

End of life

# DYING WITH CANCER

**WE ARE  
MACMILLAN.  
CANCER SUPPORT**

 cancerbackup

Macmillan and Cancerbackup have merged.  
Together we provide free, high quality information for all.

# Contents

About <i>Dying with cancer</i>	4
<b>Section one: If you have cancer</b>	
Coping with the news	6
Your feelings	7
People close to you	9
If you live alone	14
Things to consider	15
Facing an uncertain future	16
Towards the end of life	17
Spiritual and religious issues	20
Choosing where to die	21
Symptom control	27
Complementary care	36
Putting your affairs in order	38
Advance decisions to refuse treatment and advance statements	43
At the end of life	48
<b>Section two: After the death – if you are a partner, relative or friend</b>	
Registering the death	56
Funeral and religious services	60

Wills and probate	63
Coping with grief and bereavement	64
Celebrating the life of your loved one	69
How we can help you	70
Other useful organisations	74
Further resources	86
Questions you might like to ask your doctor or nurse	89



# About *Dying with cancer*

**This booklet is for you if you have cancer and it's likely that you may die within the next few months. You may also find it helpful if you have a relative or close friend who is terminally ill with cancer.**

It discusses what is likely to happen, the emotional impact of knowing you may die sooner than you hoped, and the information and support people need most in this situation.

## **We have divided the booklet into two parts:**

- **Section one** is written for the person who is dying (pages 5–52).
- **Section two** gives information for partners, relatives and friends about practical and emotional issues after the person has died (pages 53–69).

You may find reading about these issues for the first time difficult and distressing. So you may want to wait to read this booklet when you are somewhere private and know that you will not be disturbed.

We hope this booklet answers some of your questions and helps you deal with some of the feelings you may have. We've also listed other sources of support and information, which we hope you'll find useful.

If you'd like to discuss this information, call the Macmillan Support Line free on **0808 808 00 00**, Monday–Friday,

9am–8pm. If you're hard of hearing you can use textphone 0808 808 0121, or Text Relay. For non English speakers, interpreters are available. Alternatively, visit [macmillan.org.uk](https://www.macmillan.org.uk)

Turn to pages 74–88 for some useful addresses, helpful leaflets and websites, and page 89 to write down questions for your doctor or nurse.

## Section one: If you have cancer

One in four people in the UK will die from cancer. Usually, we don't know when we will die and we don't think about it very much. When you're diagnosed with cancer you may start to think about death and this can be very frightening.

If a cancer comes back or has spread, there may come a time when treatment can't control the cancer and people know that they only have a limited time to live. This booklet explains what happens towards the end of life and how to plan for it.

It's important to remember that everyone is different. Some people with cancer that has spread may become ill very slowly over many months, while others may become ill more quickly, within a few weeks. It's not possible to predict accurately when someone with cancer may die.

As no one can tell you for sure how long you will live, it's important to do the things you want to do when you can get the most out of them. Your doctors, nurses and carers will help you

to stay as well as possible for as long as possible, and will help to control any symptoms that you have.

Most people find it difficult to talk about death and dying. People who are dying sometimes describe being surrounded by a 'conspiracy of silence' where they and their family and friends all know what is happening, but no one feels able to speak about it freely. We hope that this booklet will help you to talk openly throughout this difficult time.

Of course, you may not want to talk about dying, but remember that your family and friends may want to express their feelings and concerns. If this is the case, try to be open and honest and let people know if it's hard for you to talk.

## Coping with the news

Hearing the news that your cancer can't be cured is always very difficult. It can bring up many feelings and emotions.

You may be aware that your cancer is progressing, but you might find it hard to believe what you're hearing, or feel that it's like a nightmare and that 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 call our cancer

support specialists on **0808 808 00 00** – they will be able to talk things through with you.

## Your feelings

**‘Sometimes I feel so angry – not with anyone in particular, just with the situation we are in. I keep thinking, why me?’**

You may feel very angry – perhaps because you feel more could have been done to prevent your cancer. You may also feel angry with the doctors or nurses for telling you the bad news.

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 such 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.

### Talking

Dying with cancer 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 at this difficult time.

However, people who have cancer 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 to 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.

**We have a booklet called *Talking about your cancer*, which you may find helpful.**

# People close to you

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, and this can make it difficult for you to be able to say exactly 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.

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 do not necessarily reflect their true feelings. Your family and friends may be struggling to say how they really feel.

However, this can be a time when your relationships improve as you and the people you're close to 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.

## Partners

Sometimes partners try to protect each other from the truth by denying it, even though both are aware of what is really 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, 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 together. Just when you need each other most, the stresses of an uncertain future or feeling tired or unwell can drive you into arguments.

Anger needs time to settle, so giving yourselves short breaks from each other may help. This can help you think more calmly and recharge your emotional energy. Sometimes talking to someone else can help – a relative or friend, someone outside your own close circle such as a counsellor, or one of the support organisations on pages 74–85. If you think this might help, you may want to discuss it with your partner first so that they don't feel excluded or that they have failed you.

## Sex

There's no medical reason to stop having sex because you have cancer. Cancer can't be passed on through sex. In fact, physical intimacy can create warmth, comfort and a sense of well-being which can be very supportive at this time. Gentle touching, holding hands or affectionate kisses can also show how much you care for someone even if you don't feel like making love.

## Talking to children

There's no easy way to talk to children or grandchildren about your cancer and the fact that you are dying. 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 feel isolated and excluded, and unable to tell you how upset they are. They may feel that they are somehow to blame for your illness. If you can discuss your cancer with them, you can reassure them that it's not their fault.

How and what you choose to tell your children will depend on their age and how much they can understand. For example, children younger than about eight or nine find it difficult to understand that death is permanent. However, children can often discuss death more openly than adults.

It may help to tell children who they can talk to about your cancer. It's useful if they know that they can share their feelings and get support from other trusted adults, such as grandparents or teachers at their schools. It's important to talk to those adults too, and prepare them for this role, especially as they will also have their own feelings about the fact that you are dying.

**We have a booklet called *Talking to children when an adult has cancer*, which we can send you.**



It can help to warn children how they might be affected by your cancer. For example there will be days when you feel too ill or tired to be able to play with them or join in their activities. And if you talk a bit about your feelings, it may help them to talk about theirs too.

Children can react in different ways to your illness and you may find some of these difficult to deal with. For example:

- They may start to behave badly, to cover up their feelings of insecurity.
- They may withdraw from you, perhaps out of fear of being hurt or of catching cancer. You can reassure them that cancer can't be passed on from one person to another.
- They may become very clingy because they are anxious that something might happen to you when they are not there.
- Teenagers may be angry and resentful that you're not able to support them in the way that you used to.

All of this can be very distressing to cope with, but try to remember that support is available, and you don't have to deal with this alone.

# If you live alone

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 about cancer, 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.

You can ask your GP, district or community nurse about what help and support is available. It may be helpful to have a visit from a specialist palliative care nurse or doctor from your local hospice. Your nurse or doctor can also ask the local social services team to visit. They may be able to give practical help such as meals-on-wheels or home help services.

Befriending services (see page 74) can introduce you to trained volunteers who may be able to give one-to-one help and support if you are on your own.

# Things to consider

This list of questions can help you think about how and where you would like to die, so that you can talk it through with your relatives and friends, and feel confident that you'll be cared for in the way that you wish.

As you read through this booklet you may find that some of these questions are answered. They are just suggestions so if you feel they don't apply to you, just ignore them.

- Where would you prefer to be cared for towards the end of your life? At home/in a hospice/in hospital/in a nursing home/in a family member's home?
- Where would you prefer to die? At home/in a hospice/in hospital/in a nursing home/in a family member's home?
- How would you like things around you to be as you are dying?
- What information do you need about your illness and what may happen to you?
- Are there particular treatments that you don't want to have?
- Do you want to write an advance decision to refuse treatment (advance directive) or lasting power of attorney (see pages 41–46)?
- How do you want to be treated by your carers when you are dying?
- Who would you like to have around you? Are there people you don't want around?

- Are there issues that you would like to sort out with particular people?
- Are there any spiritual or religious practices that you would like to be carried out before or at the time of your death, or once you have died? Who do you need to ask to make sure this happens?
- Is there anything that you want done for the people that you love?
- What funeral arrangements would you like to be made?
- Who do you want to make the arrangements?
- Do you want to be cremated or buried?
- Have you made a will?

## 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 six months 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 will probably have good days when you feel well and positive about life and bad days when your energy reserves are lower. It's important to plan for this and appreciate the days you feel well.

Even with modern scans and x-rays, it's sometimes difficult to tell exactly what effect the cancer is having on your body. This makes it very difficult for your doctors or nurses to predict exactly when you are nearing the end of your life. However, there are some physical changes that can happen to the body that may indicate when someone is nearing the final days or hours of life. These changes are explained in more detail on pages 48–50.

## Towards the end of life

### Loss of energy

As you become more unwell you'll find that you get weaker and feel more tired. You may gradually feel less able to do things and may also have less interest in doing activities that you enjoyed before. Your need for company and activity may vary from day to day.

You may sleep more and more during the day. Gradually you may lose strength and as this happens you may only want your partner or closest family members around you. Towards the very end of life you may feel your attention withdrawing even from them. On the other hand, you may be scared to be alone and want someone with you all the time. Even if you are in a hospital or hospice it's usually possible to arrange this.

### Losses

Although death is the final loss, other 'losses' happen gradually throughout a terminal illness. These can include stopping work,

not being able to move around so easily and stopping driving. Although this slow process can be helpful in allowing you to get used to the idea of death, it can also make you feel sad and very low. A dying person often needs to spend time grieving for the things which are lost. This is a natural part of the process of dying.

## **Coping**

There is no 'right' way to die and no 'right' way to cope with the knowledge that you, a relative or a friend, is dying. You can only cope in the way that is best for you. It's up to each person to come to terms with death in their own way, at their own pace. Many people eventually find a sense of peace and appear to be ready to 'let go' when the time comes. It's natural to cry during this time and you don't have to put on a brave face. Being open about your own feelings will make it easier for both you and the people you love to be able to say the things you want to.

