

End of life

This fact sheet is about what happens towards the end of life and how to plan for it.

Any words that are underlined are explained in the glossary at the end.

This fact sheet tells you about who can help care for you at home. It explains what to expect in the last few weeks of life. It also has information for your relatives and close friends about what to do after your death. You may want to read this section too.

You may find some of this information upsetting to read. You may want to ask a close relative, friend or health professional to read it as well, so you can discuss the information together.

If you have any questions, ask your doctor or nurse.

If you have any questions or want to talk to someone, you can call Macmillan Cancer Support on **0808 808 00 00**, Monday to Friday, 9am to 8pm. We have interpreters, so you can speak to us in your own language. Just tell us, in English, the language you want to use.

We have more information in [language] about different types of cancer, treatments and living with cancer. Visit macmillan.org.uk/translations or call us on **0808 808 00 00**.

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How you may feel

Being told that you may be reaching the end of your life can be very difficult. You may know that you are becoming more ill, but it can still be a shock to learn you may not have long to live. You may feel it is unfair. You may worry about what will happen next. You may be tearful and sad. You may not know how to cope with these different feelings.

Some people find it helpful to talk about how they are feeling. You could talk to family or friends, or your doctor or nurse. Or you can speak to one of Macmillan's cancer support specialists on **0808 808 00 00**. We have interpreters.

You will probably have days when you feel well and days when you don't. On days when you feel well, you may want to do things you enjoy or spend time with people. Or you may want to do other important things, such as making a will or planning your funeral.

Religion and spirituality

Towards the end of life, people often become more aware of religious beliefs or spiritual feelings. People with a strong religious faith often find this helpful. Sometimes people question their faith and whether there is a life after death. This can be very difficult.

It may help to talk to a religious leader. You can do this even if you are not sure about what you believe. Spiritual and religious leaders are used to helping people through these times and you may find peace of mind.

Some people find comfort in prayer or meditation. Many people find it helpful knowing that other people are praying for them.

Planning ahead

Making a will

It is important to make a will. This is the only way to make sure those close to you know your wishes about belongings and property.

Your will is a legal document. It is usually best to use a solicitor when writing your will. They will make sure everyone understands what you want to happen. If you need help finding a solicitor, you can contact the Law Society (see page xx).

Planning your funeral

You may want to plan your funeral. You can think about:

- whether you want a burial or cremation
- what type of service you want
- what songs you would like
- what clothes you want to wear.

You may want to talk to your family or friends about these plans. They may also have ideas that will help them say goodbye. If there are things that you want to happen at your funeral, write them down, so that people know.

Who can look after you at home

It is important that you and those who look after you have all the support you need. There are many people who can help you when you are at home

Your GP

While you are at home, your GP is responsible for your medical care. They can help if you:

- are worried about any changes in your symptoms
- want to talk about the future and what may happen
- need advice about getting nursing care or other help in the home.

Community nurses

Community nurses work closely with GPs. They can help with any symptoms you have. They can:

- give you medicines and change dressings
- help make you more comfortable and arrange equipment if needed
- give your relatives or carers advice on looking after you
- contact other people who can help, like social workers or specialist nurses
- help you cope with your feelings.

Marie Curie Nurses

Marie Curie Nurses care for people who are nearing the end of their life. They visit people at home and can provide care during the day or overnight. This allows your carers to have a break or get a good night's sleep.

Your district nurse or GP can arrange a Marie Curie Nurse for you.

Palliative care teams

These are specialist nurses and doctors. They support people and their families who are coping with cancer and other serious illnesses

You may have a palliative care team if you have symptoms that you need help with.

Hospice teams

Some hospices have nurses who can help care for you at home. This is usually for the last few weeks and days of life. Your palliative care team can arrange it for you.

Social workers

Social workers can arrange help with housework and other practical tasks. You, or your doctor or nurse, can contact a social worker to ask for this help. If you can afford it, you may be asked to pay for some of it.

