of your questions.

## Questions to ask

These questions are just suggestions. You can ignore any that aren't relevant to you.

### Sorting things out

- What information do you or your carers need to know about your illness to help you understand what may happen to you?
- Would you like a doctor or nurse to speak to you, your relatives or close friends about any particular issues?
- Is there anything that you want to do before you get too ill?
- Is there anything you want done for the people you love?
- Is there anything you want done for any pets?
- Are there any issues you'd like to sort out with particular people?
- Are there any spiritual or religious practices that are important to you? Do you need help to make sure these happen?
- Have you made a will? See page 23.
- Do you want to create a Power of Attorney? See pages 24-25.
- Are there any particular treatments you don't want to have? If there are, do you want to write an Advance Decision to Refuse Treatment? See pages 25-28.
- Have you considered tissue donation or donating your body for medical research? See page 28.
- Have you made any funeral arrangements? For example, have you decided whether you would prefer to be cremated or buried? See page 29.
- Are there any 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?

## Financial support

- Are you aware of possible sources of financial support?  
See pages 31-35.

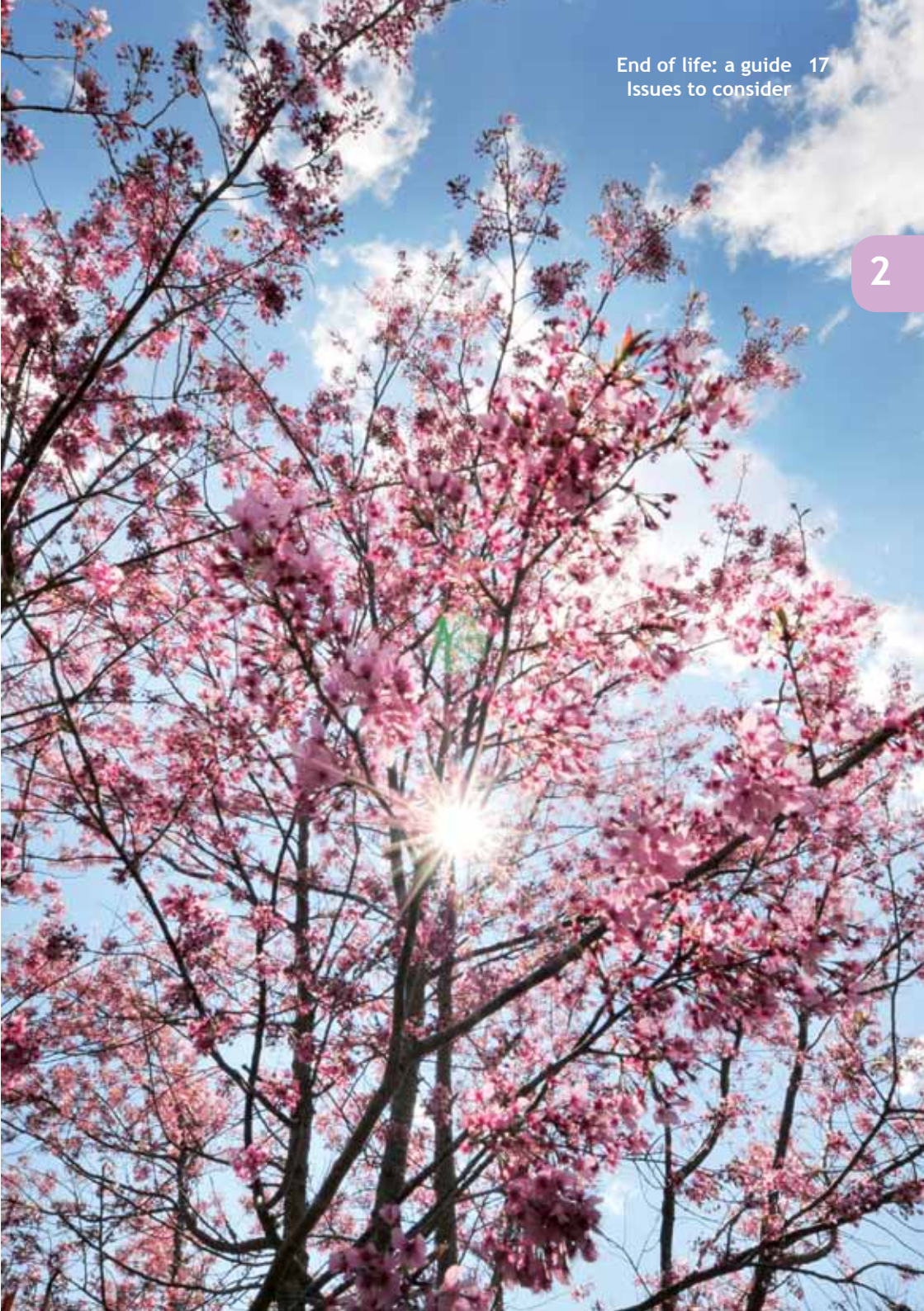
## Choosing where and how you'd like to be cared for

- Where would you like to be cared for? For example, at home, in a relative or friend's house, in a nursing home, in a hospice or hospital? See pages 37-42.
- Is the place you have chosen to be cared for the best place for you to be?
- If the first choice of where you'd like to be cared for isn't possible for some reason, where's the next best place?
- How would you like your surroundings to be as you're dying?
- If you want to be at home, do you need to think about sleeping in a different room to make it easier for you? For example, in a room downstairs?
- 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?
- How do you want to be treated by your relatives and close friends when you're dying?

## If you're a carer

A carer is someone who provides unpaid support to a family member or friend with an illness or disability.

- 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 3

# Sorting things out

This chapter includes information on:

- Unfinished business
- Spiritual and religious issues
- Making a will
- Making choices
- Power of Attorney
- Advance Statements and Advance Decisions to Refuse Treatment
- Tissue, organ and body donations
- Planning your funeral

Many people find that when they're told they may be nearing the end of their life, they have unfinished business that they need to sort out. As well as dealing with any practical and financial affairs, you may find that there are emotional loose ends that you want to tie up. For example, there may be old friends you want to see or wrongs you want to put right.



## Unfinished business

You may find yourself thinking a lot about the past, talking about shared joys, fears and regrets. You may go over old events in your mind or look through photo albums. If you're well enough, you may want to visit certain places again, such as somewhere you used to live. You may also find yourself thinking about the future, and grieving for a time when you will no longer be there.

If you have old quarrels that you would like to settle, you could try writing to or ringing the person, explaining your illness and asking them to visit or get in touch. This sort of openness can often heal old hurts and you'll probably find you feel more at peace.

You may like to write letters to people who are important to you, or perhaps record a CD, video or DVD to be given to them after your death. Some people like to write down their family history for the next generation or to put together a scrapbook for their children or grandchildren.

Memory boxes can also be very special mementos for loved ones. They can include messages and letters, a piece of jewellery, photographs, or a present to mark a special birthday. If the memory box is for a child, they may want to help with making it and filling it with special items.

Macmillan has information on creating memory boxes (see page 120).

These are sad and perhaps difficult things to do, but they can also be satisfying as they give you a chance to reflect on the things that have happened in your life, both good and bad. They may even make you laugh and give you light-hearted memories. The important thing is to do what feels right for you, when it feels right.

## Spiritual and religious issues

Towards the end of life, people often become more aware of religious beliefs or spiritual feelings.

Death can challenge what we believe in so many ways. Some people find that, often for the first time in their lives, they feel the need to think about and discuss the meaning of life, their own experiences or relationships with others. Many people find that they become more aware of spiritual feelings or religious beliefs during this time. Spirituality can be expressed in many ways, through music, arts, nature, or how a person relates to their family or community.

People with a strong religious faith often find comfort in prayer or meditation. Many people gain a lot of support from knowing that other people are praying for them. Other people may start to question their faith, especially when they are suffering.

It's important to be able to talk through these issues with someone you trust. You can choose the people you want to talk to, and who you feel will be able to support you. You only need to share as much as you want to, and at a time when you feel ready. Don't be put off talking to a chaplain or religious leader. They are used to dealing with uncertainty and being with distressed people. They are also usually very good listeners and may be able to help you find peace of mind.

## Making a will

It's normal to want to think about what will happen to your possessions and your dependants, such as children, after your death. If you haven't already made a will, there are several good reasons for making one. It's the best way to take care of the people you love and can spare them painful decisions, bureaucratic hassles and financial problems that may occur if you haven't made your wishes clear. If you die without a will, it often takes much longer to deal with the estate. It may mean that the people who inherit your estate aren't the people you would have chosen. Putting your affairs in order can clear your mind of little worries, leaving you free to enjoy the time you have left.

Making a will isn't as expensive or difficult as you might think, but it is a legal document and must be prepared properly. It's usually best to use a solicitor who will be able to help with the precise wording to make sure your wishes are clear and that they are carried out exactly as you wish.

Macmillan has a step-by-step guide to making a will, which you may find useful. See page 120.

## Making choices

You may want to make important choices about your care and treatment 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.