## **Talking about dying**

If you find that you need to talk about how you feel, but find it difficult to talk to the people closest to you, perhaps because they are too upset, talking to a trusted friend may help. You may also find it helpful to talk to your district nurse or a palliative care nurse if you have one. They will always try to answer your questions and talk openly with you about dying. They can also tell you about counsellors or other people who you can talk to.

## Unfinished business

Many people find that when they are told they won't recover from their cancer, they start thinking about all the things they still want to do. It's important to go ahead and do the things you can while you are fit enough to enjoy them.

There may also be unfinished business that you need to sort out. As well as dealing with practical and financial affairs, you may find that there are emotional loose ends that you want to tie up – for example, old friends you want to see or wrongs you want to put right.

If you would like to settle old quarrels, 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 find yourself thinking a lot about the past, talking about shared joys, fears and regrets, going over old events in your mind or looking through photo albums. If you're well enough, you may want to visit 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.

You may like to write letters to people who are dear to you, or perhaps record a tape or video, 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.

**We have a fact sheet about creating memory boxes, which we can send you.**

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 to you, both good and bad. They may even make you laugh and have light-hearted memories. The important thing is to do what feels right for you, when it feels right.

## Spiritual and religious issues

Many people find that they become more aware of religious beliefs or spiritual feelings during this time. People with a strong religious faith often find this very supportive during illness. Other people may start to question their faith. Some may find that, perhaps for the first time in their lives, they feel the need to think about and discuss religious or spiritual issues. Spiritual issues cover the meaning of life and relationships with others and can be expressed in many ways, including through music, arts, nature, community, or family.

You may start thinking about whether there is a life after death. Some people find comfort in prayer or meditation. Many people gain a lot of support from knowing that other people are praying for them.

Some religions have very specific practices for when people are very ill or dying. If you want to follow a specific practice in a hospital or hospice, it's helpful to discuss this with the staff. They will be able to help find the space and time for you to do this.

Don't be put off talking to a chaplain, minister, priest, rabbi or other religious leader just because you have not attended services regularly in the past, or because you're not sure about what you believe. Spiritual and religious leaders are used to dealing with uncertainty and with people who are distressed, and they may be able to help you find peace of mind.

## Choosing where to die

Most people would prefer to die at home, as long as they know they will have good quality care. Nowadays, there are many support services available to help families look after a person dying at home.

Often the choice of where you will die depends on what you want, what help you have from family and friends, and what services are available in the area where you live. The Department of Health has produced a document called the *End of Life Care Strategy* (available from [dh.gov.uk](https://www.dh.gov.uk)), which recommends that people who wish to die at home should have access to support services and specialist care, day or night when needed.

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, not just at home. Even if you choose not to die at

home, you can still be surrounded by people and possessions that are dear to you.

If you are a carer reading this, it's important that you don't feel guilty if you encourage your partner or relative to die in a hospice, hospital or nursing home. As time goes on, you may feel that they would be better cared for by health professionals. If you need to move them at a late stage, this shouldn't be seen as a failure, but rather because you want to make sure that your loved one gets the expert care they need.

## **Staying at home**

If home is where you want to be, it's essential that you and your carers have as much support as possible. Caring can be hard work, both physically and emotionally. It's not always easy to ask for help, and some people find it impossible. However, it's important that your carers have enough energy to do the things that only they can do, such as spending time talking to you and supporting you. They can pass on some jobs to other people where possible.

Your GP, district or community nurses, and specialist palliative care teams from the local hospital or hospice can tell you about the support they will be able to provide. This may include nursing care, advice on controlling symptoms, emotional support, spiritual care and rapid access to dedicated telephone helplines and homecare services, day and night.

If you need a commode, bedpan, bottle, special mattress or incontinence sheets, ask your district nurse. You may need to rearrange your home, for example make a dining room into a bedroom, so that you can be cared for on the ground floor and don't have to cope with stairs.

**We have details of all these services in our booklets *Caring for someone with advanced cancer and Coping with advanced cancer.***

Volunteers from local organisations may also be able to help. For example, they might sit with you while your carer shops, or they may be able to do the shopping themselves. Care at night (nurses or night-sitters) may also be available in your area. Marie Curie nurses can stay in your home overnight, or for part of the day, so that your carers can get a good night's sleep or a break. The services of Marie Curie nurses are free and are usually arranged through district nurses.

You can make an appointment with your GP or specialist palliative care team to talk through what may happen and make a plan for dealing with emergencies which may occur. It's important to know how to reach the district nurses or out-of-hours doctor. If you're being looked after by a community palliative care team, you need to know how to contact them in the middle of the night or at weekends. This should help you to sort out most problems that might happen at home.

## **Hospices**

Hospices specialise in the care of people who are dying. They can offer a wide range of services such as complementary therapies, counselling, spiritual care and bereavement support. They specialise in controlling pain and other symptoms, and in supporting the patient and their family.

Hospices are very different from hospitals. They are quieter and tailor their care to suit each person. People can often go into hospices for short periods for their symptoms to be controlled or for a period of respite care to give their carer a break.

There are now more than 200 hospices in the UK. Many have home-care teams and day centres for people living at home. Some are funded by charity and some are part of the NHS. Care in a hospice is always free. You can find out more about your local hospice from your GP, district nurse or palliative care nurse.

## Nursing or residential homes

If you're likely to need nursing care for some time, a nursing home will probably be more appropriate. You may still be able to go to a hospice for day care, or a specialist palliative care 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 if you are reaching the end stages of your illness or if you have a complex medical condition which means that you require a lot of care and support.

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 get information about finding a nursing home and all the issues to consider on the Nursing Home Fees Agency (NHFA) website **[nhfa.co.uk](http://nhfa.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. However, this may be difficult to organise if the ward is very busy. Many people die in hospital, but a busy ward may not be the most peaceful place. Often you'll need to fit into the ward routine, rather than being looked after in the way that you would like.

Nowadays, hospitals have palliative care teams which include specialist nurses and doctors. A specialist nurse or doctor from this team will be able to see you while you are in hospital. They can advise on controlling your symptoms and give you and your family emotional support. Some hospitals have specific palliative care wards for people who are dying. Care is more personalised on these wards.

# Symptom control

This section describes some of the symptoms that may occur during the final stages of cancer and ways to help you control them. Some symptoms are caused by the cancer itself, while others are the result of treatment. You may have one or more of these symptoms, or none at all. Any symptoms can usually be controlled with help from the healthcare team or specialist palliative care team working in the community or in hospital.

## Cancer treatments

You may be given treatments such as chemotherapy or radiotherapy, with the aim of controlling the cancer for a time and reducing symptoms.

If you want to discuss your treatment options or get a second opinion, it may be a good idea to make a specific appointment to go over all the options with your doctor. You can ask them to explain the treatments fully and tell you about the possible benefits and disadvantages of each one. You can also ask them what is likely to happen if you don't have further treatment.

It's important that you don't feel under pressure from your family or friends to accept or refuse further treatment. The final decision is yours, even if you discuss the options with your family or friends.

## Pain

Many people are frightened of pain. However, there are many effective painkillers and other ways of controlling pain, so it can usually be well controlled. Everyone feels pain differently.

Even people with the same condition have very different experiences. It's important to explain to your doctors and nurses exactly where your pain is, how it feels and how it affects you, so that they can treat it effectively.

Many people believe that they should put off using painkillers for as long as possible, and only take them when their pain gets unbearable. However, if pain isn't treated it may be harder to control, so it's important to take any painkillers that you are prescribed in the way that your doctor advises.

## **Painkillers**

The right painkiller for you depends on the type of pain you have and how bad it is. There are different types of painkillers:

- mild painkillers, such as paracetamol
- moderate painkillers (weak opioid painkillers), such as tramadol and codeine or codeine combinations such as cocodamol
- strong painkillers (strong opioid painkillers), such as morphine, oxycodone, fentanyl and diamorphine.

You may also be given other types of drugs to take as well as painkillers. For example: anti-inflammatory drugs may be particularly helpful for bone pain; antidepressants and anticonvulsants, which are usually used to treat epilepsy, are often used to treat nerve pain; and muscle relaxants can help relieve muscle spasm. It's quite common to be given more than one type of painkiller for your pain.

If you have frequent or constant pain it's important to take painkillers regularly. Each dose should be enough to control your pain right through to the next dose. If the pain comes back

before your next dose is due, let your doctor or nurse know so they can give you a more effective dose or a different drug. It may take a few days to get the drugs and doses right. It's important to let your doctor know if the pain is not controlled. Some people find it helpful to keep a diary recording when they get pain.

### **Side effects of painkillers**

Strong painkillers such as morphine, and painkillers containing codeine, have three common side effects: drowsiness, sickness and constipation.

The drowsiness usually wears off after a few days, so it should be possible for you to be free of pain and still be alert enough to do all that you want to do.

If you feel sick, anti-sickness tablets can help, and the sickness usually settles over a few days.

Constipation is a very common side effect and everyone taking strong painkillers should take a laxative regularly. There are a number of different types of laxatives. Some soften the stool, some stimulate the bowel and others contain a combination of both a softener and a stimulant. Your doctor or pharmacist will be able to advise you on the most suitable laxative for you. Don't be afraid to vary the dose of your laxatives to keep your bowels moving easily.

### **Taking painkillers**

Most painkillers are available as soluble tablets or liquid medicines, so you can use these if you have problems with swallowing tablets. Some painkillers, such as fentanyl, can be given as a patch stuck onto the skin. If you can't swallow, or if you're drowsy or confused and unable to swallow tablets

or liquid medicines, some painkillers can be given through a tiny needle inserted just under the skin of the tummy or arm. Enough painkiller for 24 hours is made up and a small portable pump (a syringe driver) is used to give a continuous dose of the drug.