Occupational therapists

Occupational therapists can visit your home and provide any equipment you need. This may be things like:

- rails to help you move around
- equipment for your shower or bath
- special cups and cutlery to make eating easier.

Your nurse or doctor can arrange any of the services described above. They will also tell you about other help available in your area.

The last few weeks of life

During the last few weeks of life, you may notice some of the following changes.

Emotional changes

It is natural to feel worried or anxious when you are facing death. You may feel angry. Some people become sad and withdrawn. Sometimes this may be due to depression. If you think you may be depressed, talk to your doctor.

Talking to your family or your nurse may help you feel better. Some people prefer to talk to a person they don't know, such as a counsellor. Your doctor or nurse can arrange this for you.

Physical changes and symptoms

Tiredness

It is normal to gradually lose energy and not be able to do as much. You may need to rest a lot during the day. Ask for help with things that are tiring, like washing and dressing. Your nurse or doctor can tell you about local services that can help. If eating a meal makes you tired, try to eat small amounts regularly instead.

Sleep problems

Some people find it hard to sleep well. There may be many reasons for this. You may be worrying or you may have symptoms that are bothering you.

Some medicines can keep you awake. Tell your doctor or nurse if you are not sleeping well.

To help you sleep:

- reduce light and noise
- make sure you are not too hot or cold
- have a hot drink before going to bed, but avoid caffeine and alcohol
- avoid using a TV or computer for about an hour before you go to bed
- use a relaxation CD or DVD, or listen to some relaxing music

If these things don't help, your doctor or nurse may suggest you try sleeping tablets for a short time.

Pain

Tell your doctor or nurse if you have pain. They can help with this and give you painkillers if you need them.

There are many types of painkiller. Your doctor or nurse will decide which one is best for you.

Always follow your doctor's instructions on when to take painkillers. Most work best when they are taken at regular times during the day.

You usually have painkillers as tablets, liquid medicines, or patches stuck onto the skin. If you can't swallow or are being sick, there are other ways you can have painkillers.

Your nurse or doctor can explain more about your painkillers.

Side effects from painkillers

Stronger painkillers can cause drowsiness, sickness and constipation. Drowsiness usually stops after a few days. If you feel sick, you can be given anti-sickness drugs to help. Sickness usually gets better in a few days. Constipation is common. Most people taking strong painkillers also need to take a medicine called a laxative to help with this. Your doctor or nurse can tell you more.

Reducing pain

There may be simple things you can do to reduce your pain:

- Find a comfortable position to sit or lie in
- Try putting something warm or something cool on the painful area
- Use relaxation techniques such as deep breathing or meditation
- Try to distract yourself by listening to music or watching a film

Feeling sick or vomiting

If this happens, your doctor or nurse can give you anti-sickness drugs to help. It is important to take the medicine regularly to prevent the sickness returning. Your doctor or nurse will tell you more about this.

If you feel sick, try these things:

- ginger tea, ginger beer or ginger biscuits
- sipping fizzy drinks
- eating small amounts regularly, rather than a big meal
- eating dry foods, like crackers
- eating warm or cold food, rather than hot food.

Losing weight or losing your appetite

You may not want to eat if you feel sick or tired. You may lose weight, which can be upsetting for you and your relatives.

As time goes on, you may not want to eat. Try eating smaller amounts more often and have snacks. Choose foods that have lots of calories. Medicines called steroids can sometimes help improve your appetite. Your doctor can provide these if they may help you.

As you near the end of your life, you may not want to eat at all. Don't force yourself to eat. Have small amounts of things you enjoy. You may find nutritious drinks easier to have. There are drinks called Build Up® and Complian®. Your doctor or nurse can get these for you.

Constipation

Many people get constipation. This is because they are not moving around and not eating and drinking as much. Some medicines also cause constipation. Tell your doctor or nurse if you have this problem. They can give you medicines called laxatives to help. Make sure you drink plenty of fluids.

Feeling breathless

This is very common and can be frightening. Tell your doctor or nurse if you feel breathless. There are many ways they can help you with your breathing.

