

End of life

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

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 talk about the information together.

If you have any questions about this information, ask your doctor or nurse at the hospital where you are having treatment.

You can also call Macmillan Cancer Support on freephone **0808 808 00 00**, 7 days a week, 8am to 8pm. We have interpreters, so you can speak to us in your own language. When you call us, please tell us in English which language you need.

There is more cancer information in your language at [macmillan.org.uk/translations](https://www.macmillan.org.uk/translations)

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Learning that you are near the end of life

How you may feel

You are likely to have many emotions when you find out you may be nearing the end of your life. You may feel upset and unsure of how to cope with your feelings. You might feel numb and anxious about what will happen in the future.

Talking about your situation can help. You may find it helpful to talk about your thoughts and feelings with someone you trust. This may be a close friend, partner or family member. You might find it easier to talk to a healthcare professional. Your GP, specialist nurse or healthcare team at the hospital can support you. You can also speak to one of Macmillan's cancer support specialists on **0808 808 00 00**. We have interpreters.

Relationships with people close to you

Sometimes, having a terminal illness can affect your relationships. Some people may find it hard to know what to say. Or they may avoid talking about your illness. Others may be overly cheerful.

If you have a partner, you may try to protect each other. If you can, talk to each other about your situation and your feelings. Being open and honest can help you both cope with sadness, anxiety and uncertainty.

What you choose to tell children depends on their age and how much they can understand. It is often best to be honest with them, and try to give them information they can understand.

Macmillan's cancer support specialists can provide advice and support for your family and friends. You can call them on **0808 808 00 00**.

Spiritual, religious or pastoral support

Some people become more aware of religious beliefs or spiritual feelings towards the end of life. You may find it helpful to talk to a close friend or family member, or a health and social care professional. You can also speak to a chaplain or religious leader, even if you are not religious. They are usually good listeners and are used to being with people who are distressed or upset.

You may prefer to talk to someone who is not religious. Humanists UK (www.humanists.uk) has volunteers who can provide non-religious pastoral support.

Planning ahead

Planning ahead can help other people know about how you would like to be looked after. It means you are more likely to get the care you would like. Planning ahead includes:

Your wishes for your care

You may want to think about how and where you would like to be cared for. It is best to write down your wishes and what is important to you.

Deciding if there are any treatments you do not want

You can decide about any treatments you do not want to have in the future. This is called an 'Advance decision to refuse treatment' in England, Wales and Northern Ireland and an 'Advance directive' in Scotland. It is best to write these down. They will only be used if you cannot make or communicate a decision yourself.

Deciding who can make decisions for you

You can choose someone to make decisions for you if you become unable to make decisions yourself. This is called giving someone power of attorney. The power you give them can be long or short term. Power of attorney laws are different in England, Wales, Scotland and Northern Ireland.

Making a will

A will is a legal document that gives instructions about who you want to give your money and belongings to when you die. It means your loved ones and friends will be looked after in the way you want.

It is usually best to use a solicitor when writing your will. A solicitor is a legal professional trained to help people write their will. They will make sure everyone understands what you want to happen.

Planning your funeral

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

- a burial or cremation
- specific songs, readings or prayers
- certain customs or rituals to be followed
- to be dressed or presented in a certain way.

You can talk to your family or friends about these plans. They may also have ideas that will help them say goodbye.

Your care at the end of life

Different healthcare professionals can help you when you are near the end of your life:

Your GP

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

- prescribe any drugs you need
- arrange help from other professionals
- talk to you about what might happen as you become less well.

Nurses

There are different nurses who can visit you at home.

District nurses often work with palliative care nurses to help support you and your carers. They can:

- change dressings and give you medicines
- give advice
- show your carers how to look after you
- arrange for a social carer or healthcare assistant
- arrange practical aids, such as pressure-relieving mattresses or commodes.

Palliative care nurses care for people who are close to the end of their life. They can help with pain and other symptoms. They can provide emotional support to you and your family, friends or partner.

In some parts of the country there are Marie Curie nurses who care for people at home who are nearing the end of their life. Your GP or district nurse can tell you if there are Marie Curie nurses in your area.

Other healthcare professionals such as an occupational therapist or a physiotherapist can also help support you. Social services may be able to help if you need help with things like personal care, cleaning and cooking.

Choosing where to die

Some people prefer to die at home. Other people may prefer to be in a hospice, a care home or a hospital.

Hospices care for people who have a terminal illness and may be close to the end of their life. They have doctors and specialist palliative care nurses who are experts in controlling symptoms such as pain. They also provide emotional support. Some people go into a hospice for a short time to get help with managing symptoms. Some people choose to die in a hospice.

You may prefer to be looked after in a residential care home or nursing home, if you need care for several months. Some people may prefer to be in a hospital.