A syringe driver is easy to set up and this is usually done by a nurse. If you're able to move around and walk, the syringe driver can be carried in a special holster or a pocket. If you're in bed then it can be put on the bedside table or tucked under a pillow. Other medicines, including those that treat sickness to help you feel more relaxed, can also be given by the syringe driver. Your doctor or palliative care team will be able to discuss if you need a syringe driver and how it works.

Some people fear that being given drugs by a syringe driver will hasten their death. This isn't true. A syringe driver is simply a different way of giving the same or similar drugs at the doses needed to control your symptoms.

### **Painkillers and addiction**

Many people with cancer ask if they will become addicted to drugs such as morphine, or become confused and unable to look after themselves. The answer is no. People who become addicted to drugs choose to take them – usually for reasons other than pain and at larger doses – and then keep taking them because they have a psychological need for them, for example, they may make them feel 'high'. This is very different to someone who is in pain and who needs to keep taking the drug to keep their pain under control. People in pain have a physical need to take the drug rather than a psychological need.

**There is no danger of you becoming addicted to painkillers when they are used to control cancer pain.**

The dose you take will be tailored to your needs. The right dose is the dose that controls your pain but doesn't make you feel drowsy or confused. It can be increased if your pain gets worse. Many people stay on the same dose of morphine for months. However, it can be harmful to stop taking morphine suddenly. If you have another treatment to relieve the pain, for example radiotherapy, the dose of morphine can be gradually reduced under the supervision of your doctor or nurse.

**We have a booklet called *Controlling cancer pain*, which we can send you.**

### **Emotions and pain**

Strong emotions such as fear, anxiety, depression and tiredness can make your pain worse. So, it's important to try to treat the emotional as well as the physical causes of your pain. Learning to relax, even for short periods of time each day, can play a very useful part in controlling pain. You can relax by becoming aware of different groups of muscles around your body and learning to relax them, so that you can do this consciously when you are under stress or in pain.

In visualisation or guided imagery, you bring happy, relaxed pictures into your mind and this can help to reduce pain. Massage with soothing aromatherapy oils can also help you relax.

**Our booklet *Cancer and complementary therapies* has more information about these techniques and tells you how to find a registered complementary therapist.**

Another way of reducing pain is to use distraction, such as listening to music you enjoy or watching a good film.

## Feeling sick

If you feel sick or have trouble keeping food down, your doctor can prescribe anti-sickness medicines to help. These should be taken regularly to prevent the nausea coming back. They can be taken as tablets or given as suppositories, which are inserted into your back passage. Sometimes anti-sickness medicines are given as an injection by a nurse or doctor. They may also be given in a syringe driver (see page 30).

**We have a fact sheet about controlling nausea and vomiting, which may be helpful.**

## Eating problems

Many people lose their appetite, especially if they feel sick. The illness itself, or treatments such as radiotherapy and chemotherapy, can cause sickness and loss of appetite. You may be put off even by the sight and smell of food. Small, frequent, simple meals, concentrating on your favourite foods, are likely to be most tempting.

However, as you become more ill, your metabolism slows down and your body can't digest food so well or take up the goodness from it. At this stage, it's important not to force yourself to eat.

You may want to try liquid meals when you don't feel able to eat a proper meal. There are many different types of liquid meals such as Ensure<sup>®</sup> or Fortisip<sup>®</sup>, which are complete meals in liquid form. Your doctor or nurse can advise which is best for you and can arrange a supply, often on prescription. There may come a time when even liquid meals are too thick and difficult to digest and you may only want to have clear fluids such as water, squashes or tea.

At this stage, small amounts of liquids may be all that you need to keep you comfortable. You may notice that your mouth feels very dry. This is not a sign that you're dehydrated or that you need to drink more fluid. At some point, people stop drinking even water and just need to have their mouth kept moist by cleaning it gently.

You may want to try sucking pieces of fruit, such as pineapple. Fruit juices can be made into ice lollies or ice cubes, which you can suck to moisten your mouth. If a dry mouth is stopping you from being able to eat or talk, artificial saliva spray or lozenges may help.

**We can send you a fact sheet with tips on coping with a dry mouth.**

You may also wish to see a dietitian for advice on any of the above issues. Your doctor or nurse can arrange this for you.

## **Tiredness and weakness (fatigue)**

Fatigue (feeling exhausted all or most of the time) is a common and difficult problem for people with advanced cancer. It can be caused either by the cancer or by symptoms such as pain.

If you feel tired, it's important to pace yourself and save your energy for the things that matter to you and that you enjoy instead of feeling that you have to do things around the house. Letting other people do these jobs can help you have more energy for things that you really want to do. Just do as much as you feel like. You won't do yourself any harm if you do too much – you can simply rest and relax a bit more the next day if you need to.

Tiredness and weakness can make it harder for you to concentrate or take part fully in what is going on around you. So, if you have important things to do, such as putting your affairs in order, it's best to do them as soon as possible and at a time of day when you have more energy. You may also feel more relaxed once they are out of the way.

**We can send you our booklet, *Coping with fatigue*.**

## Other symptoms

The cancer may cause certain symptoms that your doctors may want to treat, even at a late stage. Treating these can make a big improvement in how you feel.

They include:

- High calcium levels in your blood (hypercalcaemia). This can make you feel sick or be sick, and can cause confusion and constipation. A few days of treatment in hospital or a hospice with medicine (bisphosphonates) given through a drip will help bring your calcium levels down.
- Severe anaemia can make you very tired and breathless. A blood transfusion may make you feel better very quickly.
- Infections can make you feel very ill, but they can usually be treated by antibiotics given as tablets or by drip.
- Fluid around your heart or lungs or in your abdomen can make it difficult to breathe, and can make you feel bloated and uncomfortable. Taking away some of the fluid through a drainage tube may make you much more comfortable. This may need to be repeated if fluid builds up again.

- Pressure sores are common when you spend a lot of time in bed or in a chair without moving. Special mattresses and cushions can help to prevent these.
- If you feel agitated or confused, or have difficulty sleeping, your doctors can prescribe medicines to help you relax and sleep.
- If you have problems emptying your bladder, this can be dealt with by putting a thin, flexible tube (catheter) into the bladder to drain the urine. Having a catheter will mean that you don't have the discomfort of trying to use a bedpan or bottle if you can't get out of bed.
- If you're breathless, your doctor can prescribe medicines to help, such as a low dose of morphine. Your doctor or palliative care nurse can also organise for you to have oxygen.

**There is more information about controlling pain and symptoms in our booklets *Controlling cancer pain* and *Controlling the symptoms of cancer*.**

# Complementary care

Many people find complementary therapies or practices help them feel stronger and more confident in dealing with dying. They can sometimes be used alongside conventional treatments and medicines.

Complementary therapies may help to improve quality of life and well-being and can sometimes help to reduce symptoms. Some complementary therapies, such as meditation or visualisation, can be done by the dying person themselves and may reduce anxiety. Carers and relatives can learn how to do other therapies, such as gentle massage, so that they can use them to support the dying person.

Physical contact and touch can be among the most powerful ways of supporting people who are facing uncertainty, fear or pain, whether emotional or physical. Touching someone gently may express how much you care about them.

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

- aromatherapy
- massage
- relaxation, visualisation or guided imagery techniques
- acupuncture
- reflexology
- Reiki.

**Our booklet *Cancer and complementary therapies* has more information about these therapies.**



# Putting your affairs in order

## Making a will

It's normal to want to think about what will happen to your possessions after your death. Making a will is a thoughtful and effective way of taking care of the people you love, and it can spare them painful decisions, bureaucratic hassles and financial problems which may occur if you don't make your wishes clear. Sometimes, putting your affairs in order can clear your mind of little worries, leaving you free to enjoy the present time.

Making a will is not as expensive or difficult as you might think, but it's a legal document and must be properly prepared. 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.

Age UK produce a fact sheet about making a will, aimed at people aged 60 and over who are living in England. You can get a copy by contacting them directly (see page 84). If you live in Scotland, Wales or Northern Ireland, you should contact the specific Age UK organisation for the country (see pages 84–85) because different rules for making a will may apply.

## **We have a step by step guide to making a will which you may find useful.**

You may find it helpful to make a list of the documents which may be needed to register your death: your bank and building society details; any insurance policies you have; and the details of your accountant, solicitor and tax inspector. Include on the list where to find this information and make sure that your

partner or the executor of your will knows where it is kept.

## Financial matters

A serious and long illness will often put a strain on your finances, as you may no longer have your wages or other income.

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

The benefits agency has two booklets called IB1 and SD1, which outline these and other benefits you may be entitled to. You can get a copy from your local Citizens Advice Bureau (see page 80), where staff will also be able to advise you about the benefits you can claim. You can also get information from the Benefit Enquiry Line on **0800 882 200** or the Department for Work and Pensions website **dwp.gov.uk**

For more information about benefits and financial support, please call us on **0808 808 00 00**. You may also find our booklet *Help with the cost of cancer* useful.

We give grants and benefits advice to people with cancer. You may also be able to claim grants from other organisations or charities. The social worker or benefits adviser at the hospital or hospice can give you advice on where to get financial help.

*A Guide to Grants for Individuals in Need* gives details of all the trusts and organisations that provide financial support. It's available from bookshops or local libraries.

**We can send you information about financial issues and sources of financial support.**

### **Bank accounts**

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

### **Pension schemes**

Some private or occupational pension schemes will not pay out any benefits to partners if the owner of the pension scheme was not married. This means that the pension fund is lost. Sometimes people in this situation can transfer their money to a personal arrangement to give them immediate access to their money, or to their partner's money later. An independent financial adviser can advise you on how to do this. You can contact a financial adviser through the Personal Finance Society or Independent Financial Advisers Promotion (see pages 80–81).