Your nurse can show you and your carers the best place for you to sit or stand to help your breathing. Sit down to do jobs like washing and dressing. If you are feeling breathless, use a cool fan to blow air onto your face or sit by an open window. If you need to talk to someone in another room, use a baby monitor or bell so that you don't need to shout or get up.

Your doctor may give you medicines to help with your breathing. You can also have oxygen at home if you need it.

Mouth problems

You may have a dry mouth, or get ulcers or an infection. Some medicines can make these problems worse. Tell your nurse or doctor if you have mouth problems so that they can treat them.

It helps to keep your mouth clean. Brush your teeth twice a day using a toothpaste that contains fluoride (most toothpastes do). Use a soft baby toothbrush if your mouth is sore. If your doctor gave you a mouthwash, follow their instructions about how to use it.

It can help to avoid caffeine, alcohol or smoking, as these can make your mouth worse. If your mouth is dry, sip tonic water, suck ice cubes or chew sugar-free gum.

Managing difficult symptoms

Your symptoms can often be treated at home. But sometimes you may need to go into a hospice or hospital. Your nurse or doctor will talk to you about this. Once you are feeling a bit better, you can usually go home again.

The last few days of life

People have different experiences in the last few days of life. It can be difficult to know exactly what will happen and when. Usually you will slowly become very weak and have little energy. You may:

- find it difficult to move around
- need help getting from your bed to a chair
- need to spend most or all of the day in bed
- lose interest in what is happening around you
- sleep a lot and feel drowsy when you are awake
- feel confused and unsure whether you are dreaming.

Physical care

You will need more care from those looking after you. If your family needs help to look after you, your nurse can arrange this.

Your mouth and lips may become dry. They will need to be moistened regularly. Your nurse may use a swab to do this (like a big cotton bud). They can show your carers how to use them. They can also put lip balm on your lips to stop them cracking.

Your carers will need to moisturise your skin and change your position regularly. This will stop your skin becoming sore. The nurses can show your carers how to make you comfortable when you cannot move yourself.

There may be a lot of time when you do not need to have anything done. You can lie quietly and your relatives or friends can sit with you. Let them know whether you'd like to talk or have some time on your own. You may want to listen to some favourite music.

Symptoms

Sometimes your nurse or doctor may change your medicines. They may stop any medicines you no longer need. If you develop new symptoms, you may start a new medicine.

If you have problems swallowing tablets, medicines can also be given:

- by injection
- by patches stuck on the skin
- by a syringe attached to a small pump.

It can sometimes be hard to get medicines quickly at night or at weekends. Your doctor or nurse may leave some with you in case you need them. These are called 'just in case' medicines. When you have 'just-in-case' medicines at home, there is no delay if you need them.

Some people develop the symptoms below. You are unlikely to be aware of these symptoms, as you will be sleepy.

Breathing changes

Fluid can sometimes collect in your throat or chest. This may make your breathing noisy but it won't usually cause you any distress. Your nurses can help you find ways to stop the fluid building up or give you medicines to help.

Restlessness

Some people become restless. This may be because they are worried. You can have medicines to help you relax and sleep. Having a close family member with you can help, or a religious leader who can sit, talk or pray with you.

Bladder changes

You may not be able to control your bladder. Your nurse can get you special bed covers and pads. They may put a tube into your bladder to drain away urine.

If your carers are worried about any of your symptoms, they should contact your GP or nurse.

Nearing death

Thinking about dying can be very frightening. It's normal to worry about what will happen.

You may want certain things done as you near death. This might include:

- parts of books or prayers being read out
- favourite music playing
- being quiet.

You may also want a spiritual or religious leader with you. Tell your carers or relatives what you would like so they can make sure it happens.

What happens

For many people, dying is very peaceful. You will usually fall into a deep sleep and find it difficult to wake up.

Usually you are so deeply asleep you cannot wake up. You may still be able to hear and be aware that family and friends are close by. Some people have times when they are awake and can talk, and then they go back into a deep sleep.

If you are at home and anything happens that worries your carers, they should contact your nurse or GP.