There are different ways you can plan ahead for a time when you may not be able to make decisions yourself. This is sometimes known as advance care planning and includes Power of Attorney, Advance Statements and Advanced Decisions to Refuse Treatment.

If you live in England and Wales, you may also find it helpful to read *Your life and your choices: plan ahead* (Macmillan) or *Planning for your future care: a guide* (Dying Matters Coalition/National End of Life Care Programme/Nottingham University). See pages 120-121 for more information.

## Power of Attorney

### England and Wales

In England and Wales, a Lasting Power of Attorney (LPA) is a legal document. It allows you to put in writing the name of someone you trust to make decisions or manage your financial, legal or health affairs on your behalf in the future if you're no longer able to do so. The people you choose to make decisions on your behalf are known as attorneys. An LPA must be made while you're able to understand what it is and what it means for you.

There are two types of LPA: the Health and Welfare LPA and the Property and Financial Affairs LPA. The Health and Welfare LPA can only make decisions about your care and treatment. They can't make any decisions about any of 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 you may 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 (see page 119) or organisations such as Age UK (see page 113). 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 legal document that appoints one or more people to make decisions on your behalf about your care and treatment, should you become incapable, is called the Welfare Power of Attorney (WPA). 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 (see page 119) and organisations such as Age Scotland (see page 113).

### Northern Ireland

In Northern Ireland, it's not yet possible to appoint other people to make decisions about your care and treatment.

## Advance Statements and Advance Decisions to Refuse Treatment

Normally, you'll be able to discuss with your doctor or other healthcare professionals how you'd like to be treated and which treatments you don't want to have. Some people write down their choices in advance. If they become unable to discuss things with their doctors or to make any decisions, the doctors and their family will know what their wishes are.

An **Advance Statement** is a general statement of your views and wishes. It can indicate the treatment you would prefer and how and where you would like to be cared for. An Advance Statement isn't legally binding, but your doctors should take it into account when deciding what's best for you.

It can be very helpful if you write down your preferences and wishes. If you do this, the key people involved in your care will know how you wish to be cared for. If you find it difficult to know what to say, or how to say it, your doctor or specialist nurse will be happy to help you write a document or a letter that includes your wishes.

One example of a document where you can write down your wishes and preferences is a Preferred Priorities for Care document. You can order a copy of the *National End of Life Care Preferred Priorities for Care* document from Macmillan (see page 120). This document may not be used in all parts of the UK, so check with your healthcare professionals if they have a specific document they recommend.

An Advance Decision to Refuse Treatment (Advance Decision, Advance Directive or Living Will) 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 back to life (resuscitate you). Or, that if you're very ill and have an infection, you don't want to be given antibiotics.

An **Advance Decision** can only be made by someone aged 18 or over (16 in Scotland) who is able to make the decision (this is called having mental capacity). It must indicate exactly what treatment you want to refuse and in which situation. Demands to be given treatments or interventions can't be included in an Advance Decision to Refuse Treatment.

## Advance Decisions to Refuse Treatment and the law

In England and Wales, an Advance Decision to Refuse Treatment is legally binding. This means it must be followed by your healthcare team, provided they know about it. It must also meet certain criteria set out in the Mental Capacity Act (2005). Your healthcare team will be able to tell you more about this.

In Northern Ireland and Scotland, an Advance Decision is legally binding, although it's governed by common law instead of an Act and similar criteria apply.

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Before making an Advance Decision, it's important to discuss the decisions you'd like to make with one of your healthcare professionals. They can tell you the likely effects of any decisions you make. Remember that it's important to share your decisions with your family so that they understand your wishes. Once you've made your Advance Decision, it's best to document it so that it can be kept in your medical and nursing notes. There are certain situations where the law says an Advance Decision must be in writing, for example if it refuses treatment to keep you alive.

It's helpful to give a copy of your Advance Decision to your GP. You may also be advised to give copies to the ambulance service, out-of-hours doctor, and district nursing and palliative care services. This makes sure that your wishes and preferences are known to the teams that you may need to contact, day or night.

You can change your mind and rewrite your Advance Decision at any time, but this should be clearly recorded.



Macmillan has more detailed information about Advance Decisions to Refuse Treatment (see page 120). You can also visit the Advance Decisions to Refuse Treatment NHS website (see page 113).

## **Tissue, organ and body donations**

Many people think that if they have a medical condition, such as cancer, they won't be able to donate their organs or tissue to another person when they die. Although it may not be possible for you to donate your organs, you can usually donate tissue, such as the corneas of your eyes. Your corneas could help to restore a person's sight. You can ask your doctor or nurse for more information about donations.

The NHS Blood and Transplant website also has information about donations and keeps a register of people who wish to donate their organs and body tissues (see page 119).

Some people may want to donate their body for medical research. If you're thinking about doing this, it's important to discuss it with your GP, hospital or palliative care team and your family or friends closest to you. As part of the donation process, you and your next of kin will be asked to sign a consent form. You can find out more about donating your body by contacting the Human Tissue Authority (visit [hta.gov.uk](https://www.hta.gov.uk)). You should bear in mind that not everyone who wishes to donate their body will be able to do so.

## Planning your funeral

Funerals allow families and others to pay their respects to the person who has died. For family or close friends who are left behind, arranging a funeral can be stressful if they don't know exactly what type of funeral service you want. If you tell your family and friends what you want, your funeral is much more likely to reflect your wishes. It may also be one less thing for your family or friends to worry about.

Discussing your funeral plans with family and friends can be helpful. They may have ideas and suggestions for arrangements that may help them celebrate your life, say goodbye and remember you. Here are some suggestions of what you may want to include in your funeral plan:

- whether you want a burial or cremation
- whether you want to have a religious service or not
- whether you want specific songs played or things read out
- whether you want flowers
- whether you want donations given to specific charities
- what clothes you want to wear.

Funerals can be expensive so you may want to pay for your funeral in advance by taking out a funeral pre-payment plan. You can find out more about this from your local funeral directors. It's important to look into prices first. Make sure that you know what services are included in the price as they can vary.

You may find it helpful to make a list of your documents, such as your will, your Advance Decision to Refuse Treatment and your funeral plan. Include your bank and building society details, any insurance policies you have and the details of your accountant, solicitor and tax inspector. Write on the list where to find this information and make sure that your partner or the executor of your will knows where it's kept.



## Chapter 4

# Financial help

This chapter includes information on:

- Benefits
- Other financial help
- Other things to think about

Having an illness, such as cancer, nearly always involves unexpected expenses. This can cause extra worry at a time when you least need it. Financial help is available from a number of sources and can sometimes be accessed at short notice.

## Benefits

Most people who need care towards the end of their lives qualify for either Disability Living Allowance (DLA), if under the age of 65, or Attendance Allowance (AA), if over the age of 65.

As part of the welfare reforms, DLA will gradually be replaced by Personal Independence Payment (PIP), starting from April 2013. If you live in Northern Ireland, you'll need to check with your benefits adviser or social worker whether you should claim DLA or PIP.

These benefits aren't means-tested. Anyone who isn't expected to live longer than six months because of an illness can apply for DLA/PIP or AA under special rules. Under these rules, the claim will be given priority and will be dealt with more quickly. You'll also receive the benefit at the highest rate. People who are claiming under this special rule need to ask their doctor to complete a form.

Your district nurse, specialist nurse or social worker can tell you more about these benefits and whether you can apply for them. You can also get more information by visiting the Department for Work and Pensions website [gov.uk/browse/benefits](http://gov.uk/browse/benefits) If you live in Northern Ireland, you should contact your nearest Social Security Agency Office for advice on benefits (visit [dsdni.gov.uk](http://dsdni.gov.uk)).

## Other financial help

### Grants

You may be able to claim grants from other organisations or charities. Macmillan gives grants and benefits advice to people with cancer. You can call the Macmillan Support Line for free on **0808 808 00 00**. You can also order Macmillan's booklet *Help with the cost of cancer* (see page 120).

Your union or professional organisation, if you belong to one, may be able to give you financial help or advice. In some professions, there may be special funds that can 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 121).

### Prescriptions

These are free in Scotland, Wales and Northern Ireland. In England, people with cancer can also get free prescriptions, but you need to apply for an exemption certificate by collecting an FP92A form from your GP surgery or oncology clinic.

## Other things to think about

### Bank accounts

These are frozen at the time of death and can't be used, so you may want to consider putting bank accounts into joint names.

### Pension schemes

Some private or occupational pension schemes won't pay out any benefits to partners if the owner of the pension scheme wasn't married. This means that the pension fund is lost.

An Independent Financial Adviser (IFA) may be able to give you advice in these situations. You can contact a financial adviser through the Personal Finance Society or [unbiased.co.uk](https://unbiased.co.uk) (see pages 118-119).





## Chapter 5

# Choosing where you would like to be looked after

This chapter includes information on:

- Staying at home
- Hospices
- Nursing or residential homes
- Hospitals

We have included some information for relatives and friends on page 42.

Often the choice of where you'll die depends on what you want, what help you have from family and friends and what services are available in the area you live. Most people would prefer to die at home, as long as they know they will have good quality care.