Wherever you are, you can get help from a palliative care team. This is a group of healthcare professionals that care and support people who have an illness that cannot be cured. There are palliative care teams at hospices, in the community and in hospitals.

The last few weeks of life

During the last few weeks of life, you may go through emotional and physical changes.

Emotional changes

It is natural to feel different emotions, including anxiety, anger or sadness in the last few weeks of your life.

Talking to your family or someone in your healthcare team may help. Some people prefer to talk to a person they don't know, such as a counsellor.

Tiredness

It is normal to have less energy. You may need help to do things you usually do for yourself. You may find you need to rest more.

Things that can help:

- Save your energy for the things that matter to you and that you enjoy
- Ask family or friends to help with things like cooking and cleaning
- If eating is tiring, try eating little and often.

Sleep problems

You may find it difficult to sleep. This might be because you feel anxious 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. Sleeping tablets may help some people.

Things that can help:

- reduce light and noise
- if your mattress is uncomfortable ask your nurse for advice about a more comfortable one
- have a hot drink before going to bed but avoid caffeine and alcohol
- avoid using a screen for at least 1 hour before you go to bed
- simple breathing and relaxation exercises.

Pain

Many people are worried about pain as they approach the end of their life. If you are in pain, it is important to tell your healthcare team. They can make sure you have the right dose of painkillers to control your pain.

Always follow your doctor or nurse's instructions on when to take painkillers.

You may have painkillers as tablets, liquid medicines, or patches stuck onto the skin. If you cannot swallow or are being sick, you may have them as an injection under the skin or through a small pump.

You may get side effects from taking painkillers. Strong painkillers can cause

drowsiness, sickness and constipation. Drowsiness and sickness usually get better after a few days. If you are having a strong painkiller you may need to take a medicine called a laxative to help with constipation. Constipation is when you find it difficult or painful to poo. You might not go as often as usual.

Weight loss and loss of appetite

It is normal to feel less hungry as you near the end of your life. Even if you are eating well, you may lose weight, and this can be upsetting.

Things that can help:

- Have snacks or small meals more often. Only eat what you can manage.
- If you don't like the smell of cooking, ask someone else to cook your food if this is possible.
- Try eating foods that are easy to digest.

Your body does not need as much food towards the end of life.

Feeling sick or being sick

You may feel sick (nausea) or be sick (vomit), Your doctor or nurse can give you anti-sickness drugs (anti-emetics) to help. They can be given as tablets or liquid medicines. If you cannot swallow medicines, you can have them in a different way.

Things that can help

- Take anti-sickness medicines regularly.
- Have warm or cold food, as this does not smell as strong as hot food.
- Eat dry foods.
- Ginger can help – try crystallised ginger, ginger tea, ginger beer or ginger biscuits.
- Eat little and often.
- Ask someone else to prepare food for you if this is possible.

Constipation

You may get constipation because you are not moving around and not eating and drinking as much. It is important to tell your doctor or nurse if you have this problem.

Things that can help:

- Take your laxatives as your doctor or nurse tells you to.
- Drink as much fluid as you can.
- Try to have some high-fibre foods, such as fruit and vegetables, brown rice, brown bread or brown pasta.
- If you can, do some gentle exercise like walking.

Feeling breathless

Tell your doctor or nurse as soon as possible if you are breathless or you suddenly become more breathless than usual. Different things may help depending on what is causing the breathlessness.

Breathlessness can be very frightening and may make you feel anxious. Your nurse or a physiotherapist can teach you ways to relax, so that you feel less anxious and breathless.

Your doctor may prescribe medicines to help. They can also prescribe oxygen that you breathe in through a mask.

Things that can help:

- try sitting by an open window
- use an electric or handheld fan to blow air onto your face
- a nurse or physiotherapist can show you and your carers the best positions to sit or stand to help with your breathing
- sit down to do tasks like washing and dressing
- try using a mobile device to talk to someone in another room.

Difficulty moving around

You may gradually find it harder to move around. If you are not moving around very much, your skin may get sore. It is important to change your position regularly if you can. If you need help, your nurse can show your carers how to move you safely so you are comfortable.

Mouth problems

Looking after your mouth is important. It can help prevent problems such as a dry or sore mouth, ulcers or an infection. Tell your nurse or doctor if you have any mouth problems.

Things that can help:

- If you can, brush your teeth twice a day using a fluoride toothpaste. Use a soft children's toothbrush if your mouth is sore.
- If you have false teeth, clean them as usual.
- Use any mouthwash that you have been prescribed.
- If you have a dry mouth, try sipping water – some people find tonic water helpful. You could also try sucking ice lollies or ice chips, or chewing sugar-free gum.

The last few days of life

Each person's experience of the last few days of life will be different. It can be difficult to know exactly what will happen, or how quickly things might change. Usually, you slowly become weaker and have very little energy.