As you near death, your hands and feet become cold. Your lips and nails may turn slightly blue. This is normal. Your breathing may also change, becoming slower with longer gaps between each breath. Finally, your breathing will completely stop.

After death

This section is written for your relatives or carers, but you may want to read it too.

Everyone reacts to death differently. At first you may feel shocked or numb. You may also be very upset or angry. Or you may feel relieved that your relative or friend is now at peace.

You can spend time with the person who has died if you want to. Many people like to sit and talk or hold hands. You may want to have a relative or friend there to support you. Do what you feel is right.

Take time to carry out any traditions that are important to you. It may also help to have a spiritual or religious leader with you at this time.

What the GP will do

If the person died at home, you will need to tell their GP or community nurse. They will come to the house to confirm the death.

If the GP comes, they will give you a death certificate. This confirms the cause of death. They will also give you a form called 'Notice to informant'. This tells you how to register the death (see below).

If a nurse or out-of-hours doctor comes, they will confirm the death. But you may need to get the death certificate from your GP the next day.

What the funeral director will do

Once the death has been confirmed, you can contact the funeral director (undertaker). They are available 24 hours a day. They can tell you what to do next. You can find a funeral director in your local phone book or on the internet.

The funeral director will come as soon as you want them to. They will take care of your relative's or friend's body. You can tell the funeral director how you would like them to do this and if there are any traditions to follow.

They will take your relative's body to the chapel of rest in the funeral home. You can visit the chapel to be with your relative's body if you would like to. Tell the funeral director if you would prefer to have your relative's body at home until the funeral. The funeral director will also ask you what clothes you would like them to wear.

Registering the death

Before the funeral can happen, you need to register the death at your local register office. This must be done within five days (or eight days in Scotland). You can find details of your local register office in the phone book. They may also be written on the envelope containing the death certificate. Phone the register office before going to register the death. You may need to make an appointment. You can also visit gov.uk/register-a-death for more information.

Planning the funeral

Your relative or friend may have told you what they want for their funeral or written it down. In some cultures and religions, it is important to have the funeral soon after the death. Tell the funeral director if this needs to happen.

The funeral director will help you arrange the funeral. You can also get help from a religious or spiritual leader. If your loved one did not leave any information about their wishes, the funeral director will guide you through planning the funeral.

How grief might make you feel

Grief is normal after the death of someone close to you. You may feel numb, in denial, angry or guilty. You may feel a longing for the person or feel depressed. Although these feelings can be very strong at first, with time they slowly lessen.

Talking about your feelings can help. You may want to talk to close family or friends. The charity Cruse Bereavement Care can also offer support – see page xx.

Tell your GP if you are struggling with how you are feeling. They may be able to help. They can also refer you to other support, for example a counsellor. Many people find talking to a counsellor helpful.

How Macmillan can help

Macmillan is here to help you and your family. You can get support from:

- **The Macmillan Support Line (0808 808 00 00)**. We have interpreters, so you can speak to us in your language. Just tell us, in English, the language you want to use. We can answer medical questions, give you information about financial support, or talk to you about your feelings. The phone line is open Monday to Friday, 9am to 8pm.
- **The Macmillan website (macmillan.org.uk)**. Our site has lots of English information about cancer and living with cancer. There is more information in other languages at macmillan.org.uk/translations
- **Information centres**. At an information centre, you can talk to a cancer support specialist and get written information. Find your nearest centre at macmillan.org.uk/informationcentres or call us. Your hospital might have a centre.
- **Local support groups** – Find a group near you at macmillan.org.uk/supportgroups or call us.
- **Macmillan Online Community** – You can talk to other people in similar situations at macmillan.org.uk/community

Contact details of useful organisations

Care at the end of life:

Marie Curie

Telephone 0800 090 2309 (Monday to Friday, 8am to 6pm, Saturday, 11am to 5pm)

Email supporter.services@mariecurie.org.uk

www.mariecurie.org.uk

Marie Curie nurses provide free care to people approaching the end of life. They can look after you at home or in a hospice. They can provide care at night too.

