

End of life

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

Any words that are underlined are explained in the word list at the end. The word list also includes the pronunciation of the words in English.

This fact sheet tells you about who can help care for you at home and in other places where you may receive end of life care. 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 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 (say "xxxxx").

There is more cancer information in [LANGUAGE] at **macmillan.org.uk/translations**

This information is about:

- How you may feel
- Planning ahead
- At home
- In a hospital, hospice or care home
- Relationships with people close to you
- Spiritual, religious or pastoral support
- The last few weeks of life
- The last few days of life
- Nearing death
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How you may feel

Finding out that you may be nearing the end of your life can be very difficult. You might find it hard to believe, even if you know your illness is getting worse. You may feel it is unfair. You may be tearful and sad. You may not know how to cope with these different feelings. And you may worry about what will happen next.

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.

Planning ahead

It can be helpful to plan ahead and make the most of the days when you feel well. You may want to plan to do some nice things with your family and friends, or just spend time with them.

There are some important things you may want to think about before you die. These include:

- making a will
- planning your funeral
- planning where you will be cared for.

It may be helpful to talk about these with your family and your doctor or specialist nurse.

Writing 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 may also include instructions about:

- who you would like to look after your children or anyone who is financially dependent on you (dependants)
- any specific funeral arrangements you want.

It is important to write a will. 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 the list of useful organisations later in this information).

Your wishes for your care

You can talk to people about your wishes and what matters to you. It is usually better to use a document to help plan and write down your wishes for your care. You can write down any specific wishes about how and where you would prefer to be cared for if you become unwell.

You can also write down your wishes 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.

You may want to arrange for someone to help make decisions for you if you are unwell or if you are unable to make decisions for yourself. This is called giving someone power of attorney.

Your healthcare team can tell you more about these.

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
- if there are specific 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 people know.

Choosing where to die

The choice of where you will die often depends on:

- what you would like
- what help you have from family and friends
- the services available where you live
- your medical condition.

You can be cared for in different places.

Depending on your situation, you may be cared for:

- **at home** – with close family members or friends to look after you. There are different healthcare professionals that can support you and your carers at home and help you manage any symptoms.
- **in a hospice** – which is a place that specialises in caring for people who have a terminal illness and may be close to the end of their life.

- **in a residential home or care home with nursing** – that usually offer short-stay or long-stay care. Your GP or healthcare team can explain the different types of care homes.
- **in a hospital** – which has palliative care teams that can help manage any symptoms and provide emotional support.

At home

You may need extra help if you are being looked after at home. There are health and social care professionals who can help you:

Your GP

While you are at home, your GP is responsible for your 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.

District nurses

District nurses will visit you at home. They work closely with GPs and often work with palliative care nurses to help support you and your carers so you can stay at home. 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.

Palliative care teams

Palliative care teams provide care for people who are close to the end of their life. They can help with symptoms, including pain, and can provide emotional support. They can also provide support for the person's family and friends.

Marie Curie Nurses

Marie Curie Nurses care for people at home who are nearing the end of their life. They can provide nursing care and support 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.

Social workers

Social workers can arrange help with personal care, such as washing and dressing, housework and other practical tasks. You, or your doctor or nurse, can contact a social worker to ask for this help. You usually have to pay towards the cost of personal care, depending on your financial situation. But you may be able to claim extra financial benefits to help you get care.

Occupational therapists

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

- rails to help you move around your home
- equipment to help you shower or bath
- a wheelchair.

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

In a hospice, hospital or care home

If it is not possible for you be cared for at home, you can get help and support from a palliative care team, wherever you are being cared for.

- **Community palliative care teams** are based in the community. They often work with a hospice and can visit you if you are in a care home.
- **Hospice palliative care teams** care for people in the hospice. They can also visit people in their own homes.
- **Hospital palliative care teams** are usually based in a hospital. They care for people who are in hospital.

Relationships with people close to you

Your partner, family and friends can provide support and reassurance to help you cope with what is happening. However, terminal illness can sometimes make relationships difficult. It can sometimes help to talk to each other about how you feel. Or you may find it easier to talk to your GP, community nurse, or an organisation that offers emotional support (see the list of useful organisations later in this information). Your GP may refer you to a counsellor to talk about how you are feeling.

Spiritual, religious or pastoral support

Some people may find they become more aware of religious beliefs or spiritual feelings towards the end of life. Even if you are not sure about what you believe, it may be helpful to talk to a religious leader or advisor. They may be able to offer you emotional or spiritual comfort and help you to feel more at peace with your situation.