You may:

- find it difficult to move around
- need to spend most, or all, of the day in bed
- lose interest in eating and drinking

- sleep a lot and feel sleepy when you are awake
- feel disorientated or confused, and unsure whether you are dreaming
- dream about people who are not there or that you knew in the past
- lose interest in your surroundings and the people around you.

These are all natural things that can happen as you approach the end of your life.

Nearing death

Although death is a natural process, it is normal to worry about what will happen. You may feel anxious or frightened. Or you may feel calm and peaceful.

Usually, you slip into a deep sleep where you are unconscious. You cannot be woken, but you may still be able to hear and be aware of the people around you.

The final moments of life are usually very peaceful. Your breathing may gradually become even slower and more irregular, with very long pauses between each breath. Eventually, you will stop breathing altogether.

Caring for someone at the end of life

This information is written for your relatives or carers. You may want to read it together

This information explains more about caring for someone in the last few days of life and what happens after a person has died.

You may be anxious about looking after them at home. However, it can be a rewarding experience. It can also bring you closer to the person who is dying.

Looking after yourself

Caring can be hard, both physically and emotionally. If you have been looking after your partner, family member or friend for some time, you may start to feel very tired.

It is important to get support and to look after yourself too. Talk to the district nurse or GP if you are finding caring difficult. They may be able to provide extra support. Or they can give you advice about where your loved one could be cared for.

Caring during the last few days of life

As your family member, partner or friend gets close to the end of their life, they will probably not want anything to eat or drink. You can keep their mouth and lips moist to help them feel comfortable.

If the person you are caring for seems distressed or has new or uncomfortable symptoms, tell a member of the healthcare team. Make sure you have phone numbers for the:

- GP
- district nurse
- specialist or palliative care nurse

- out-of-hours services (to use in the evening, at night and at weekends). Keep the numbers in a safe place. Make sure you know who to contact first.

Breathing changes

The person you are caring for may have different symptoms such as pain or changes in their breathing. Sometimes the breathing can get noisy or be irregular. A doctor or nurse can give medicines to help.

Restlessness

Some people become restless. They may seem confused or call out. There are different reasons for this. A doctor or specialist nurse can treat the cause of the restlessness or give drugs to help the person relax.

Bowel and bladder changes

The person may lose control of their bowel and bladder. The bowel is a long tube inside your body that helps you digest food. The bladder is the organ in your body that stores urine until you go to the toilet to pee (pass urine). This is natural. A district nurse can provide aids to help manage this. This includes:

- disposable bed pads
- pads to wear inside, or instead of, underwear
- a tube (catheter) that is put into the bladder and drains urine into a bag. A catheter is a thin plastic tube that can be put into the bladder so you can pee without going to the toilet.
- a urinary sheath that fits over the penis like a condom – it collects urine and drains it into a bag.

Sometimes the person cannot pass urine. They may have a lot of abdominal pain, and their tummy (abdomen) might feel hard and bloated. If this happens, contact their doctor or nurse straight away and ask them to come urgently. They can put a catheter into the bladder to drain urine and relieve the pain.

If you have any concerns, contact the person's GP or a member of their healthcare team for advice.

Caring for someone nearing death

You can help keep your family member, partner or friend comfortable as they near death. Even if they cannot respond, they may still be able to hear you and know you are there.

Tell them what you are doing, especially if you are giving them medicines or moving them. You may need to move them regularly to keep them comfortable.

In the last few hours, the person's hands, feet and skin may feel very cold and sometimes moist. Their skin may change colour and become slightly more blue, grey or pale. Their breathing pattern will probably change. At times there may be longer gaps between breaths. At other times, their breathing might be quicker.

For most people, the final moments of life are very peaceful. The person's breathing

may become even slower and more irregular, with very long pauses between breaths. Finally, they will stop breathing altogether. Sometimes it can be difficult to know the exact moment of death. Often, the person's body will relax completely, and they may look very peaceful. You may feel that you can sense when the person has died.

After death

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

If the person dies at home, and this was expected, you need to tell their GP or district nurse. You do not need to rush to do this. It is fine to spend some time with your loved one before making any phone calls. If they died during the night or outside your GP's usual working hours, you do not need to contact the doctor until the following morning. But you can contact them during the night if you want to.

If you are alone when your relative or friend dies, it may be helpful to have someone with you soon after the death to support you. This might be a relative, friend, religious adviser or someone from the health or social care team.

Many cultures and religions have ceremonies or rituals that are important when someone dies. A spiritual or religious adviser can help you with these.

What the GP will do

If the person's GP comes, they will verify the death. They will give you a Medical Certificate of Cause of Death (MCCD) with a form called Notice to Informant. This tells you how to register the death.