Wherever you're cared for, the most important thing is that you get the care you need and your symptoms are well controlled. This can happen in a variety of places. Even if you choose not to die at home, you can still be surrounded by people and possessions that are dear to you.

## Staying at home

There may be many advantages to staying at home. For example, you may benefit from being in familiar surroundings with close family or friends to care for you. Being at home may help you feel more in control and may make it easier for you to say your goodbyes.

If home is where you want to be, it's important that you and your carers have as much support as possible. There are a number of healthcare professionals and voluntary organisations that can help manage any symptoms you may have and support you and your family at home. If you'd like to be at home, let your nurse or doctor know.

There is more information about being looked after at home on pages 45-53.

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## Hospices

Hospices specialise in caring for people who are dying. They have staff who are experts in controlling symptoms, such as pain, and providing emotional support.

You can go into a hospice for different reasons. It may be for a short time to have your symptoms controlled or for a period of respite care to give your carer a break. You may decide that you'd like to die in a hospice rather than at home or elsewhere. If so, you'll need to discuss your wishes with the hospice team involved with your care.

Hospices are very different from hospitals. They are quieter and tailor their care to suit each person. Visiting is usually less restricted than in a hospital. They offer a wide range of services for patients and their families, such as counselling, spiritual care, complementary therapies and bereavement support.

Many hospices have specialist palliative care nurses (expert nurses in symptom control and emotional support) and staff nurses or healthcare assistants who can also visit and help care for people at home. Some have day centres for people living at home.

Accommodation and care in a hospice is always free of charge. Sometimes there's a waiting list but urgent admissions can usually be organised within a couple of days.

You can find out more about your local hospice from your GP, district nurse or palliative care nurse. Help the Hospices also has useful information about hospices and where they are located across the UK (see page 114). If you're not sure about the idea of hospice care, you can ask to visit the hospice before making a decision. The staff will be able to show you around and chat through any questions or concerns you have.

## Nursing or residential homes

If you're likely to need nursing care for several months, a nursing home may be more appropriate than a hospice. You may still be able to go to the hospice for day care, or a specialist nurse from a hospice may be able to visit you in the nursing home.

Private nursing homes usually offer short-stay or long-stay care. Your GP, district nurse or social worker can arrange this for you, but it may take some time. A fee is charged for care in private nursing homes, although you can sometimes get help in paying for this if you have little or no savings.

You may be able to apply for the NHS to fully fund your care in a nursing home. For example, if you're reaching the end stages of your illness or if you have a complex medical condition that means you require a lot of care and support.

A ward nurse, district nurse or hospice nurse will give you more information about the process for making an application for fully funded care. If you live in Northern Ireland, funding for care in nursing homes is means-tested.

Lists of local registered care homes and details of registered nursing homes are available from your local social services department and your area health authority. You can also search for a nursing home by visiting [carehome.co.uk](http://carehome.co.uk)

## Hospitals

If you've been in and out of hospital over the last few months, you may want to go back to your usual hospital ward when you need full-time nursing care. This may be easier to organise if you've been in a small local hospital (for example, a cottage hospital) rather than in a busy district general or teaching hospital.

Although many people die in hospital, it may not be the most peaceful place to be if the ward is busy. Often you'll need to fit into the ward routine, rather than being looked after in the way that you'd like.

Hospitals have palliative care teams that include specialist nurses and doctors. A specialist nurse or doctor from this team will be able to see you while you're in hospital. They can advise you on controlling your symptoms and can give you and your family emotional support.

## Information for relatives and friends

If you're a relative or friend, it's important that you don't feel guilty if you encourage your loved one to die in a hospice, hospital or nursing home. As time goes on, you may feel that they would be better cared for by healthcare professionals in a hospice or nursing home. This may be because their situation has changed and you don't have the nursing or medical skills to look after them.

Always talk to their district nurse or GP if you feel you need more help to care for them at home. They may be able to provide the extra support you need or they can advise you on the best place for your relative to be cared for.

If you need to move them from home at some point near the end of their life, you shouldn't see this as a failure. Instead, you should see it as you wanting to make sure that they get the best possible care.







## Chapter 6

# Being looked after at home

This chapter includes information on:

- Who can help if you're looked after at home
- Where to get the equipment you need

Although dying is a natural process, few people have experience of looking after someone who is dying. If you're 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.

## Who can help if you're looked after at home

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

### Your GP

While you're at home, your GP has overall responsibility for your care. They can help you if:

- You're worried about any changes in your symptoms. They can arrange to see you either in the surgery or at home and 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 an Advance Decision to Refuse Treatment (see pages 27-28) or 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 pages 49-50). They can arrange for you to be seen at home by a palliative care nurse.

## District nurses

District nurses work closely with GPs. They make visits to patients and their carers at home. They can assess a person's needs and help with:

- Coordinating your care. They will contact other health or social care professionals to help with your care, if they're needed.
- Monitoring and treating any difficult symptoms you may have.
- Giving injections, changing dressings, giving advice and support on pressure area care and toilet problems, such as incontinence and constipation. They may organise to supply appropriate equipment to help with pressure care or continence.
- Showing your relatives or carers how to move you and take care of your personal needs.

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 for a social carer or 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 Nursing Service

The Marie Curie Nursing Service's team of nurses across the UK offers hands-on nursing care to people with cancer, heart failure or other illnesses, who are nearing the end of their life. Marie Curie nurses visit people in their home to provide care overnight, or for part of the day, so carers can get a good night's sleep or a break during the day. The nurses also provide emotional support.

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

### **Hospital or community specialist palliative care teams**

Specialist palliative care teams provide care to improve the quality of life of people and their carers who are coping with life-limiting progressive illnesses, including cancer. You may be referred to a palliative care team if you need specialist support or care. For example, if you have troublesome symptoms that need controlling.

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** 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.

Some specialist palliative care nurses are called 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.

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.

### **Social workers/care managers**

Social workers can organise help with housework, shopping and cooking, or a personal care assistant to help with tasks such as washing and dressing. They can arrange a care package for you that addresses your individual needs. You or your doctor or district nurse can contact them to ask for an assessment of your needs. If you can afford it, you may be asked to pay towards the cost of this help, but it may be funded for you in some circumstances.

Social workers or care managers can also give you information about any benefits you may be able to claim. They may also be able to provide more advanced counselling and emotional support for you and your carers.

### **Physiotherapists**

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

### **Occupational therapists**

Occupational therapists can help you maintain your independence and quality of life. They can visit your home to assess whether specialist equipment would help you move around and be able to do as much for yourself for as long as possible. Following their assessment, they will arrange to provide the equipment you need.



Occupational therapists will also help you manage symptoms such as fatigue and anxiety.

### Counsellors

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

Spiritual care coordinators offer spiritual care and support.

### Voluntary organisations and charities

Voluntary organisations and charities can also offer various kinds of help, including information, loans of equipment, grants and transport.

Some organisations have volunteers who can provide short periods of respite care to give your carer a break during the day time. Others provide befriending services for people who are on their own. They can introduce you to a trained volunteer who may be able to give one-to-one help and support.

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Your district nurse, specialist nurse or GP can tell you how to access these health and social care professionals and voluntary organisations. They will also be able to tell you 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 assess your needs and organise equipment to help you manage at home.

For example, your district nurse can arrange for you to have:

- a commode, urinal, bedpan or incontinence sheets
- a special mattress or chair cushion
- a hoist or sling
- a special bed - like a hospital bed with adjustable head and foot sections.

Your occupational therapist can assess you and possibly supply you with:

- a wheelchair or ramp
- stair rails
- specialist equipment to help you move or to help others to move you
- grab rails and other equipment for your shower or bath.

Your occupational therapist can also give advice on small gadgets and where you can buy them. For example, two-handled mugs and special cutlery.

If you haven't seen an occupational therapist, but need some equipment that 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 British Red Cross (see page 118) hires out equipment such as commodes and wheelchairs. You can also buy items such as incontinence pads and urinals from most large chemists or on the internet.





## Chapter 7

# The last few weeks of life

This chapter includes information on:

- Emotional changes
- Coping with physical changes and symptoms
- Complementary therapies

We have included information for relatives and friends on page 77.

During the last few weeks of life, you may experience a number of emotional and physical changes and symptoms. Even though these changes and symptoms are normal, 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.

## Emotional changes

You may have a lot of different emotions that can include worry, anxiety, panic, anger, resentment, sadness and depression. It's natural to be worried or anxious when you're facing death. You may also feel the decline in your health and worry about the loss of your role in your family or with friends.

Talking about how you're feeling can help. If you're at home and have a nurse, you can talk to them about any specific concerns that you have. You may find that once you've shared your concerns you feel much better, especially if you've been worrying about something. Some people prefer to talk to a person they don't know, such as a trained counsellor. If you'd like to see a trained counsellor, your GP can refer you. Many support organisations (see pages 113-117) can also help and some have helplines. 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 before.