### **Making choices**

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

The Mental Capacity Act 2005 came into force in 2007 and applies to people aged 16 and over in England and Wales. It aims to protect people who cannot make a decision for themselves. This means that a person can plan ahead for a

time when they may not be able to make decisions on their own behalf. It makes it clear who can take decisions in which situations, and how they should go about this. There are many parts to this act including parts on Lasting Power of Attorney and advance decisions. The Adults with Incapacity Act (2000) relates to people in Scotland.

### **Lasting Power of Attorney (LPA)**

A Lasting Power of Attorney is where you 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 are no longer able to do so. An LPA must be made while you are able to understand what it is and what it means for you. It is only valid in England and Wales (see page 44 for information about Scotland and Northern Ireland).

The personal 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 are receiving certain benefits or have a low income you may be exempt from paying the registration fee or only have to pay part of it.

You can get more information about registering an LPA from a social worker at the hospital, The Office of the Public Guardian (see page 75) or organisations such as Age UK (see page 84).

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 76) and organisations such as Age Scotland (see page 85).

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

# Advance decisions to refuse treatment and advance statements

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

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

**An advance statement** is a general statement of your views and wishes. It can indicate the treatment you would prefer and can include non-medical things, such as your food likes and dislikes or religious beliefs. An advance statement is not legally binding, but your doctors should take it into account when deciding what is best for you. 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.

**An advance decision to refuse treatment** is simply a decision to refuse treatment. For example, you may decide that if your condition suddenly worsens and your breathing stops, you don't want people to try to bring you round (resuscitate you). Or that if you are very ill and have an infection, you don't want to be given antibiotics. In England and Wales, an advance

decision is legally binding under the Mental Capacity Act 2005 and must be respected by your doctors. In Scotland and Northern Ireland, an advance decision isn't legally binding. However, it must be taken into account by the medical team and others making decisions on your behalf. In Scotland, an advance decision is known as an advance directive.

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

An advance statement can include who you would like to be consulted about your care, if you're unable to make those decisions yourself. If you want to give these people the power to make decisions on your behalf, you will need to create a Lasting Power of Attorney or LPA (see page 41). The LPA can include your advance statement so that the people named in the LPA take your wishes into account when deciding what is best for you.

An advance decision to refuse treatment must indicate exactly what treatment you want to refuse and in which situation. It can only be made by someone aged 18 or over (16 in Scotland) who has the mental capacity to make the decision. You can change your mind and rewrite your advance decision at any time. A copy of your advance decision to refuse treatment can be kept in your medical and nursing notes. It's also helpful if you provide your GP with a copy. You may also be advised to provide further copies for the ambulance service, out-of-hours doctor, and district nursing and palliative care services. This ensures your wishes and preferences are known to the teams that you may need to contact, day or night.



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

You can get information about advance statements and advance decisions to refuse treatment from a social worker or from some of the organisations listed on pages 74–85, such as Age UK. You may find it helpful to read the leaflet *Planning for your future care: A guide*, which has been produced by The NHS National End of Life Care Programme. You can ask for a copy from your GP or at your local hospital information centre. The leaflet is also available on the Department of Health Care Network's website [dhcarenetworks.org.uk](http://dhcarenetworks.org.uk)

**We have a fact sheet about advance decisions, which you may find helpful.**

It's important to discuss your wishes with a medical professional such as your GP or consultant and your nurse, family and friends. Remember that your family and friends may see things differently to you. For example, they may treasure every possible minute of your life, even though you may be in a coma or unable to respond to them. If possible, it's good to have an honest and open discussion with your partner, relatives or closest friend in advance, so that they understand your wishes.

It can be difficult to discuss these issues and you may want support from someone who knows you and who you can trust. You can also talk to some of the organisations on pages 74–85.

## **Assisted dying or voluntary euthanasia**

Currently under UK law any action that speeds up a person's death is illegal. Although your doctor and nurses can make

sure that you have enough painkillers to keep you comfortable, it is illegal for them to give you more than you need with the intention of ending your life more quickly.

## **Donating your body for medical research**

Some people may want to donate their body for medical research. You can find out more about donating your body by contacting the Human Tissue Authority (see page 78).

If you're thinking about donating your body, it's important to discuss this 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 get this from your local medical school. A copy should be kept with your will.

If you want your tissue to be used for a specific type of research, you will need to let the healthcare professional who is dealing with the consent form know. Your wishes will need to be in writing on the consent form.

Not everyone who wishes to donate their body will be able to do so.

# At the end of life

When death is due to cancer it's normal for someone to gradually get weaker and more tired over several weeks or months. As it's not possible to accurately predict what will happen, it's helpful to do important things, such as getting your affairs in order, sooner rather than later. However, as with all other seemingly healthy people, there is a small risk that you may die suddenly.

## The last weeks

The changes that occur in the body are discussed in this section. It can be hard to understand how cancer can cause death. The changes it causes in your body will depend on the type of cancer you have and where it is in the body.

### Body changes

Most cancers affect the body's ability to use food to make energy. This can lead to you feeling exhausted and weak. Cancer cells can prevent the body from working normally, and they may cause a change in the chemical balance in the body and sometimes a build-up of waste chemicals.

These changes can make people lose weight, no matter how much they eat. Your appetite will gradually reduce. Your appearance may change, your muscles may waste away and you may also start to look more tired. Once a person stops eating, they usually only live for a couple of weeks.

As you become weaker and less able to do things, just carrying out ordinary daily activities such as getting up can make you feel exhausted. You will gradually feel more and more tired and

will need to rest or sleep more during the day.

### **Loss of interest**

During this time, it's common for people to lose interest in things that were previously important to them. It is sometimes as though people need to withdraw their attention from the world in order to prepare for death.

### **Care and support**

People may need quite a lot of physical help and support during this time as they get weaker and less able to do things. However, a lot of the time they may just want to lie still and have people sitting nearby, without necessarily talking to them.

Occasionally, a dying person stays aware and able to talk right up until very close to the end and can have a meaningful conversation with people around them. However, this is the exception rather than the rule, so it's important to say all the things that you want to at an early stage.

### **The last few days**

There usually comes a time when people are not able to get out of bed at all. After needing to sleep and rest a lot, most people move into a phase where they become more and more drowsy and then become unconscious.

Some people may drift in and out of consciousness before becoming unconscious. During this time they may become confused, and not recognise family or friends. They may also hear or see things which are not there (hallucinations). Some may have thoughts or experiences which are like dreams, where they're not sure what's real or not. This confusion can be due to chemical changes that are happening in the body and

the build-up of waste chemicals (toxins). Sometimes, a person may appear distressed and restless to those around them. If this is the case, a nurse or doctor will be able to give medicines to help them relax. These medicines can be given by injection or by a syringe driver (see page 30).

## **Sensations**

Your feet and hands may feel cold, or your skin may feel very sensitive to any touch. People looking after you may need to be very gentle when moving or touching you.

## **Coma**

The drowsiness and sleepiness usually gradually develops into a phase where people become unconscious and can't respond at all to anything around them. You may seem to be peacefully asleep or you may move, twitch or grimace occasionally as though you are dreaming. Although you won't be able to respond to the people around you, it's likely that you will be aware that they are there and able to hear them if they talk to you. This phase may last only a few hours or can continue for a few days.

At this stage, food and drink are not necessary as your body is no longer able to absorb or use them. Moistening your lips or mouth are all that's needed. When a person who is near the end of their life stops drinking, they usually only live for a few days.

## **Breathing**

If a person isn't moving around, the fluid normally produced by their lungs is not able to drain away and may collect in the air passages. This means that when they breathe they make a slight groaning (rattling) noise. Medicines can be given to help with this. Although noisy breathing can be upsetting for the people around, it doesn't seem to be uncomfortable for the

dying person themselves. Breathing may also become irregular, with long gaps between breaths.

## **Final moments of life**

For most people, the final moments of life are very peaceful. Usually, you will be deeply unconscious and unaware as your breathing becomes gradually slower and more irregular, before stopping. With some people this seems to take a long time, while for others it happens over a few minutes.

People who have survived a near-death experience tell very different stories about their experience. Although many describe moving towards a bright light and a welcoming environment which they find hard to resist, others describe sinking or floating into nothingness.

Many people feel that they don't know exactly what will happen to their mind after their death. Some people feel that their soul or consciousness will live on (perhaps in a new form) or go to another place. Other people feel that once they have died that is the end and their mind just stops.

It can be difficult to pinpoint the exact moment of death. Often the person's body will relax completely and their face will look very peaceful. Many people say that they can sense when the person's consciousness has gone from the body.

In some cultures and religions, it's believed that the person's mind (consciousness) stays around the body for some time after death. In other cultures and religions it is thought that the consciousness moves on to another place quickly. Some people believe that once the person has died there is nothing left of their mind (consciousness).

## Spiritual needs

If you have a faith where the moments leading up to death and the actual moment of death are important for your future, it's important that the people who are looking after you are aware of your needs. Let them know beforehand if you need special practices to be done or if you don't want to be touched or moved for some time before or after death.

The staff in hospital or hospices will try to find out what is appropriate for people of different cultures in their final hours. However, it may be easier if you or your family make the staff aware of your needs. This will allow them to make arrangements for your spiritual or religious adviser to visit, if you feel that this is helpful, and to make sure that your body is treated in the appropriate way after death.

## **Section two: After the death – if you are a partner, relative or friend**

**'I wish we'd spent more time preparing for his death. We knew it wasn't far away but somehow couldn't bring ourselves to discuss it with each other or anyone else. I think it would have been easier if we had talked about it. As it was, I had to make the decisions all at once, after he died.'**

While the first part of this booklet is written for the person who is dying, this section is written for their partner, relatives or friends. However, you may want to read this section together and discuss plans well in advance. This can make things a lot easier for the people left behind. When a person has planned their funeral and taken care of their financial affairs, they can then make the most of the time they have left and do the things they want to do.

### **Dealing with death**

When the person you are caring for has died, you may feel very shocked, however well prepared you were. You may feel confused and bewildered. Don't feel that you have to do anything. You can just stay with your relative or friend's body for a while. You may have many different emotions or you may just feel numb.