If a district nurse comes, or you have called an out-of-hours doctor, they can verify the death. But you may need to get the MCCD from the person's GP the next day.

When you have the MCCD, you need to take this to the local register office to register the death. The register office is a local government building where births, marriages and deaths are recorded. This needs to be done:

- within 5 days in England, Wales and Northern Ireland
- within 8 days in Scotland.

You may need to make an appointment to register the death.

The registrar will give you the death certificate. It is a good idea to ask for extra copies of the death certificate. They may be needed for sorting out things such as the person's insurance, pensions or banking.

What the funeral director will do

When the death has been verified by a nurse or doctor, you can contact a funeral director (undertaker). They provide a 24-hour service and can advise you on what to do next. A funeral director is a person who arranges funerals. They can look after the person's body before the funeral and support the family. You can get contact details of funeral directors from your local phone book or online.

The funeral director will come as soon as you want them to. Tell them if you or your family and friends would like to spend some time alone with your loved one's body.

Some people wish to look after their family member or friend's body at home until the funeral. Or you may want the funeral director to take care of your family member or friend's body. You can help the funeral director wash and dress your loved one. If the funeral director dresses the person, they will also ask what you would like your loved one to be dressed in.

You can tell the funeral director if there are any cultural or religious practices you would like to be followed.

Your emotions after someone has died

After the death of your loved one, and for some time afterwards, it is normal to feel different emotions. These can include feeling sad, anxious, angry and numb.

You may also have a sense of relief that your loved one is not suffering anymore. The thoughts and feelings you have will vary. Sometimes they may be very strong and stop you doing things. At other times they may be in the background and you can still do your day-to-day activities.

Sometimes your feelings can be difficult to deal with. You may want to talk to your family and friends about how you are feeling. Or you may prefer to talk to someone you do not know.

Some people need extra help to manage their emotions. There are organisations that can support you when you are bereaved, including Cruse Bereavement Care. Your GP can support you and may be able to put you in contact with a local bereavement counsellor, this is a person who is trained to help people cope with difficult emotions or situations. Many hospices also provide bereavement support.

Children or teenagers will have many different emotions and these may affect their behaviour. There are organisations that can help you support children. Some hospices work with schools and also offer a wide range of support.

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)

www.mariecurie.org.uk

Marie Curie nurses provide free end-of-life care across the UK. They care for people in their own homes or in Marie Curie hospices, 24 hours a day, 365 days a year. Visit <https://www.mariecurie.org.uk/help/support/different-languages> to see how Marie Curie can help you in your language.

Support when someone dies:

Cruse Bereavement Care

Telephone 0808 808 1677

Provides bereavement support to anyone who needs it across the UK. You can find your local branch on the website. Visit <https://www.cruse.org.uk/understanding-grief/understanding-grief-information-in-other-languages/> for information in your language

Getting the right care and support for you

If you have cancer and do not speak English, you may be worried that this will affect your cancer treatment and care. But your healthcare team should offer you care, support and information that meets your needs.

We know that sometimes people may face extra challenges in getting the right support. For example, if you work or have a family it can be hard to find time to go to hospital appointments. You might also have worries about money and transport costs. All of this can be stressful and hard to cope with.

But help is available. Our free support line **0808 808 00 00** can offer advice, in your language, about your situation. You can speak to nurses, financial guides, welfare rights advisers and work support advisers.

We also offer Macmillan Grants to people with cancer. These are one-off payments that can be used for things like hospital parking, travel costs, childcare or heating bills.

How Macmillan can help you

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

- **The Macmillan Support Line.** 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. Just call **0808 808 00 00** (7 days a week, 8am to 8pm).

- **The Macmillan website.** Visit macmillan.org.uk for lots of English information about cancer and living with cancer. There is more information in other languages at macmillan.org.uk/translations
- **Information and support services.** At an information and support service, 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.** At a support group you can talk to other people affected by cancer. Find a group near you at macmillan.org.uk/supportgroups or call us.
- **Macmillan Online Community** – You can also talk to other people affected by cancer online at macmillan.org.uk/community

More information in your language

We have information in your language about these topics:

<p>Types of cancer</p> <ul style="list-style-type: none"> • Breast cancer • Cervical 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"> • Cancer and coronavirus • Claiming benefits when you have cancer • Eating problems and cancer • End of life • Help with costs when you have cancer • Healthy eating • If you are diagnosed with cancer – a quick guide • 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

References and thanks

This information has been written and edited by Macmillan Cancer Support's Cancer Information Development team. It has been translated into your language by a translation company.

The information included is based on the Macmillan booklet A guide for the end of life. We can send you a copy, but the full booklet is only available in English.

This information has been approved by our Senior Medical Editor Dr Viv Lucas, Consultant in Palliative Care.

Thanks also to the people affected by cancer who reviewed this information.

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