It's not uncommon for people to become withdrawn. For some this may be due to depression, which your doctor or nurse can help with. For others, it's a natural part of gradually withdrawing from the world and you may find yourself losing interest in the things and the people around you, even close family.

### If you're 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, but remember it's often a natural part 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 more helpful than you think.

## 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 nurse. Some medicines may be stopped if they're no longer needed. If someone has symptoms such as pain, feeling sick or breathlessness, the doctor or nurse may prescribe new medicines to control them. Medicines can be changed and tailored to what you need. Complementary therapies may improve quality of life and well-being, and can also sometimes help to reduce symptoms (see page 76).

### Tiredness and lack of energy

It's normal 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 in what's going on around you. 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 help prevent soreness. You can also help by changing your position as often as you can.

### Helpful hints for managing tiredness

- Pace yourself and save your energy for the things that matter to you and that you enjoy.
- Cut down on any unnecessary tasks, such as cooking, cleaning or making the bed. You could ask your friends and family to help you with these.
- Ask a carer to help with washing and dressing if these tire you out.
- Accept and use equipment (such as a raised toilet seat, bath board, walking frame) that helps you with daily tasks and avoids you getting so tired.
- If you have important things that you want to do, such as sorting out your financial affairs, do them at a time of day when you have more energy.
- If you're struggling with eating, try to eat little and often to keep your energy levels up.

### Sleep disturbance

Some people find they can't sleep well at night. There may be many reasons for this. These include:

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



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. Your nurse can advise you about this.

### Helpful hints for helping 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 up 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 an hour before going to bed.
- Keep a 'worry book' so that if you wake up during the night you can write down the things you're 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 to 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.

If you find that, despite following these hints, you aren't sleeping enough, talk to your doctor or specialist nurse. They may advise you to try taking sleeping tablets. You may only need to take sleeping tablets for a limited amount of time or on an 'as required' basis.

## Pain

Not everyone who is terminally ill gets pain, but if you do, it can be reassuring to know there can be effective ways of controlling it. If you have pain, it's important to let your doctor or 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
- moderately strong painkillers such as codeine and tramadol
- strong painkillers such as morphine, oxycodone, fentanyl and diamorphine
- anti-inflammatory drugs such as ibuprofen and diclofenac
- painkillers for nerve pain such as gabapentin, pregabalin, amitriptyline and dosulepin. Some of the drugs for nerve pain are also used for depression and epilepsy.

Painkillers are usually given as tablets, liquid medicines, or patches stuck on to the skin. If you're 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, which is set up by your nurse or doctor.

A syringe containing enough drug(s) for usually 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.

Many people worry that their pain will get worse 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 (anti-emetics) 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.

### Helpful hints for controlling your pain with painkillers

- Always take your painkillers regularly and as prescribed by your doctor or nurse.
- Let your doctor or nurse know as soon as possible if your pain isn't controlled.
- Keep a pain diary if you can. Ask your district nurse or specialist nurse if they can give you one.
- Be aware of the side effects of some painkillers and take medicines if needed to keep them controlled.
- If you get side effects that aren't being treated or responding to treatment, let your doctor or nurse know.

### Other ways of controlling pain

There are a number of other ways to control pain that can be used alongside painkillers.

#### Helpful hints for using other ways to control your pain

- Find a comfortable position to sit or lie in.
- Use warmth or cold on the area of pain.
- Use relaxation techniques such as deep breathing or meditation.
- Try to distract your attention away from the pain, for example by playing music or watching a film you enjoy.
- Talk to your doctor or nurse about Transcutaneous Electrical Nerve Stimulation (TENS) and acupuncture, which are more specialised ways of controlling pain. They will let you know if these are suitable for you.
- If you know of methods that have helped control your pain in the past, try them to see if they help now.

You may find Macmillan's booklet *Controlling cancer pain* useful (see page 120).

## Feeling sick and vomiting

Your illness, or your medicines, may make you feel sick (nausea) or be sick (vomit). If this happens, your doctor or nurse can prescribe anti-sickness drugs (anti-emetics), which usually control sickness effectively. These may be taken as tablets. If you can't swallow tablets, they can also be given as suppositories that are inserted into your back passage, as injections or by a syringe driver (see page 62).

### Helpful hints for reducing sickness

- If you've been given anti-sickness medicines, take them regularly to prevent the sickness returning.
- Have warm or cold food, as this doesn't smell as strong as hot food.
- Eat dry foods such as crackers.
- Food or drink containing ginger can help. Try crystallised ginger, ginger tea, ginger beer or ginger biscuits.
- Sip fizzy drinks.
- Eat little and often.

## 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. Your doctor can prescribe these if they are suitable for you.

### Helpful hints for boosting your appetite

- Eat small frequent meals.
- Put smaller portions on your plate rather than being put off by larger portions.
- Make your food look attractive.
- Get someone else to cook your food if you find yourself put off by the smell of cooking and avoid foods with a strong smell.
- Have a glass of sherry, brandy or your favourite alcoholic drink about 30 minutes before eating. But 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 or nurse.
- Have snacks handy to nibble.
- Have nourishing drinks.
- Avoid filling your stomach with fluid before meals as this may cause you to eat less.
- Eat slowly.

As you near the end of your life, your metabolism slows down and your body no longer needs food as it can't digest it 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.

You may want to try liquid meals when you don't feel able to eat a proper meal. There are many different types of complete meals in liquid form such as Build-up® or Complan®. Your doctor or nurse can advise which is the best for you. They can often arrange a supply on prescription.

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 they get constipated more easily 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.

### Helpful hints for managing constipation

- If you've been prescribed laxatives to help with constipation, take them as prescribed.
- Let your GP or nurse know as soon as possible if you're constipated. You should also let them know if your laxatives aren't working.
- Drink as much fluid as possible.
- Add high-fibre foods to your diet, such as fruit and vegetables, brown rice, bread or pasta if you're able to eat them.

## Breathlessness

Some people may feel breathless. There can 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, depending on the cause. It's important to let your doctors and nurses know if you're 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 help with your breathing. You can also be taught how to breathe more effectively, pace your activity and save your energy. Anxiety is very common in patients with breathlessness and this can make your breathing feel even more difficult. Your nurse or physiotherapist can teach you ways to relax, so that you feel less anxious and breathless.

### Helpful hints for managing breathlessness

- Think about ways to arrange your home to make tasks easier. For example, a chair in the hallway or a chair at the top and bottom of the stairs could be used to take a rest when walking between rooms or climbing up and down the stairs.
- Sit down to carry out everyday tasks like washing and dressing.
- If you feel breathless, try using a cool fan to blow air on to your face or sitting by an open window.
- If you need to talk to someone in another room without getting up or shouting, try using a baby monitor or alarm.
- If you're breathless in bed, try using a V-shaped pillow to help you sit in an upright position.
- If you have difficulty getting to the toilet, use a commode or urine bottle.

There are several medicines that can be used for breathlessness, such as a very low dose of morphine. Your GP or nurse can also arrange for you to have oxygen 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 page 74).

Macmillan's booklet *Managing breathlessness* has information about living with breathlessness and learning how to cope with it (see page 120).

## Mouth problems

You may develop problems with your mouth such as dryness, ulcers or an infection. These problems can sometimes be made worse by the medication you're taking. You will also be more at risk of mouth problems if you find it difficult to maintain good mouth care. It's important to let your nurse or doctor know if you develop any mouth problems so that they can help.

### Helpful hints for preventing mouth problems

- Brush your teeth twice a day using a fluoride toothpaste. Use a soft children's toothbrush if your mouth is sore. Rinse your mouth with fresh water after brushing.
- Rinse your mouth three or four times a day to remove debris and keep it clean. You can use water or a salt-water rinse (1 teaspoon of salt to 1 pint of cold or warm water). You should rinse your mouth with cold or warm water after using a salt-water rinse.
- If you have false teeth, clean these as usual and soak them overnight.
- Use any mouthwashes that have been prescribed for you, and follow the instructions.
- Cut down on substances that can dry or irritate the mouth, such as caffeine, alcohol or smoking.
- If you have a dry mouth, sip tonic water or lemonade, or try sucking ice lollies, ice cubes or chewing sugar-free gum.
- You may also find it helpful to listen to Marie Curie's film guide (video) on *How to help with mouth care* (see page 121).



### **Cough and wheezing**

You may have a cough or feel wheezy, which 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.

### **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.

### **Changes in appearance**

You may find it upsetting if your appearance has changed, for example if you've lost weight or put some on. 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 may prescribe antibiotics to treat the infection.

### **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'll usually have this as a day patient in a hospital or hospice. However, 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 if it's needed and has helped you before.

### **Bladder problems**

If you have problems emptying your bladder or can't 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 often be relieved 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. Ascites can also be managed by taking water tablets (diuretics), which your GP or specialist palliative care nurse will discuss with you.

### High calcium levels (hypercalcaemia)

Some types of cancer can cause high calcium levels in the blood. This can make you feel drowsy or sick and can cause confusion or constipation. It may also make pain more difficult to cope with. If you develop these symptoms, let your 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.