The death of someone close to you is a very significant event in a person's life. Most cultures and religions have developed rituals or processes to mark this event and to help the people left behind to adjust to the change.

During the first few hours, the loss of your loved one may seem very unreal, but there are some things you will need to do. It's important though, that you don't feel rushed 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 a strain.

In many religions this is a time when there are things that the people who have been left behind need to do to help their relative or friend to pass onwards. It's important to follow your instincts and do what you feel is appropriate.

If you are in a hospital or hospice, the nursing staff will be nearby. If your relative died at home, you should let your doctor know within a few hours. Your GP or district nurse, or someone who is covering for them, will come as soon as possible to verify the death. If you're alone, you can ring a relative or friend to come and be with you. You may want a spiritual leader to be with you as well.

## **Caring for the body**

You might want to help wash and clothe (lay out) the body. In a hospice or hospital, the nurses will usually do this, but they will be happy to let you help if you would like to. At home, if you contact an undertaker they will show you what to do. This process is different for different religions but may involve carefully washing and drying the body, closing the eyelids,

and making sure the mouth is supported and closed. The person's hair is tidied and sometimes washed.

You can keep the person's body at home, if that's what you'd like to do, but you will need your doctor, district nurse or an out-of-hours GP to verify the death. As soon as the death has been verified, you can contact the undertaker if you wish, as they will be able to take the body to a chapel of rest. You can find details of your local undertaker in your phone book or on the internet. Undertakers all provide a 24-hour service. However, you may want to wait until morning if the death has occurred during the night.

## **Certifying the death**

One of the GPs from your own practice will usually give you a medical certificate for the cause of death if your relative died at home. You may be given this when the doctor verifies the death or you may need to get the death certificate from your GP the next day. If your relative or friend dies in hospital, one of the hospital doctors will complete the medical certificate for the cause of death and you will usually be asked to collect it the next day.

You can make all arrangements for the funeral and burial by yourself if you'd like. Many people, however, want to use the services of an undertaker (funeral director). The undertaker can answer most of the questions you have and guide you through the practicalities of arranging a funeral.

You'll need to wait until you have spoken to the doctor and they have decided whether a post-mortem is needed (see page 59), before you set a date for the funeral or other service. The undertaker can arrange for you or other family

members to see the person's body at home or at the chapel of rest if this is what you and your loved one wanted.

## **Embalming**

Some people wish to be embalmed. This is a process by which the body is disinfected and treated with chemicals to slow the process of decay. Blood is drained out of the body and replaced with embalming fluid. Embalming is carried out at the funeral directors (undertakers).

# **Registering the death**

The doctor will give you a medical certificate stating the cause of death, with a slip of paper known as the 'Notice to informant', which tells you how to register the death. If a post-mortem has been arranged, a certificate may not be available until after the post-mortem.

You need to take the medical certificate, and details of the deceased's place and date of birth, to the registrar's office in the area where the death occurred. This needs to be done within five days (eight days in Scotland). Your local council can give you the contact details for your local registrar.

## **At the registrar's office**

The registrar will ask you several questions about the person who has died. They will then enter the details in a register, which you will need to sign. A certified copy of the entry in the register, commonly known as a 'death certificate', will then be completed.



Some registrars' offices have an appointment system, so check before you go. You can find the number of your local registrar's office listed under 'Registration of births, deaths and marriages' in the business section of your local phone book, and it may be on the envelope containing the medical certificate.

If you're not able to attend yourself, certain other people can act as an 'informant' and register the death for you. Details of who can act as an informant are listed on the back of the 'Notice to informant'. These include a relative of the person who has died or a person who is not a relative but who was present at the time of death.

The information you need to provide when registering a death depends on where you live in the UK, so it's important to read the details of the 'Notice to informant' carefully and make sure you have all the information before you go to the registrar's office.

## **Number of copies**

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. They are duplicate original certified copies of entry, not photocopies. It is wise to obtain the copies you need when you register the death as certificates obtained at a later date may cost more.

You will usually need one certified copy for each life insurance policy, or similar, which you need to claim. Other organisations, such as a bank, will just need to see the original certificate or will make a copy for their records. The executor, if there is a will, can help you work out how many copies you will need.

## Certificate of burial or cremation

The registrar will give you a certificate of burial or cremation, also known as a green form, to say that the death has been registered and that the funeral can take place. You need to give this to the undertaker. The registrar will also give you a Certificate of Registration of Death Form (BD8) if you need this for social security purposes.

The booklets *What to do after a death in England and Wales* and *What to do after a death in Scotland* may be useful to have as they outline things that you need to do at this time. See page 86 for more details on how to get copies.

## Post-mortem

A post-mortem will not usually be needed when someone dies from cancer if the death was expected and the person was seen by their GP in the two weeks before their death.

However, there are occasions when a post-mortem can give helpful information. For example, the cancer may have been diagnosed at an advance stage and only the secondary tumours identified. A post-mortem may show where the cancer started. This may be information you will want to know, to help you understand exactly what happened.

People who die from mesothelioma need to have a post-mortem, as this is an occupational disease. A post-mortem may also be necessary for anyone who has ever been a miner and for some people who are claiming occupational compensation. Remember that you can agree to a limited post-mortem, where only the relevant parts of the body will be examined. This may feel like a more acceptable option for you and will still allow the

doctors to get the answers needed. A post-mortem can usually be done within two or three days and should not delay the funeral.

## Funeral and religious services

The UK is a multi-cultural and multi-faith society, and each group has its own traditions and ceremonies. Funerals and memorials are one way in which we seek to pay our respects to the person who has died. They play a big part in helping us to acknowledge the death and say goodbye to someone. This allows people to express grief and draw strength from other people who knew the deceased. It's also an opportunity to celebrate their life.

Before making any funeral arrangements it is important to consider several issues:

- What were the wishes of the dead person?
- Have they expressed their wishes in a will?
- What are the wishes of their relatives and friends?
- How will the funeral be paid for? Is there a pre-paid funeral plan?

Some people have no religious beliefs, while others will 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, or an undertaker can guide you through issuing the death notices and planning the funeral service. You can also get information from the registrar.

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. Often, services are 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 like.

## **Burial or cremation**

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

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

Burial is usually in a churchyard or other designated burial place. It's also possible for people to be buried in other places, such as a garden. If you want to bury the person on property that you own or in a place that they loved, you can get

information from The Natural Death Centre (see page 77).

If you and your relative or friend didn't have the chance to discuss their choice of burial or cremation, and there is 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 death, this makes it easier to be sure you're arranging a service of remembrance which 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 [dwp.gov.uk](https://www.dwp.gov.uk) or contact your local Jobcentre Plus office.

# Wills and probate

Probate is the official validation and approval of a will. Application for probate must be made to the local probate court before the will can be executed (carried out). This will take several weeks.

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 but this process may take even longer. 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 'appointment of executor-dative' is equivalent to 'letters of administration'.

It's important that the executors of the will understand their role and that they keep you up-to-date on progress. If you are 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 incidental costs, but it's much easier to have independent funds in a joint account.

Age UK has a fact sheet about how to deal with someone's estate. Its contact details and those of other useful organisations are on pages 74–85.

# Coping with grief and bereavement

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.

## Grief

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

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

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.

## Physical effects

Some people feel physically ill. They might have:

- headaches
- dizziness
- a dry mouth
- weakness
- breathlessness
- a feeling of tightness in the chest and throat
- feeling sick.

This is normal and it doesn't mean you have a serious illness.

## Emotional effects

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 which holds strong memories can trigger the distress, even months or years afterwards.

## Practical help

On the first day or so after the death, while you are feeling numb, you will probably need help to do 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. Don't be afraid to show your emotions during the grieving process – it's perfectly natural to cry when you are thinking and talking about your loved one. Tears can help you to feel better, although long periods of crying can make you feel exhausted.

## 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 or by calling the Benefit Enquiry Line on **0800 882 200**. You can also visit the Department for Work and Pensions website at **dwp.gov.uk** or contact the Macmillan Support Line on **0808 808 00 00**.

## After the funeral

This can be the hardest time as everyone has gone home and you are expected to pick up the pieces of your life. Try not to do too much too soon. You will need time to get used to your loss and the changes that the death of the person you cared for has brought. If you make decisions in a hurry, you may find later that you regret them. It's important to take time to look after yourself. Some cultures have specific practices to follow, which can help to mark each phase after a person's death.

## The person's presence

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

## Support

Talking through your feelings at this time may be helpful. There are many organisations, such as Cruse (see page 74), which run groups for people who are grieving. Your GP or the National Association of Bereavement Services (see page 75) can put you in touch with a local bereavement counsellor if you would like more formal one-to-one counselling.

## Delayed grief

The grieving process is variable 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.

Soon after a person's death you may feel that you'll never be able to live your life normally again. However these feelings usually resolve over time, although this can take a year or more. You will never forget the person and will always have memories of them. However, it's usual to be able to get on with life again after a while and to be 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 are buried, or somewhere that meant a lot to you both. You may want to hold a gathering of relatives and close friends to share memories of the person and celebrate their life. You will know the best way to remember them and pay your respects.

# How we can help you

Cancer is the toughest fight most of us will ever face. But you don't have to go through it alone. The Macmillan team is with you every step of the way.

## Get in touch

### Macmillan Cancer Support

89 Albert Embankment,  
London SE1 7UQ

### Questions about cancer?

Call free on **0808 808 00 00**  
(Mon–Fri, 9am–8pm)

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

### Hard of hearing?

Use textphone  
0808 808 0121 or Text Relay.

### Non-English speaker?

Interpreters are available.

## Clear, reliable information about cancer

We can help you by phone, email, via our website and publications or in person. And our information is free to everyone affected by cancer.