Hospices usually provide spiritual support to people of all faiths or no faith. You may prefer to talk to someone who is not religious. Humanist Care (www.humanist.org.uk) has volunteers who can provide non-religious pastoral support.

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 different emotions, including anxiety, panic or anger 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. Your doctor or nurse can arrange this for you.

Some people become sad and withdrawn. You may not want to talk about what is happening. Communicating less and spending time thinking can be a way of mentally preparing to die.

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 a lot during the day. Ask for help with things that are tiring, like washing and dressing. If you find eating tiring, try eating small amounts more often instead of eating meals.

Sleep problems

Some people find it hard to sleep well at night. There may be many reasons for this. You may be feeling 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.

There are things you can do to help you sleep:

- reduce light and noise and make sure your room is not too hot or cold
- 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 device with a screen, such as a smartphone, tablet or TV for at least an hour before you go to bed
- if you wake up during the night, write down anything you are worried about or need to do
- use a relaxation CD or DVD, or listen to some relaxing music.

If these things don't help, your doctor or nurse may have other suggestions, such as medicines to help you sleep.

Pain

Many people are worried about pain as their illness gets worse. 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 cannot swallow or are being sick, there are other ways you can have painkillers. Your nurse or doctor can tell you more.

Side effects from painkillers

Strong painkillers can cause drowsiness, sickness and constipation. Drowsiness usually stops after a few days. If you feel sick, you can have 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.

Other ways to reduce pain

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

- Use any special equipment you have been given. For example, you could use pressure-relieving cushions on chairs to help find a comfortable position to sit or lie in.
- Use relaxation techniques such as deep breathing or meditation.
- Try to distract yourself by listening to music or watching a film.

Your doctor or nurse can tell you about other ways to help reduce your pain.

Feeling sick or being sick

Your illness, or your medicines, may make you feel sick (nausea) or be sick (vomit). 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. You can have anti-sickness drugs as tablets or in liquid form. If you find it difficult to swallow, you can have them in a different way, including as an injection. Your doctor or nurse will tell you more about this.

If you feel sick, things that can help include:

- having ginger tea, ginger beer or ginger biscuits
- sipping fizzy drinks
- eating small amounts more often instead of eating meals
- eating dry foods, like crackers
- eating warm or cold food, rather than hot food
- asking someone else to prepare food for you.

Losing weight or losing your appetite

You may lose weight, even if you are eating well. This can be upsetting.

Try eating small amounts more often and have snacks nearby to eat. Medicines called steroids can sometimes help improve your appetite. Your doctor can prescribe these if they may help you.

Your body does not need as much energy at this stage. It is also difficult for your body to digest food as you near the end of your life. So do not force yourself to eat as this could make you feel unwell. Your family and friends might feel anxious or upset because you no longer feel hungry or enjoy food. Talk to them about what you would like to eat or drink.

Constipation

Many people get constipation. This is because they are not moving around and not eating and drinking as much. Medicines such as strong painkillers can 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. If you can, try to have a high fibre diet, with fruit and vegetables, brown rice, bread and pasta.

Feeling breathless

Breathlessness can be frightening. Tell your doctor or nurse if you are breathless or you suddenly become more breathless than usual. Different things may help depending on what is causing the breathlessness.

Your nurse can show you and your carers the best place for you to sit or stand to help with 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 without getting up, you could use a mobile phone. Your GP or nurse can arrange for you to have oxygen at home if you need it.

Your doctor may give you medicines to help with your breathing. Your nurse or a physiotherapist can teach you ways to relax, so that you feel less anxious. If anxiety has caused the breathlessness or made it worse, then feeling less anxious can help with your breathing.

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.

Looking after your mouth is important and can help prevent mouth problems. It helps to keep your mouth clean. Brush your teeth twice a day using a fluoride toothpaste. Use a soft children's toothbrush if your mouth is sore. If your doctor gave you a mouthwash, follow the 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 or lemonade, 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 have symptoms treated in 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 or how quickly things will change. 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.

If you have a dry mouth, a district nurse can show your carers how to regularly moisten your mouth. 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 helps to 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 would like to talk or have some time on your own. But also tell them if you would like someone to be with you all the time. It will help your carers in planning your care.