Counselling and emotional support:

It's Good to Talk (British Association for Counselling and Psychotherapy)

Telephone 01455 883 300

Email bacp@bacp.co.uk

www.itsgoodtotalk.org.uk

You can search for a counsellor on the website and read about therapy and how it can help.

Support for carers:

Carers UK

Telephone (England, Scotland, Wales) 0808 808 7777

Telephone (Northern Ireland) 028 9043 9843

(Wed–Thu, 10am–12pm and 2–4pm)

Email advice@carersuk.org

www.carersuk.org

Gives information and support to carers across the UK. They can put you in contact with support groups for carers in your area.

Support when someone dies:

Cruse Bereavement Care

Telephone 0808 808 1677 (Monday and Friday, 9.30am to 5pm, Tuesday to Thursday, 9.30am to 8pm)

Email: helpline@cruse.org.uk

www.cruse.bereavementcare.org.uk

There are branches across the UK where you can get support if someone you love has died. You can find your local branch at **www.cruse.org.uk/cruse-areas-and-branches**

Finding a solicitor:

The Law Society for England and Wales

Telephone 020 7242 1222

www.lawsociety.org.uk

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

The Law Society of Scotland

Telephone 0131 226 7411

www.lawscot.org.uk

Represents solicitors in Scotland and can provide details of solicitors.

The Law Society of Northern Ireland

Telephone 028 9023 1614

www.lawsoc-ni.org

Represents solicitors in Northern Ireland and can provide details of solicitors.

Glossary

Bladder – The organ in your body that stores urine until you go to the toilet.

Calories – Calories are units of energy found in food. Your body needs energy from food to function.

Chapel of rest – The place where someone's body is kept before their funeral.

Constipation – When you find it difficult or painful to poo. You might not be going as often as usual, or your poo might be hard and lumpy.

Counsellor – A professional who is trained to help people cope with their emotions or personal problems.

Fluoride – A natural mineral that is used in most toothpastes.

Funeral director – A person who arranges funerals. They also look after the person's body before the funeral and provide support to the family.

Funeral home – The building where a person's body is prepared for the funeral. The chapel of rest is inside the funeral home.

Grief – Grief is how you feel when someone dies. It is different for everyone.

Register office – A local government building where births, marriages and deaths are recorded.

Solicitor – A legal professional trained to help people write their will.

More information in [language]

We have information in [language] about these topics:

<p>Types of cancer</p> <ul style="list-style-type: none">• Breast cancer• Large bowel cancer• Lung cancer• Prostate cancer <p>Treatments</p> <ul style="list-style-type: none">• Chemotherapy• Radiotherapy• Surgery	<p>Coping with cancer</p> <ul style="list-style-type: none">• If you're diagnosed with cancer – A quick guide• Claiming benefits• Eating problems and cancer• End of life• Healthy eating• Tiredness (fatigue) and cancer• Side effects of cancer treatment• What you can do to help yourself
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To see this information, go to macmillan.org.uk/translations

Speak to us in [language]

You can call Macmillan free on **0808 808 00 00** and speak to us in your own language through an interpreter. You can talk to us about your worries and medical questions. Just tell us, in English, the language you want to use.

We are open Monday to Friday, 9am to 8pm.

References and thanks

All of this information has been written and edited by Macmillan Cancer Support's Cancer Information Development team.

The information in this fact sheet is based on the Macmillan booklet **End of life**. This booklet was produced with Marie Curie. We can send you a copy, but the full booklet is only available in English.

This content has been reviewed by relevant experts and approved by our Chief Medical Editor, Dr Tim Iveson, Macmillan Consultant Medical Oncologist.

With thanks to Kirsty Clayton, Deputy Director of Nursing at Myton Hospice, and Dr Anna-Marie Stevens, Macmillan Nurse Consultant. Thanks also to the people affected by cancer who reviewed this edition.

All our information is based on the best evidence available. For more information about the sources we use, please contact us at **bookletfeedback@macmillan.org.uk**

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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 your 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.

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