### Macmillan Support Line

Our free, confidential phone line is open Monday–Friday, 9am–8pm. Our cancer support specialists provide clinical, financial, emotional and practical information and support to anyone affected by cancer. Call us on **0808 808 00 00** or email us via our website, **[macmillan.org.uk/talktous](http://macmillan.org.uk/talktous)**

### Information centres

Our information and support centres are based in hospitals, libraries and mobile centres, and offer you the opportunity to speak with someone face-to-face. Find your nearest one at **[macmillan.org.uk/informationcentres](http://macmillan.org.uk/informationcentres)**

## Publications

We provide expert, up-to-date information about different types of cancer, tests and treatments, and information about living with and after cancer. We can send you free information in a variety of formats, including booklets, leaflets, fact sheets and audio CDs. We can also provide our information in Braille and large print.

You can find all of our information, along with several videos, online at **macmillan.org.uk/cancerinformation**

## Review our information

Help us make our resources even better for people affected by cancer. Being one of our reviewers gives you the chance to comment on a variety of information including booklets, fact sheets, leaflets, videos, illustrations and website text.

## Need out-of-hours support?

You can find a lot of information on our website, **macmillan.org.uk**

For medical attention out of hours, please contact your GP for their out-of-hours service.

## Someone to talk to

When you or someone you know has cancer, it can be difficult 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.

We can also 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 healthcare and social care professionals offer expert treatment and care. They help individuals and families deal with cancer from diagnosis onwards, until 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 on **0808 808 00 00**.

## 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 it themselves. That's why we help to bring people with cancer and carers together in their communities and online.

### Support groups

You can find out about support groups in your area by calling us or by visiting **macmillan.org.uk/selfhelpandsupport**

### Online community

You can also share your experiences, ask questions, get and give support to others in our online community at **macmillan.org.uk/community**

## Financial and work-related support

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. Some people may have to stop working.

If you've been affected in this way, we can help. Call the Macmillan Support Line and one of our cancer support specialists will tell you about the benefits and other financial help you may be entitled to.

We can also give you information about your rights at work as an employee, and help you find further support.

### Macmillan Grants

Money worries are the last thing you need when you have cancer. A Macmillan Grant is a one-off payment for people with cancer, to cover a variety of practical needs including heating bills, extra clothing, or a much needed break.

Find out more about the financial and work-related support we can offer at [macmillan.org.uk/financialsupport](https://www.macmillan.org.uk/financialsupport)

## Learning about cancer

You may find it useful to learn more about cancer and how to manage the impact it can have on your life.

You can do this online on our Learn Zone – [macmillan.org.uk/learnzone](https://www.macmillan.org.uk/learnzone) – which offers a variety of e-learning courses and workshops. There's also a section dedicated to supporting people with cancer – ideal for people who want to learn more about what their relative or friend is going through.

## Other useful organisations

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

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

**Tel** 01455 883 300

**Email** [enquiries@bacp.co.uk](mailto:enquiries@bacp.co.uk)

**www.bacp.co.uk**

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

### **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**

A national, multi-professional group of organisations and individuals working with bereaved children and young people. Has an online

directory, which you can search for local services.

### **The Compassionate Friends**

53 North Street, Bristol BS3 1EN

**Tel** 0845 120 3785

**Helpline** 0845 123 2304 (open every day of the year, 10am–4pm and 7–10pm)

#### **Helpline email**

[helpline@tcf.org.uk](mailto:helpline@tcf.org.uk)

**www.tcf.org.uk**

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

### **Cruse Bereavement Care**

PO Box 800, Richmond, Surrey TW9 1RG

**Helpline** 0844 477 9400 (Mon–Fri, 9.30am–5pm)

#### **Helpline email**

[helpline@cruse.org.uk](mailto:helpline@cruse.org.uk)

#### **Young person's freephone**

**helpline** 0808 808 1677

### **Young person's helpline**

**email** [info@rd4u.org.uk](mailto:info@rd4u.org.uk)

**www.crusebereavementcare.org.uk**

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

### **London Friend Bereavement Helpline**

86 Caledonian Road,  
London N1 9DN

**www.londonfriend.org.uk**

**Helpline** 020 7403 5969  
(Tues, 7.30–9.30pm)

A helpline for lesbian, gay, bisexual and transgendered callers. Also welcomes calls from affected family, friends, colleagues and carers.

### **National Association of Bereavement Services**

2<sup>nd</sup> Floor, 4 Pinchin Street,  
London E1 6DB

**Helpline** 020 7709 9090  
(Mon–Fri, 10am–4pm)

**Tel** 020 7709 0505

Has a national directory of bereavement and loss services, and can direct people to their nearest appropriate

source of support.

### **National Association of Widows**

3<sup>rd</sup> Floor, 48 Queens Road,  
Coventry CV1 3EH

**Tel** 0845 838 2261

**Email** [info@nawidows.org.uk](mailto:info@nawidows.org.uk)

**www.nawidows.org.uk**

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

### **The Office of the Public Guardian**

PO Box 15118, Birmingham  
B16 6GX

**Tel** 0845 330 2900

(Mon–Fri, 9am–5pm  
except Wed, 10am–5pm)

**Fax** 020 7664 7551

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

**www.publicguardian.gov.uk**

Supports and promotes decision making for people with mental impairment or disability who would like to plan for their future. Also has an office in Scotland (see page 76).

### **The Office of the Public Guardian - Scotland**

Hadrian House, Callendar  
Business Park, Callendar  
Road, Fallkirk KT1 1XR

**Tel** 01324 678300

**Fax** 01324 678301

**Email** [opg@scotcourts.gov.uk](mailto:opg@scotcourts.gov.uk)

### **Ruby Care Foundation**

PO Box 21, Llandysul,  
Wales SA39 9WA

**Email** [info@rubycare.org](mailto:info@rubycare.org)

**www.rubycare.org**

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

### **Samaritans**

Chris, PO Box 9090,  
Stirling FK8 2SA

**Tel** 08457 90 90 90

**Email** [jo@samaritans.org](mailto:jo@samaritans.org)

**www.samaritans.org.uk**

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

### **The United Kingdom Council for Psychotherapy (UKCP)**

2<sup>nd</sup> Floor, Edward House,  
2 Wakley Street,  
London EC1V 7LT

**Tel** 020 7014 9955

**Email** [info@ukcp.org.uk](mailto:info@ukcp.org.uk)

**www.psychotherapy.org.uk**

A membership organisation, with over 75 training and listing organisations, and more than 6,600 individual practitioners. UKCP holds the national register of psychotherapists and psychotherapeutic counsellors, listing those practitioner members who meet exacting standards and training requirements.

### **The WAY Foundation**

Suite 35, St Loyes House,  
20 St Loyes Street,  
Bedford MK40 1ZL

**Tel** 0870 011 3450

**Email** [info@wayfoundation.org.uk](mailto:info@wayfoundation.org.uk)

**www.wayfoundation.org.uk**

Provides a social and support network to help young widows and widowers, up to the age of 50, rebuild their lives after the

death of a partner. Members' children are also included.

### **Winston's Wish**

Westmoreland House,  
80–86 Bath Road,  
Cheltenham,  
Gloucestershire GL53 7JT

#### **General enquiries**

01242 515157

**Tel** 08452 03 04 05

#### **Email**

[info@winstonswish.org.uk](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.

### **Marie Curie Cancer Care**

89 Albert Embankment,  
London SE1 7TP

**Freephone** 0800 716 146

**Tel** 020 7599 7777 (England)

0131 561 3900 (Scotland)

01495 740 888 (Wales)

028 9088 2060 (NI)

**Email** [info@mariecurie.org.uk](mailto:info@mariecurie.org.uk)

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

Marie Curie nurses provide free end-of-life care to people

with cancer in their own homes, 24-hours a day, 365 days a year. There are also Marie Curie hospices across the UK.

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

### **National Association of Funeral Directors**

618 Warwick Road, Solihull,  
West Midlands B91 1AA

**Tel** 0845 230 1343

**Email** from the website

**[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.

### **The Natural Death Centre**

In The Hill House,  
Watley Lane, Twyford,  
Winchester SO21 1QX

**Tel** 0871 288 2098

#### **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.

### **RD4U**

PO Box 800, Richmond,  
Surrey TW9 1RG

#### **Freephone helpline**

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)**

RD4U is a website designed for young people by young people. It is part of Cruse Bereavement Care's Youth Involvement Project and is here

to support young people after the death of someone close.

## **Tissue Donations**

### **Human Tissue Authority**

Finlaison House,  
15–17 Furnival Street,  
London EC4A 1CB

**Tel** 020 7211 3400

(no out-of-hours service)

**Email** [enquiries@hta.gov.uk](mailto:enquiries@hta.gov.uk)

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

Provides information about tissue donation. Licenses and inspects organisations that store and use human tissue for research, patient treatment and teaching.

## **General cancer and support organisations**

### **Cancer Black Care**

79 Acton Lane,  
London NW10 8UT

**Tel** 020 8961 4151

(Mon–Fri, 9.30am–4.30pm)

#### **Email**

[info@cancerblackcare.org](mailto:info@cancerblackcare.org)

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

Offers a range of information and support for people

with cancer from ethnic communities, their friends, carers and families. Welcomes people from different ethnic groups including African, Asian, Turkish and West Indian communities.

### **Irish Cancer Society**

43–45 Northumberland Road,  
Dublin 4, Ireland

**Cancer Helpline** 1800 200  
700 (Mon–Thurs, 9am–7pm,  
Fri, 9am–5pm)

**Email** [helpline@irishcancer.ie](mailto:helpline@irishcancer.ie)

**[www.cancer.ie](http://www.cancer.ie)**

Operates Ireland’s only  
freephone cancer helpline,  
which is staffed by qualified  
nurses trained in cancer care.

### **Tak Tent Cancer Support – Scotland**

Flat 5, 30 Shelley Court,  
Gartnavel Complex,  
Glasgow G12 0YN

**Tel** 0141 211 0122

**Email** [taktent4u@gmail.com](mailto:taktent4u@gmail.com)

**[www.taktent.org](http://www.taktent.org)**

Offers information and  
support for cancer patients,  
families, friends and health  
professionals. Runs a  
network of monthly support

groups across Scotland. Also  
provides counselling and  
complementary therapies.