### Managing difficult symptoms

Usually, it's possible to manage your symptoms at home, but sometimes it can help to spend a few days or weeks in a hospice having them treated. Your community palliative care team or GP will discuss this with you if they think it would be helpful. In the hospice, the doctors and nurses will be able to assess your symptoms. They can adjust the dose of your medicines or add in new ones to control your symptoms more quickly than if you were at home. Once your symptoms are controlled, you can go home again to the care of your GP with the support of your community palliative care team and district nurses.



## Complementary therapies

Although complementary therapies can't cure illnesses, many people find they can help them feel stronger and more confident about coping with dying. They may also improve their quality of life and reduce symptoms.

Many hospices and hospitals offer complementary therapies alongside conventional care. These may include:

- acupuncture
- homeopathy
- relaxation, visualisation, or guided imagery techniques
- aromatherapy
- reflexology
- reiki.

You might like to try some complementary therapies, such as relaxation and visualisation, to reduce anxiety. It may also be possible for hospital or hospice staff trained in complementary therapies to teach your carers how to give you a massage.

Many hospices and hospitals also offer free complementary therapies to carers. You can ask your nurse about which therapies are available in your local area.

Macmillan has a booklet, *Cancer and complementary therapies*, with more information. See page 120.

## 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 one of the nurses so they can help you cope.

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

It's important to look after yourself too. So think about making arrangements for someone to come in regularly so 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 114-115. Having some support and help can allow you to regain your previous role as a partner, friend, son or daughter.

When you get time off from caring, 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. You can also spend time just sitting with and talking to the person you're caring for, as this can be very rewarding.



## Chapter 8

# The last few days of life

This chapter includes information on:

- Physical care
- Symptoms
- Just-in-case medicines

Information for relatives and friends is also included on pages 82-85.

Each person's experience of the last few days of life will be different and it can be difficult to predict exactly what will happen or how quickly the changes will occur. Usually, you'll gradually become very weak and have very little energy. 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 no longer digest food and doesn't need it
- sleep a lot and feel drowsy when you're awake
- feel disorientated and unsure whether you're dreaming
- dream about people who aren't 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.

## Physical care

During your last few days, 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 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 put lip balm on to your lips to stop them getting dry and cracked.

To prevent your skin from getting sore, it's important that your carers moisturise it and help you change 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. These can include 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 with your relatives and 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 on your own.

## Symptoms

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

If you have problems swallowing, it's possible to give your medicines either by injection, by patches stuck on to the skin or by using a syringe driver (see page 62).

## Just-in-case medicines

You may hear your doctor, district nurse or palliative care nurse talk about leaving a small case or box of medicines in your home 'just in case' you need them. This is because it can sometimes be hard for them to access drugs quickly at night or at weekends. This might be a problem if you get more pain or start to feel or be sick. If you have just-in-case medicines in your home, it means that a nurse or doctor can give them to you without delay if you need them.

Just-in-case medicines usually include injections to help with pain, sickness, restlessness and secretions on your chest.

## 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.

As your relative or friend nears the end of their life, you may find that you need more support and help from professionals to care for them. You can contact their district nurse, specialist nurse or social worker. They will reassess their needs and arrange extra care services, if necessary.

## Pain

Your relative or friend may seem to be in pain. They may be restless, grimacing (screwing up their face) or moving 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 their doctor or specialist nurse know so they can advise you about this. They can also check for other causes of these changes, such as an infection.

## Breathing changes

Your relative or friend may develop breathing changes. For example, their breathing may become noisy due to fluid collecting in the breathing passages. Although this can be distressing for relatives and friends, the person won't usually seem distressed themselves. Their doctor or specialist nurse will be able to give medicines to help.

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

Sometimes people have symptoms of restlessness, agitation, confusion, shouting or twitching. This is often known as terminal restlessness. These symptoms can be caused by pain, constipation, infection, side effects of medicines, or a build-up of waste chemicals (toxins) in the blood. Some people become restless because of emotional distress, a fear of dying or a fear of losing control. In this situation, they may get comfort from a close friend, trusted health professional or a spiritual or religious leader.

Terminal restlessness can often be well controlled with medicines such as sedatives that can be given by injection or a syringe driver.



### 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 their 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.

### 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.

### Religious and spiritual needs

Your relative or friend may want 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.

## Contacting support services

If you're worried that your relative or friend seems to be distressed or has new or uncomfortable symptoms, contact their GP, district nurse or specialist nurse for advice and support.

You should be given telephone contact numbers for these services and numbers for use out-of-hours (for example, at night and weekends). Keep them in a safe place and use them if you need to.

### End of life care plan

You may hear the doctors and nurses talk about your relative or friend's end of life care plan. This is the care that the doctors and nurses will plan for your relative to meet their specific needs as they approach the end of their life. It will help to make sure that your relative or friends needs for food, drink, symptom control, emotional, spiritual and social support, are met.

The doctors and nurses will involve you in decisions about your relative or friend's treatment and end of life care plan. They will also give you support.

If you would like more information about your relative or friend's care plan speak to one of the doctors or nurses looking after them.



## Chapter 9

# Nearing death

**This chapter includes information on:**

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

**We have included information for relatives and friends on page 89.**

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.

## What happens

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

Generally, people eventually become completely unconscious. They can't 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 you're at home and anything happens that worries your carers, 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.

## Information for relatives and friends

Even if your relative or friend is unable to respond, they may still be able to hear you and know you're 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 can't respond, but it can be comforting for both of you. You may need to move them regularly to keep them comfortable. There may be times where not much needs to be done and you can just sit with them and be close to them.

It's fine to call your relative or friend's GP or specialist nurse to let them know what's happening and to ask for advice if you need it.

## Physical changes

Your relative or friend won't usually feel thirsty at this stage but their mouth may be dry and need to be moistened. If they feel sick, anti-sickness medicines (anti-emetics) can be given by a syringe driver (see page 62).

### Skin and sensation changes

In the last few hours, your relative's or friend's hands, feet and 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 or through a syringe driver to reduce the build-up of these secretions.

You may find it helpful to listen to Marie Curie's film guide (video), *How breathing patterns change towards the end of a person's life* (see page 121).

## Other changes

If your relative or friend is drifting in and out of consciousness, there may be times when they don't seem to recognise you or 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 restless or agitated, this can be eased by giving sedatives by injection or through 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.

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's a belief that the person's consciousness (mind or soul) stays around the body for some time after death. Other people feel that their 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 10

# After the death if you're a partner, relative or friend

This chapter includes information on:

- What the GP will do
- What the funeral director will do
- Registering the death
- Planning a funeral and burial or a cremation
- Help with the cost of a funeral
- Wills and probate
- How grief might affect you

The death of someone close to you is very significant and everyone reacts differently to it. In the first few hours after their death, you may feel very shocked or numb however well-prepared you were. You may have lots of overwhelming emotions, such as feeling extremely upset and angry. Many people 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 but don't feel that you have to do anything straight away or rush to 'get on with things'. If you want, you can just spend some quiet time with the person who has died. Many people like to sit and talk or hold hands, and see the person at peace, especially if the last few hours or days were difficult.

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.

## What the GP will do

If your relative or friend dies in a hospital or hospice, the nursing staff will be nearby. They will guide you through what needs to be done over the next few hours.

If your relative or friend dies at home, you'll need to let their GP or district nurse know what's happened within a few hours. The GP or a district nurse will come as soon as possible to confirm the death. This is also known as verifying the death. If the 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 district 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.

When you have the medical death certificate, you need to take this to the local registrar's office to register the death (see page 97).

### Post-mortem

The doctor who certifies the death has a legal responsibility to inform the coroner (procurator fiscal in Scotland) if a post-mortem is needed. A post-mortem isn't usually necessary if the death was expected and the person was seen by their GP in the last 14 days (28 days in Northern Ireland) before their death. However, there are some exceptions. For example, a post-mortem may be needed when a person dies of an occupational disease such as mesothelioma.

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

## What the funeral director will do

Once the death has been 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 (see page 119). The funeral director will come as soon as you want them 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'd like the body to be taken to the funeral director's chapel of rest. You can visit the chapel of rest to be with the 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.

### Embalming

Some people want to be embalmed. This is when 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.

## Registering the death

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. 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 and not photocopies. You'll usually need one certified copy for each life insurance policy (or similar) that you need to claim.

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

Your district or palliative care nurse can give you information about what to do when someone dies. You may also find the booklets on pages 120-121 helpful.

## 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. The 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?
- How will the funeral be paid for? Is there a pre-paid funeral plan?

Some people have no strong religious beliefs, while others have a strong religious or spiritual faith or may have lived their lives as humanists, agnostics or atheists. You may have very clear ideas about how you want to pay your respects to the person's body and how you want the service to be dealt with. Remember, you don't need to have a religious leader to conduct a funeral or memorial service.

If you're unsure what to do or didn't have a chance to discuss this with your loved one, you can get ideas from books or the internet. An undertaker can also guide you through issuing the death notices and planning the funeral service. You can also get information from the registrar.