Symptoms

If your symptoms change, your doctor or nurse may change your medicines. Sometimes your nurse or doctor may stop some of your medicines. Or 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 onto 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, a nurse or doctor can give them to you straight away 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 loud but it will not usually cause you any distress. Your nurses can help to stop the fluid building up or give you medicines to help.

Restlessness

Some people become restless. This may be for different reasons. You can have medicines, through an injection or a syringe pump, 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 and bowel changes

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

Sometimes urine cannot drain out of the bladder and you are not able to pass urine. This causes severe tummy pain (abdominal pain), and your tummy (abdomen) will feel very hard and bloated. If this happens, your carer needs to contact your doctor or nurse straight away and ask them to come urgently. They can put a catheter into the bladder to drain the urine and relieve the pain.

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 is normal to worry about what will happen. It can be comforting to have someone with you as you die. Not everyone has family or friends who can do this. But you may want to have a religious or spiritual adviser with you. Tell your carers or relatives what you would like so they can make sure it happens.

What usually happens

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

Usually you gradually become completely unconscious. You cannot be woken at all but may still be able to hear and be aware of the people around you. There might be times when you are awake and can talk, and then you become unconscious again.

If you are at home your carers can contact your district nurse, specialist nurse or GP 24 hours a day, 7 days a week.

As you near death, your hands, feet and skin feel very cold. Your skin may be very sensitive to touch. Your breathing pattern may change. It may become irregular, with longer and longer gaps between each breath. You will not be aware of these changes. For most people, the final moments of life are very peaceful. Finally, your body will completely relax and your breathing will stop.

After death

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

If your family member 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.

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 and this was expected, you will need to tell their GP or community nurse within a few hours. They will come to the house as soon as possible, to confirm the death. If your family member or friend died during the night or outside your GP's usual working hours, you do not need to contact the doctor until the following morning, unless you want to.

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. Details of funeral directors are in your local phone book or on the internet. You can also get information from the National Association of Funeral Directors (<https://nafd.org.uk>).

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.

Tell the funeral director if you or your family and friends would like to spend some time alone with the person's body. Some people wish to look after their family member or friend's body at home until the funeral. The funeral director can help you with this.

Or you may prefer for the body to be taken to the funeral director's chapel of rest. The funeral director will ask if you would like the person who has died to be dressed in any specific clothes, such as a favourite outfit. You can visit the chapel of rest to be with the body if you wish.

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 or by visiting the website www.gov.uk/register-a-death. 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 friend or relative 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 different emotions, including numbness, disbelief, anger or guilt. 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 to family or friends about how you are feeling may help. But you might prefer to talk to someone you do not know. There are organisations that have people you can talk to, such as, Cruse Bereavement Care (see the list of useful organisations later in this information). Your GP can provide support and may be able put you in contact with a local bereavement counsellor. Many people find talking to a counsellor helpful.

Many hospices also provide bereavement support for the families of people who have used their services. Some may offer support even if your family member or friend did not use the hospice.

If you have young children or teenagers, they will also have many different emotions. These may affect their behaviour. There are many organisations that can help you support your children, including Winston's Wish (www.winstonswish.org). 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)

Email supporter.relations@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:

British Association for Counselling and Psychotherapy

Telephone 01455 883 300

Email bacp@bacp.co.uk

www.bacp.co.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

(Mondays and Tuesdays 10am–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.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.

How Macmillan can help you

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 7 days a week, 8am 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 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

Word list

Word (target language)	In English	How to say in English (transliteration of English word)	Meaning
	Bladder		The organ in your body that stores urine until you go to the toilet.
	Bowel		A long tube inside your body that helps you digest food.
	Catheter		A thin plastic tube that comes out of the hole you pee (urinate) from. It is put there so you can pee without getting up to go to the toilet.
	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.
	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 are diagnosed with cancer – a quick guide• Eating problems and cancer• End of life• Financial support – benefits• Financial support – help with costs• 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](https://www.macmillan.org.uk/translations)

Speak to us in [language]

You can call Macmillan free on **0808 808 00 00** and speak to us in [language] through an interpreter. You can talk to us about your worries and medical questions. Just say [language] in English when you call (say “xxxxx”).

We are open 7 days a week, 8am to 8pm.

References and thanks

This information has been written and edited by Macmillan Cancer Support's Cancer Information Development team. It has been translated into [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 Senior Medical Editors Dr Sara Booth Associate Lecturer, University of Cambridge and Emeritus Consultant in Palliative Medicine; and 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**

MAC14363 _Language



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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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