### **Tenovus**

9<sup>th</sup> Floor, Gleider House,  
Ty Glas Road, Llanishen,  
Cardiff CF14 5BD

### **Freephone helpline**

0808 808 1010

**Tel** 029 2076 8850

**Email** [post@tenovus.com](mailto:post@tenovus.com)

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

Based in Wales, Tenovus  
provides a range of services  
to people with cancer and  
their families, including  
counselling and a freephone  
cancer helpline.

### **The Ulster Cancer Foundation**

40–44 Eglantine Avenue,  
Belfast BT9 6DX

### **Freephone helpline**

0800 783 3339

### **Helpline email**

[infocis@ulstercancer.org](mailto:infocis@ulstercancer.org)

**Tel** 028 9066 3281

**Email** [info@ulstercancer.org](mailto:info@ulstercancer.org)

**[www.ulstercancer.org](http://www.ulstercancer.org)**

Provides a range of services  
for people with cancer and  
their families, including a

freephone helpline, which is staffed by specially trained nurses with experience in cancer care.

## Money or legal advice and information

### Benefit Enquiry Line

2<sup>nd</sup> Floor, Red Rose House,  
Lancaster Road, Preston  
Lancashire PR1 1HB

**Tel** 0800 882 200

**Textphone** 0800 243 355

**Email** BEL-Customer-  
Services@dwp.gsi.gov.uk

**www.direct.gov.uk/en/DI1/  
Directories/DG\_1001165**

Provides advice about benefits, and can also provide help to complete some disability-related claim packs.

### Citizens Advice Bureau

Find contact details for your local office in the phone book or at **citizensadvice.org.uk**

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

Citizens Advice Bureaus provide free, confidential, independent advice on a variety of issues including

financial, legal, housing and employment.

### Citizens Advice Scotland **www.cas.org.uk**

### Independent Financial Advisers Promotion (IFAP)

2<sup>nd</sup> Floor, 117 Farringdon  
Road, London EC1R 3BX

### Consumer hotline

0800 085 3250

### Email

ifacontact@unbiased.co.uk

**www.unbiased.co.uk**

Helps people search for details of local member independent financial advisers via the consumer hotline and online searches at **unbiased.co.uk** and **moneymadeclear.fsa.gov.uk**

### The Law Society

113 Chancery Lane,  
London WC2A 1PL

**Tel** 0870 606 2555

**Email** info.services@  
lawsociety.org.uk

**www.lawsociety.org.uk**

Represents solicitors in England and Wales and can provide details of local solicitors.

## **Law Society of Scotland**

26 Drumsheugh Gardens,  
Edinburgh EH3 7YR

**Tel** 0131 226 7411

**Email** [lawscot@lawscot.org.uk](mailto:lawscot@lawscot.org.uk)

**www.lawscot.org.uk**

## **Law Society of Northern Ireland**

96 Victoria Street,  
Belfast BT1 3GN

**Tel** 028 9023 1614

**Email** [info@lawsoc-ni.org](mailto:info@lawsoc-ni.org)

**www.lawsoc-ni.org**

## **Personal Finance Society – ‘Find an Adviser’ service**

42–48 High Road, South  
Woodford, London E18 2JP

**Tel** 020 8530 0852

**Email** [info@findanadviser.org](mailto:info@findanadviser.org)

**www.findanadviser.org**

The UK’s largest professional body for independent financial advisers. Use the ‘Find an Adviser’ website to find qualified financial advisers in your area.

## **Support for carers**

### **Carers Direct**

PO Box 4338,  
Manchester M61 0BY

**Helpline** 0808 802 0202

(Mon–Fri, 8am–9pm,  
weekends, 11am–4pm)

**Email** from the website

**www.nhs.uk/carersdirect**

Aims to offer all the information you should need as a carer to access the financial help you’re entitled to, as well as advice on getting a break from caring, going to work and much more.

### **Carers UK**

20 Great Dover Street,  
London SE1 4LX

**Tel** 020 7378 4999

**Carers line** 0808 808 7777

(Wed and Thurs, 10am–12pm  
and 2–4pm)

**Email** [info@carersuk.org](mailto:info@carersuk.org)

**www.carersuk.org**

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

### **Carers Scotland**

The Cottage, 21 Pearce Street,  
Glasgow G51 3UT

**Tel** 0141 445 3070

**Email** [info@carerscotland.org](mailto:info@carerscotland.org)  
**www.carerscotland.org**

### **Carers Wales**

River House, Ynsbridge  
Court, Gwaelod-y-Garth,  
Cardiff CF15 9SS

**Tel** 029 2081 1370

**Email** [info@carerswales.org](mailto:info@carerswales.org)  
**www.carerswales.org**

### **Carers Northern Ireland**

58 Howard Street,  
Belfast BT1 6PJ

**Tel** 028 9043 9843

**Email** [info@carersni.org](mailto:info@carersni.org)  
**www.carersni.org**

### **Crossroads – Caring for Carers**

10 Regent Place, Rugby,  
Warwickshire CV21 2PN

**Tel** 0845 450 0350

**Email** from the website  
**www.crossroads.org.uk**

Provides respite care for carers  
by providing practical support  
in the home. Has over 200  
schemes in England and Wales.

### **Crossroads Scotland**

24 George Square,  
Glasgow G2 1EG

**Carers Information and  
Support Line** 0141 353 6504

**Email** [info@crossroads-  
scotland.co.uk](mailto:info@crossroads-scotland.co.uk)

**www.crossroads-scotland.  
co.uk**

Has nearly 50 schemes  
running in Scotland that  
provide trained staff to take  
over the carer's role for an  
agreed period of time.

### **Crossroads Northern Ireland**

7 Regent Street, Newtownards,  
Co Down, Northern Ireland  
BT23 4AB

**Tel** 028 9181 4455

**Email** [mail@crossroadscare.  
co.uk](mailto:mail@crossroadscare.co.uk)

**www.crossroadscare.co.uk**

Offers practical support to  
carers by sending fully trained  
care attendants into the home.

### **The Princess Royal Trust for Carers**

Unit 14, Bourne Court,  
Southend Road, Woodford  
Green, Essex IG8 8HD

**Tel** 0844 800 4361

**Email** [info@carers.org](mailto:info@carers.org)  
**www.carers.org** and  
**www.youngcarers.org**

The largest provider of carers' support services in the UK. Through its network of 144 independently managed carers' centres, 85 young carers' services and interactive websites, the trust currently provides information, advice and support services to more than 400,000 carers, including approximately 25,000 young carers.

### **Young Carers Net (YCNNet) Princess Royal Trust for Carers**

Unit 14, Bourne Court,  
 Southend Road, Woodford  
 Green, Essex IG8 8HD  
**Tel** 0844 800 4361

#### **Email**

[youngcarers@carers.org](mailto:youngcarers@carers.org)  
**www.youngcarers.net**

Young Carers Net (part of The Princess Royal Trust for Carers) provides information and support for young carers. YCNNet provides online discussion forums and advice for young people aged 18 and under in the UK, who

help to look after someone in their family who has an illness, disability, drug/alcohol addiction or mental health condition.

### **Equipment and advice on living with disability**

#### **Assist UK**

Redbank House, 1 Portland  
 Street, Manchester M1 3BE  
**Tel** 0161 238 8776

#### **Email**

[general.info@assist-uk.org](mailto:general.info@assist-uk.org)  
**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 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**  
 Offers a number of services

for people with a disability, including a medical equipment and a transport loan service.

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

4 Nasmyth Place, Hillington, Glasgow G52 4PR

**Tel** 0141 891 4000

#### **Email**

scotland@redcross.org.uk

**www.redcross.org.uk**

### **Disabled Living Foundation (DLF)**

380–384 Harrow Road, London W9 2HU

**Helpline** 0845 130 9177

(Mon–Fri, 10am–4pm)

**Email** helpline@dlf.org.uk

**www.dlf.org.uk**

A national charity that provides free, impartial advice about disability equipment and mobility products through its helpline, website and demonstration centre.

### **DIAL UK**

St Catherine's, Tickhill Road, Balby, Doncaster DN4 8QN

**Tel** 01302 310 123

**Email** informationenquiries@

dialuk.org.uk

### **www.dialuk.info**

A national network of approximately 120 local Disability Information and Advice Line services (DIALs) run by and for disabled people. Based throughout the UK, the services provide information and advice to disabled people and others on all aspects of living with a disability. You can search for your local DIAL on its website.

### **Support for older people**

#### **Age UK**

207–221 Pentonville Road, London N1 9UZ

**Advice Line** 0800 169 6565 (daily, 8am–7pm)

**Email** contact@ageuk.org.uk or from the website

**www.ageuk.org.uk**

Age UK combines Age Concern and Help the Aged. Provides information and advice on anything from health to housing. Also publishes impartial and informative fact sheets and advice guides.