### After the death if you're a partner, relative or friend

People who have a spiritual or religious faith often have a clear idea of who they want to conduct the funeral and where they want the funeral or memorial service to take place. A funeral, religious or spiritual service can be held wherever you like, for example, in the person's home or their favourite place. Services are often held in the church where the body will be buried or in the chapel next to a crematorium, but they can be held in other places if you prefer.

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 and your loved one may have discussed what they wanted done with their ashes. You can carry out these wishes when you're 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. If you want to bury someone on a property that you own or in a place that they loved, you can get information from The Natural Death Centre (see page 119).

If you and your relative or friend didn't have the chance to discuss their choice of burial or cremation, and there's a will, it's important to consult the executor to see if the will contains this information. If you discussed plans for the funeral before their death, this makes it easier to be sure you're arranging a service of remembrance that reflects the person's wishes. Some people also have strong views on the clothes they want to be buried or cremated in.



## Help with the cost of a funeral

The Social Fund is a government fund that makes payments to people in need. These payments include Funeral Payments to help with the cost of arranging a funeral. To be eligible for most Social Fund payments you need to be receiving certain benefits when you apply. The fund is run by the Department for Work and Pensions.

For more information on Funeral Payments, visit [gov.uk](http://gov.uk) or contact your local Jobcentre Plus office. If you live in Northern Ireland, contact nidirect ([nidirect.gov.uk](http://nidirect.gov.uk)) or your nearest social security agency office ([dsdni.gov.uk](http://dsdni.gov.uk)) for more information. You'll find their number in the phone book.

## Wills and probate

When a person dies, the person who deals with their estate (their executor), needs to apply for probate before the will can be executed (carried out). Probate is the official validation and approval of a will. Application for probate needs to be made to the local probate court and usually takes several weeks. Probate may not be needed in some situations, for example when the person who died owned everything jointly with their spouse.

If a person dies without making a will this is known as “dying intestate”. If this is the case, “letters of administration” should be applied for. This process usually takes longer and none of the dead person’s property should be sold or given away until probate is granted. If you have questions about probate, it might be helpful to discuss these with a solicitor.

In Scotland, probate is called “confirmation” and letters of administration is called “appointment of executor-dative”.

It's important that the executors of the will understand their role and keep you up-to-date on the progress. If you're a likely beneficiary of the will, bear in mind that probate can take a long time. Try to make sure that you have access to enough money in your own account to see you through the first few weeks and months. Some money can be released early to pay for immediate costs, but it's much easier to have independent funds in a joint account.

## How grief might affect you

Grief is a normal response to the death of someone close to you. It's usually felt as a yearning for the other person. At times, the yearning can be so strong that it feels like very real physical pain.

Everyone experiences grief in a different way, but most people move through some or all of the stages listed here. People often move backwards and forwards between these stages:

- numbness
- denial, anger and guilt
- pining or yearning
- depression
- gradual recovery and acceptance.

## Emotional effects

Immediately after the death, and for some time afterwards, you may feel numb. You may find it hard to believe that the person is dead. It's common to feel angry that the person has died. The 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 stop 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 where they see the dead person as fit and well. These are perfectly normal experiences, although they can be shocking and upsetting.

You may have times of severe anxiety and distress, where you strongly miss the dead person and sob or cry aloud for them. Although this tends to happen less often after the first couple of weeks, finding a photograph of them or visiting a place that holds strong memories can trigger the distress, even months or years afterwards.

Talking through your feelings at this time may be helpful. There are many organisations, such as Cruse Bereavement Care (see page 116), which run groups for people who are grieving. Your GP can put you in touch with a local bereavement counsellor if you’d like more formal one-to-one counselling. Many hospices also provide bereavement support for the families of people who have used their services.

If you have young children and teenagers, they will also experience a range of emotions. Very young children may not understand that they will not see the person who has died again. You may need to remind them of this several times. This can be hard when you’re coping with your own grief. Teenagers can find coping with the death of a parent particularly difficult at a time when they’re also coping with other changes in their lives. There are many organisations that can help you to support your children (pages 113-117).

### After the death if you're a partner, relative or friend

If you have an older child or teenager, they may find it helpful to join an online forum for bereaved young people. Organisations such as RD4U and Winston's Wish (see pages 116-117) have forums where children and teenagers can chat to others or just share their feelings.

You may find it helpful to read Marie Curie's publication *Finding the words - how to support children when someone close dies*. Marie Curie also has information for teenagers, *How are you feeling? Coping with grief as a teenager*. See page 120.

### Physical effects

When someone close to you has died, it's also 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

On the first day or so after the death, while you're 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.

### Financial help

You may be entitled to bereavement benefits such as a bereavement payment, widowed parent's allowance or a bereavement allowance. You can find out more about any benefits you may be entitled to from your local Citizens Advice Bureau. You can also visit the Department for Work and Pensions website at [gov.uk/browse/benefits](https://gov.uk/browse/benefits). If you live in Northern Ireland, contact your local Social Security Benefits Office Agency ([dsdni.gov.uk](https://dsdni.gov.uk)). You can also contact Macmillan's Support Line on **0808 808 00 00**.

### After the funeral

The period of time after the funeral, when everyone has gone home and you're expected to get on with 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. 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.

### Delayed grief

The grieving process is different for everyone and very personal. Sometimes, it can be hard to tell if your feelings and emotions are normal. You may find that you get stuck at one stage of the grieving process, for example feeling very angry. If this happens, you may want to talk to your GP who may recommend counselling.

### After the death if you're a partner, relative or friend

Soon after a person's death you may feel that you'll never be able to live your life normally again. These feelings usually reduce over time, although this can take a year or more. You will never forget the person and will always have memories of them. But people are usually able to get on with life again after a while and are able to enjoy activities and make plans for the future.

A very small number of people develop suicidal thoughts as part of the grieving process, either because they feel unable to face life without the person, or because they feel that their own death might bring them closer again. If you have suicidal thoughts, don't be afraid to discuss them with your GP or a trusted friend or relative. You may need expert counselling and possibly medicines to help you feel better.

### Celebrating the life of your loved one

It's common for feelings of grief to be brought up again at particular times. This may happen on the anniversary of the person's death or on birthdays and anniversaries. At these times, you may feel many conflicting emotions and may like to do something to remember the person, such as go to the place where they're buried, or somewhere that meant a lot to you both. You may want to have a gathering of relatives and close friends to share memories of the person and celebrate their life. You'll know the best way to remember them. If you have children or teenagers, remember to include them in the plans. They may have their own ideas of how they can celebrate a parent, grandparent or a loved one's life.

As well as reading this chapter, you may also find it helpful to read Marie Curie's booklet *Bereavement - helping you to deal with the death of someone close to you* (see page 120). It provides information on the practical and emotional issues that may happen if you lose someone close to you.



## Chapter 11

# National organisations that can help

We've listed organisations that may be able to help you. This chapter is divided into the following sections:

- How Macmillan Cancer Support can help you
- How Marie Curie Cancer Care can help you
- General organisations
- Support for carers
- Counselling, bereavement and emotional support
- Practical and financial support
- 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  
**[www.macmillan.org.uk](http://www.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](http://macmillan.org.uk)**, or join our online community at **[macmillan.org.uk/community](http://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 England**  
**0845 4647**  
**[www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)**

**NHS Scotland**  
**0845 24 24 24**  
**[www.nhs24.com](http://www.nhs24.com)**

**Samaritans**  
**0845 790 9090**  
**[www.samaritans.org.uk](http://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](http://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](https://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 leaflet, *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](https://macmillan.org.uk/legacies) or email [leavealegacy@macmillan.org.uk](mailto: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](http://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)  
[www.mariecurie.org.uk](http://www.mariecurie.org.uk)

Given the choice, most of us would want to be cared for and to die at home, surrounded by the people and things we cherish. Marie Curie Cancer Care makes this possible.

Working across the UK, Marie Curie Nurses give free hands-on care to people with serious illnesses in their own homes, and vital emotional support to those caring for them. Our nurses help people to manage difficulties such as pain or nausea, making sure that they are as comfortable as possible in their own home.

The nine Marie Curie Hospices provide free specialist care, therapies and support to patients, carers and families. Each hospice offers a range of services to help people who are seriously ill to live with their illness, giving them the best quality of life. Our hospices are located in Belfast, Bradford, Edinburgh, Glasgow, Hampstead (London), Liverpool, Newcastle, Penarth (Cardiff) and Solihull.

In some areas, trained volunteers for the Marie Curie Helper service offer companionship and one-to-one support in people's homes.

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

### **Further information for you and your carer**

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 lots of information for people who are seriously ill and their families. Visit [mariecurie.org.uk](http://mariecurie.org.uk)

### **How you can make a difference**

Marie Curie's services are free to patients and their families, and we rely on the generous support of the public to fund our work.

The sad fact is, every five minutes, someone in the UK dies without the care they need at the end of their life. That's why we urgently need to reach more people - and why we're counting on your support.

### **Here are ways you can help:**

#### **Donate an hour**

Fundraise for us in March by becoming a collector for the Great Daffodil Appeal.