### **Age Cymru**

Ty John Pathy, Units 13–14  
Neptune Court, Vanguard  
Way, Cardiff CF24 5PJ

**Tel** 0800 169 6565

**Email**

[enquiries@agecymru.org.uk](mailto:enquiries@agecymru.org.uk)

### **Age Northern Ireland**

3 Lower Crescent,  
Belfast BT7 1NR

**Tel** 0808 808 7575

**Email** [info@](mailto:info@ageconcernhelptheagedni.org)

[ageconcernhelptheagedni.org](mailto:ageconcernhelptheagedni.org)

### **Age Scotland**

Causewayside House,  
160 Causewayside,  
Edinburgh EH9 1PR

**Tel** 0845 125 9732

**Email** [enquiries@](mailto:enquiries@ageconcernandhelptheagedscotland.org.uk)

[ageconcernandhelptheagedscotland.org.uk](mailto:ageconcernandhelptheagedscotland.org.uk)

### **Support for children and teenagers**

#### **CLIC Sargent: caring for children with cancer**

Griffin House,  
161 Hammersmith Road,  
London W6 8SG

**Tel** 020 8752 2800

(main London office)

#### **Email** [info@clicsargent.org.uk](mailto:info@clicsargent.org.uk)

#### **Child Cancer Helpline**

0800 197 0068

(Mon– Fri, 9am–5pm)

**Email**

[helpline@clicsargent.org.uk](mailto:helpline@clicsargent.org.uk)

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

Provides support to children with cancer and to their families and carers – both during and after treatment, in hospital and at home

#### **Teenage Cancer Trust**

93 Newman Street,  
London W1T 3EZ

**Tel** 020 7612 0370

**Email** from website

**[www.teenagecancertrust.org](http://www.teenagecancertrust.org)**

A charity devoted to improving the lives of teenagers and young adults with cancer. Runs a support network for young people with cancer and their friends and families, and also raises funds to build dedicated teenage cancer units in hospitals.

# Further resources

## Related Macmillan information

You may want to order some of the booklets mentioned in this booklet. These include:

- *Cancer and complementary therapies*
- *Caring for someone with advanced cancer*
- *Controlling the symptoms of cancer*
- *Coping with advanced cancer*
- *Coping with fatigue*
- *Controlling cancer pain*
- *Help with the cost of cancer*
- *Talking about your cancer*
- *Talking to children when an adult has cancer*

To order, visit **be.macmillan.org.uk** To order the fact sheets mentioned in this booklet, call **0808 808 00 00**.

## Helpful leaflets

### ***What to do after a death in England and Wales***

Department of Work and Pensions, 2009, Free.

Gives advice on 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 or post office.

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

The Scottish Government, 9<sup>th</sup> edition, 2009, Free.

This 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/Resource/Doc/277028/0083194.pdf](http://scotland.gov.uk/Resource/Doc/277028/0083194.pdf)**

## Macmillan audio resources

Our high-quality audio materials, based on our variety of booklets, include information about cancer types, different treatments and living with cancer.

To order your free CD visit **[be.macmillan.org.uk](http://be.macmillan.org.uk)** or call **0808 808 00 00**.

## Useful websites

A lot of information about cancer is available on the internet. Some websites are excellent, others have misleading or out-of-date information.

The sites listed here are considered by nurses and doctors to contain accurate information and are regularly updated.

### Macmillan Cancer Support **[www.macmillan.org.uk](http://www.macmillan.org.uk)**

Find out more about living with the practical, emotional and financial effects of cancer.

Our website contains expert, accurate and up-to-date information on cancer and its treatments, including:

- all the information from our 100+ booklets and 350+ fact sheets
- videos featuring real-life stories from people affected by cancer and information from medical professionals
- how Macmillan can help, the services we offer and where to get support
- how to contact our cancer support specialists, including an email form to send your questions
- local support groups search, links to other cancer organisations and a directory of information materials
- a huge online community of people affected by cancer sharing their experiences, advice and support.

**www.cancer.gov  
(National Cancer Institute –  
National Institute of Health  
– USA)**

Gives comprehensive information on cancer and treatments.

**www.cancer.org  
(American Cancer Society)**

Voluntary health organisation dedicated to eliminating cancer. Aims to do this through research and education.

**www.cancerhelp.org.uk  
(Cancer Research UK)**

Contains patient information on all types of cancer and has a clinical trials database.

**www.healthtalkonline.org  
www.youthhealthtalk.org  
(site for young people)**

Both websites contain information about some cancers and have video and audio clips of people talking about their experiences of cancer and its treatments.

**www.nhs.uk (NHS Choices)**

NHS Choices is the online ‘front door’ to the NHS. It is the country’s biggest health

website and gives all the information you need to make choices about your health.

**www.nhsdirect.nhs.uk  
(NHS Direct Online)**

NHS health information site for England – covers all aspects of health, illness and treatments.

**www.nhsdirect.wales.nhs.uk  
(NHS Direct Wales)**

**www.nhs24.com  
(NHS 24 in Scotland)**

**www.patient.co.uk  
(Patient UK)**

Provides good-quality information about health and disease. Includes evidence-based information leaflets on a wide range of medical and health topics. Also reviews and links to many health and illness related websites, some of which are overseas.

**www.riprap.org.uk (Riprap)**

Developed especially for teenagers who have a parent with cancer.

# Questions you might like to ask your doctor or nurse

You can fill this in before you see the doctor or nurse, and then use it to remind yourself of the questions you want to ask, and the answers you receive.

1.

---

Answer

---

2.

---

Answer

---

3.

---

Answer

---

4.

---

Answer

---

5.

---

Answer

---

6.

---

Answer

---

## Disclaimer

We make every effort to ensure that the information we provide is accurate but it should not be relied upon to reflect the current state of medical research, which is constantly changing. If you are concerned about your health, you should consult a doctor. Macmillan cannot accept liability for any loss or damage resulting from any inaccuracy in this information or third party information such as information on websites to which we link. We feature real life stories in all of our articles. Some photographs are of models.

## Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's information development nurses and editorial team. It has been approved by our medical editor, Dr Terry Priestman, Consultant Clinical Oncologist. With thanks to: Mrs Pauline McCulloch, Palliative Care Clinical Nurse Specialist; Dr Zoe Palmer, Senior Registrar Palliative Care; Dr Amen Sibtain, Consultant Clinical Oncologist; Anna-Marie Stevens, Nurse Consultant Palliative Care; Dr Adrian Tookman, Clinical Adviser and Consultant in Palliative Medicine; and the people affected by cancer who reviewed this edition

## Sources

Hanks G, et al. *Oxford Textbook of Palliative Medicine*. 4<sup>th</sup> edition. 2010. Oxford University Press, Oxford.

Improving Supportive and Palliative Care for Adults with Cancer. March 2004. National Institute for Health and Clinical Excellence (NICE).

Department of Work and Pensions. [www.dwp.gov.uk](http://www.dwp.gov.uk) (accessed September 2010)

The Mental Capacity Act Department for Constitutional Affairs (DCA) and the Department of Health. [www.dca.gov.uk](http://www.dca.gov.uk) (accessed September 2010)

The Office of the Public Guardian. [www.publicguardian.gov.uk](http://www.publicguardian.gov.uk) (accessed September 2010)

The Office of the Public Guardian, Scotland. [www.publicguardian-scotland.gov.uk](http://www.publicguardian-scotland.gov.uk) (accessed September 2010)

End of Life Care Strategy. July 2008. Department of Health.

Palliativedrugs Ltd. *Symptom Management in Advanced Cancer*. 4<sup>th</sup> edition. [www.palliativedrugs.com](http://www.palliativedrugs.com) (accessed September 2010)

# Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we're there to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.



## **Share your cancer experience**

Support people living with cancer by telling your story, online, in the media or face-to-face.

## **Campaign for change**

We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

## **Help someone in your community**

A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

## **Raise money**

Whatever you like doing, you can raise money to help. Take part in one of our events or create your own.

## **Give money**

Big or small, every penny helps. To make a regular or one-off donation – see over.

**Call us to find out more**

**0300 1000 200**

**[macmillan.org.uk/getinvolved](http://macmillan.org.uk/getinvolved)**

## Please fill in your personal details

Mr/Mrs/Miss/Other \_\_\_\_\_

Name \_\_\_\_\_

Surname \_\_\_\_\_

Address \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Postcode \_\_\_\_\_

Phone \_\_\_\_\_

Email \_\_\_\_\_

Please accept my gift of £ \_\_\_\_\_

(Please delete as appropriate)

I enclose a cheque / postal order /  
Charity Voucher made payable to  
Macmillan Cancer Support

OR debit my:

Visa / MasterCard / CAF Charity  
Card / Switch / Maestro

Card number

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

Valid from

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
----------------------	----------------------	----------------------	----------------------

Expiry date

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
----------------------	----------------------	----------------------	----------------------

Issue no

<input type="text"/>	<input type="text"/>	<input type="text"/>
----------------------	----------------------	----------------------

Security number

<input type="text"/>	<input type="text"/>	<input type="text"/>
----------------------	----------------------	----------------------

Signature \_\_\_\_\_

Date     /     / \_\_\_\_\_

## Don't let the taxman keep your money

Do you pay tax? If so, your gift will be worth almost a third more to us – at no extra cost to you. All you have to do is write your name below, and the tax office will give 25p for every pound you give.

- I am a UK taxpayer and I would like Macmillan Cancer Support to treat all donations I have made for the six years prior to this year and all donations I make in future as Gift Aid donations, until I notify you otherwise.

I understand that I must pay an amount of Income Tax and/or Capital Gains Tax for each tax year (6 April one year to 5 April the next) that is at least equal to the amount of tax that Macmillan will reclaim on my gifts for that tax year.

Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box.

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.



If you'd rather donate online, go to [macmillan.org.uk/donate](http://macmillan.org.uk/donate)

Please cut out this form and return it in an envelope (no stamp required) to:  
Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851,  
89 Albert Embankment, London SE1 7UQ

Cancer is the toughest fight most of us will ever face. If you or a loved one has been diagnosed, you need a team of people in your corner, supporting you every step of the way. That's who we are.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you're entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The community supporting you online, any time. The fundraisers who make it all possible.

You don't have to face cancer alone. We can give you the strength to get through it. We are Macmillan Cancer Support.

Questions about living with cancer?  
Call 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.

 <p><b>The Information Standard</b> Certified member</p>	<p>This organisation has been certified as a producer of reliable health and social care information. <a href="http://www.theinformationstandard.org">www.theinformationstandard.org</a></p>
--	--

Printed using sustainable material. Please recycle.

© Macmillan Cancer Support, 2011. 5<sup>th</sup> edition. MAC11663. Next planned review 2013.  
Registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604).

**WE ARE  
MACMILLAN.  
CANCER SUPPORT**