By sparing an hour or two, you'll help us nurse many more people in their final hours. Visit [mariecurie.org.uk/daffodil](http://mariecurie.org.uk/daffodil) to play your part.

#### **Leave a gift in your Will**

The generous people who remember Marie Curie in their Wills fund one in three of our 2,000 nurses across the UK. To support us in this special way, speak to our legacy advisers who can provide support and guidance or visit [mariecurie.org.uk/legacy](http://mariecurie.org.uk/legacy)

#### **Challenge yourself**

Take on a challenge at home or abroad for your local Marie Curie Nurses. Check out our range of walking, cycling and other outdoorsy adventures at [mariecurie.org.uk/events](http://mariecurie.org.uk/events)

#### **Donate your skills**

Whether you're good with people, words or numbers, you can get involved as a volunteer with Marie Curie. Visit [mariecurie.org.uk/volunteer](http://mariecurie.org.uk/volunteer)

Visit our website [mariecurie.org.uk](http://mariecurie.org.uk) to find out more or phone **0800 716 146** (free call).

## General organisations

### **Advance Decisions to Refuse Treatment**

**[www.adrt.nhs.uk](http://www.adrt.nhs.uk)**

Has information and useful downloads about ADRT.

### **Age UK**

Tavis House, 1-6 Tavistock Square, London WC1H 9NA  
Tel **0800 169 6565**

(Daily, 8am-7pm)

**[www.ageuk.org.uk](http://www.ageuk.org.uk)**

Provides information and advice for older people on everything from health to housing via the website and Advice Line. Also publishes impartial and informative fact sheets and advice guides.

### **Age Cymru**

Ty John Pathy,  
13/14 Neptune Court,  
Vanguard Way,  
Cardiff CF24 5PJ  
Tel **0800 169 6565**

**[www.ageuk.org.uk/cymru](http://www.ageuk.org.uk/cymru)**

### **Age Northern Ireland**

3 Lower Crescent,  
Belfast BT7 1NR  
Tel **0808 808 7575**  
**[www.ageuk.org.uk/northern-ireland](http://www.ageuk.org.uk/northern-ireland)**

### **Age Scotland**

Causewayside House,  
160 Causewayside,  
Edinburgh EH9 1PR  
Tel **0845 125 9732**  
**[www.ageuk.org.uk/scotland](http://www.ageuk.org.uk/scotland)**

### **British Heart Foundation**

Greater London House,  
180 Hampstead Road,  
London NW1 7AW  
Tel **0300 330 3311**  
(Mon-Fri, 9am-6pm)  
**[www.bhf.org.uk](http://www.bhf.org.uk)**  
National charity providing information and advice to people with heart and circulatory problems. Also has advice on keeping your heart healthy.

### **British Lung Foundation**

73-75 Goswell Road,  
London EC1V 7ER  
Tel **03000 030 555**  
(Mon-Fri, 10am-6pm)  
Email **[enquiries@blf.org.uk](mailto:enquiries@blf.org.uk)**  
**[www.blf.org.uk](http://www.blf.org.uk)**  
Provides information on all forms of lung conditions. Runs support groups across the country. Produces a newsletter and publications and raises funds for research into lung disease.

### **Dying Matters**

Tel **08000 21 44 66**

Email [info@dyingmatters.org](mailto:info@dyingmatters.org)

[www.dyingmatters.org](http://www.dyingmatters.org)

Promotes public awareness of dying, death and bereavement.

### **Help the Hospices**

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

Tel **020 7520 8200**

Email

[info@helpthehospices.org.uk](mailto:info@helpthehospices.org.uk)

[www.helpthehospices.org.uk](http://www.helpthehospices.org.uk)

A charity that provides a wide range of information relevant to living with advanced illness. Compiles a comprehensive directory of Hospice Services, and practical booklets. These are all available free via the website.

### **National End of Life**

**Care Programme**

[www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)

Has information about planning for your future care, and documents for writing Advance Decisions to Refuse Treatment and Preferred Priorities for Care. Part of NHS Improving Quality from April 2013.

### **NHS Direct**

Tel **0845 4647**

[www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)

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

### **NHS 24 in Scotland**

[www.nhs24.com](http://www.nhs24.com)

### **NHS in Wales**

[www.nhsdirect.wales.nhs.uk](http://www.nhsdirect.wales.nhs.uk)

**Health and Social Care  
in Northern Ireland**

[www.n-i.nhs.uk](http://www.n-i.nhs.uk)

## **Support for carers**

### **Carers UK**

20 Great Dover Street,  
London, SE1 4LX

Tel **0808 808 7777**

(Wed and Thu, 10am-12pm  
and 2-4pm)

Email [advice@carersuk.org](mailto:advice@carersuk.org)

[carersuk.org](http://carersuk.org)

[www.carersuk.org](http://www.carersuk.org)

Offers information and support to carers. Can put people in contact with support groups for carers in their area. Carers UK have 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](mailto:info@carerscotland.org)  
[www.carersuk.org/scotland](http://www.carersuk.org/scotland)

**Carers Wales**

River House, Ynsbridge  
Court, Gwaelod-y-Garth,  
Cardiff CF15 9SS  
Tel 029 2081 1370  
Email [info@carerswales.org](mailto:info@carerswales.org)  
[www.carersuk.org/wales](http://www.carersuk.org/wales)

**Carers Northern Ireland**

58 Howard Street,  
Belfast BT1 6PJ  
Tel 028 9043 9843  
Email [info@carersni.org](mailto:info@carersni.org)  
[www.carersuk.org/northernireland](http://www.carersuk.org/northernireland)

**Counselling,  
bereavement and  
emotional support**

**British Association for  
Counselling and  
Psychotherapy (BACP)**

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

**[bacp@bacp.co.uk](mailto:bacp@bacp.co.uk)  
[www.bacp.co.uk](http://www.bacp.co.uk)**

Aims to promote awareness  
of counselling and increase  
availability. Can refer people  
to a local counsellor, and has  
a searchable list on its  
website. Provides an  
information sheet for  
those seeking help.

**The Childhood  
Bereavement Network**

8 Wakley Street,  
London EC1V 7QE  
Tel 020 7843 6309  
Email [cbn@ncb.org.uk](mailto:cbn@ncb.org.uk)  
[www.childhoodbereavementnetwork.org.uk](http://www.childhoodbereavementnetwork.org.uk)  
A national, multi-professional  
federation of organisations  
and individuals working  
with bereaved children and  
young people. Has an online  
directory where you can  
search for local and national  
support services.

**The Compassionate  
Friends (TCF)**

53 North Street,  
Bristol BS3 1EN  
Tel 0845 123 2304 (Daily,  
10am-4pm and 7pm-10pm)  
Email [helpline@tcf.org.uk](mailto:helpline@tcf.org.uk)  
[www.tcf.org.uk](http://www.tcf.org.uk)  
A befriending service for  
parents, grandparents,



or brothers and sisters 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 TW9 1RG  
Tel **0844 477 9400**  
(Mon, Wed, Fri, 9.30am-5pm,  
Tues, Wed, Thu, 9.30am-8pm)  
Email [helpline@cruse.org.uk](mailto:helpline@cruse.org.uk)  
[www.crusebereavementcare.org.uk](http://www.crusebereavementcare.org.uk)

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

**National Association of Widows**

48 Queens Road,  
Coventry CV1 3EH  
Tel **024 7663 4848**  
[www.widows.uk.net](http://www.widows.uk.net)  
Offers support, friendship and understanding to men and women who have lost their partners through bereavement.

**RD4U**

Box 800,  
Richmond TW9 1RG  
Tel **0808 808 1677**  
(Mon-Fri, 9.30am-5pm)  
Email [info@rd4u.org.uk](mailto:info@rd4u.org.uk)  
[www.rd4u.org.uk](http://www.rd4u.org.uk)  
Designed for young people by young people, RD4U is part of Cruse Bereavement Care. It supports young people after the death of someone close. Offers a private message service from the website.

**Samaritans**

Freepost RSRB-KKBY-CYJK,  
Chris, PO Box 9090,  
Stirling FK8 2SA  
Tel **08457 90 90 90**  
Email [jo@samaritans.org](mailto:jo@samaritans.org)  
[www.samaritans.org.uk](http://www.samaritans.org.uk)  
Provides confidential non-judgemental emotional support, 24 hours a day for people who are experiencing feelings of distress or despair, including those which could lead to suicide. Service provided by phone, email or letter.

**WAY Widowed and Young**

Suite 35, St. Loyes House,  
20 St. Loyes Street,  
Bedford MK40 1ZL  
Tel **0300 012 4929**

Email [enquiries@widowedandyoung.org.uk](mailto:enquiries@widowedandyoung.org.uk)  
[www.widowedandyoung.org.uk](http://www.widowedandyoung.org.uk)

The only national charity in the UK for men and women of 51 or younger whose partner has died. It's a self-help group run by a network of volunteers who have been bereaved at a young age themselves, so they understand exactly what other members are going through.

### **Winston's Wish**

3<sup>rd</sup> Floor, Cheltenham House, Clarence Street, Cheltenham GL50 3PR  
Tel **08452 03 04 05**  
Email

[info@winstonswish.org.uk](mailto:info@winstonswish.org.uk)  
[www.winstonswish.org.uk](http://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**

#### **Assist UK**

Redbank House,  
4 St. Chad's Street,

Manchester M8 8QA  
Tel **0161 832 9757**  
Email [general.info@assist-uk.org](mailto:general.info@assist-uk.org)

[www.assist-uk.org](http://www.assist-uk.org)  
An independent voluntary organisation with a network of Disabled Living Centres throughout the UK. Centres offer advice and a range of products and equipment designed to make life easier for people who have difficulty with daily activities.

### **British Humanist Association**

39 Moreland Street,  
London EC1V 8BB  
Tel **020 7324 3060**  
Email [info@humanism.org.uk](mailto:info@humanism.org.uk)  
[www.humanism.org.uk/](http://www.humanism.org.uk/)

National charity working on behalf of non-religious people who seek to live ethical and fulfilling lives based on reason and humanity.

### **British Red Cross**

44 Moorfields,  
London EC2Y 9AL  
Tel **0844 871 11 11**  
Email  
[information@redcross.org.uk](mailto:information@redcross.org.uk)  
[www.redcross.org.uk](http://www.redcross.org.uk)

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

**British Red Cross Scotland,  
Northern Ireland and the  
Isle of Man**

4 Nasmyth Place, Hillington,  
Glasgow G52 4PR  
Tel **0141 891 4000**  
**[www.redcross.org.uk](http://www.redcross.org.uk)**

**Carehome.co.uk**

A website that provides  
information about care  
homes and has a searchable  
directory of care homes.

**Citizens Advice**

Provides advice on a  
variety of issues including  
financial, legal, housing and  
employment issues. Find  
details for your local office in  
the phone book or on one of  
the following websites:

**England and Wales**  
**[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)**

**Scotland**  
**[www.cas.org.uk](http://www.cas.org.uk)**

**Northern Ireland**  
**[www.citizensadvice.co.uk](http://www.citizensadvice.co.uk)**

You can also find advice  
online in a range of languages  
at **[adviceguide.org.uk](http://adviceguide.org.uk)**

**Department for Work  
and Pensions**

Disability Benefits Helpline  
**08457 123 456**  
Personal Independence  
Payment Helpline  
**0845 850 3322**  
Carer's Allowance Unit  
**0845 608 432**

**[www.gov.uk/browse/  
benefits](http://www.gov.uk/browse/benefits)**

Manages state benefits in  
England, Scotland and Wales.  
You can apply for benefits  
and find information online  
or through its helplines.

**GOV.UK**

**[www.gov.uk](http://www.gov.uk)**  
Has comprehensive  
information about social  
security benefits.

**NI Direct**  
**(Northern Ireland)**  
Tel **0800 220 674**  
(Mon-Wed and Fri, 9am-  
5pm, Thu, 10am-5pm)  
Textphone **0800 243 787**  
**[www.nidirect.gov.uk/  
money-tax-and-benefits](http://www.nidirect.gov.uk/money-tax-and-benefits)**

**Personal Finance Society -  
'Find an Adviser' service**  
**[www.findanadviser.org](http://www.findanadviser.org)**

Use the website to find  
qualified financial advisers  
in your area.

**Office of the  
Public Guardian**

PO Box 15118,  
Birmingham B16 6GX  
Tel **0300 456 0300**  
(Mon-Fri, 9am-5pm,  
Wed, 10am-5pm)  
Email [customerservices@  
publicguardian.gsi.gov.uk](mailto:customerservices@publicguardian.gsi.gov.uk)  
[www.justice.gov.uk/  
contacts/opg](http://www.justice.gov.uk/contacts/opg)  
Protects people who lack  
the mental capacity to make  
decisions for themselves.

**Office of the Public  
Guardian (Scotland)**

Hadrian House,  
Callendar Road,  
Falkirk FK1 1XR  
Tel **01324 678300**  
Email  
[opg@scotcourts.gov.uk](mailto:opg@scotcourts.gov.uk)  
[www.publicguardian-  
scotland.gov.uk](http://www.publicguardian-scotland.gov.uk)

**National Association of  
Funeral Directors**

618 Warwick Road,  
Solihull B91 1AA  
Tel **0845 230 1343**  
[www.nafd.org.uk](http://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 **01962 712 690**  
Email  
[contact@naturaldeath.org.uk](mailto:contact@naturaldeath.org.uk)  
[www.naturaldeath.org.uk](http://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.

**NHS Blood and Transplant  
(NHSBT)**

Oak House, Reeds Crescent,  
Watford WD24 4QN  
Tel **0300 123 23 23**  
[www.nhsbt.nhs.uk](http://www.nhsbt.nhs.uk)  
NHSBT is a Special Health  
Authority in the NHS with  
responsibility for optimising  
the supply of blood, organs,  
and tissues, and raising  
the quality, effectiveness  
and efficiency of blood and  
transplant services.

**Unbiased.co.uk**

Email  
[contact@unbiased.co.uk](mailto:contact@unbiased.co.uk)  
[www.unbiased.co.uk](http://www.unbiased.co.uk)  
On the website you can search  
for qualified advisers who  
specialise in giving financial  
advice, mortgage, accounting  
or legal advice.

## Useful books and leaflets

There are several publications produced by Macmillan, which are mentioned in this booklet:

- *An Advance Decision to Refuse Treatment*
- *A step-by-step guide to making a will*
- *Cancer and complementary therapies*
- *Caring for someone with advanced cancer*
- *Controlling cancer pain*
- *Family. Friends. Macmillan?*
- *Help with the cost of cancer*
- *Managing breathlessness*
- *Memory box*
- *National End of Life Care Preferred Priorities for Care* document
- *Talking about your cancer*
- *Talking to children when an adult has cancer*
- *Your life and your choices: plan ahead* (England and Wales)

These can be ordered free from Macmillan by calling **0808 808 00 00** or by going to **be.macmillan.org.uk**

There are several publications produced by Marie Curie, which are mentioned in this booklet. You can download these at **mariecurie.org.uk/publications**

- *Bereavement - helping you to deal with the death of someone close to you*
- *Finding the words - how to support children when someone close dies*
- *How are you feeling? Coping with grief as a teenager*

Publications developed by the Marie Curie Palliative Care Institute Liverpool are available at **sii-mcpcil.org.uk/resources-and-links.aspx**

- *Saying goodbye* - a series of leaflets for children and teenagers
- *Supporting toddlers and pre-school children when a parent or close relative is dying*
- *Talking to children when someone is dying*

These publications can also be ordered by calling **0800 716 146** (for Marie Curie Cancer Care publications) or **0151 706 2274** (for the Marie Curie Palliative Care Institute Liverpool publications).

Marie Curie film guides (available at [mariecurie.org.uk](http://mariecurie.org.uk)):

- *How breathing patterns change towards the end of a person's life* (visit [mariecurie.org.uk/breathing](http://mariecurie.org.uk/breathing))
- *How to help with mouth care* (visit [mariecurie.org.uk/mouth](http://mariecurie.org.uk/mouth))

### **Planning for your future care: a guide**

Dying Matters Coalition/ National End of Life Care Programme/The University of Nottingham. 2012. Free. This publication provides a simple explanation about advance care planning and the different options open to you. Available via NHS Improving Quality (England).

### **A guide to grants for individuals in need 2011-2012**

Directory of social change. 11<sup>th</sup> edition. 2009. £75. A directory of a wide range of charities and trusts that provide financial assistance to people in need. Most public libraries will have a copy.

### **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 [dwp.gov.uk/docs/dwp1027.pdf](http://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, Citizen's Advice or visit [gov.uk](http://gov.uk)

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

The Scottish Government.  
10<sup>th</sup> edition. 2012. 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 [scotland.gov.uk/publications/2012/05/4929/downloads](http://scotland.gov.uk/publications/2012/05/4929/downloads) Or call 0131 244 3581 to order a copy.

**When someone dies. A step-by-step guide to what to do.**

Age UK. 2013.  
Available to download from [ageuk.org.uk](http://ageuk.org.uk) or by calling Age UK (see page 113).

**What to do when someone dies**

Paul Harris (ed.).  
Which? books. 2010.  
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.

## Disclaimer

We make every effort to ensure that the information we produce is accurate and up-to-date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan Cancer Support and Marie Curie Cancer Care do not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it.

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May 2012.

National Institute for Health  
and Care Excellence (NICE).  
*Quality standard for end  
of life care for adults.* Quality  
standard 13. August 2011.



## Questions about living with cancer?

Call the Macmillan Support Line free on  
**0808 808 00 00** (Mon-Fri, 9am-8pm).

Alternatively, visit [macmillan.org.uk](http://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 Cancer Care, including how to get a Marie Curie Nurse, call **0800 716 146** or visit [mariecurie.org.uk](http://mariecurie.org.uk)



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

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