

End of life

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

It tells you about who can help if you are being cared for at home and what to expect in the last few weeks and days of life. It also includes 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 the information upsetting to read. Ask a close relative, friend or a healthcare professional to read it as well. They can support you and you can discuss the information together.

We hope this fact sheet answers your questions. If you have any more questions, ask your doctor or nurse.

We have listed other helpful information from Macmillan at the end of this fact sheet. Most of this is only in English. If you would like to talk to our cancer support specialists in your own language, we have interpreters for non-English speakers.

You can call the Macmillan Support Line free on **0808 808 00 00**, Monday–Friday, 9am–8pm. If you have problems hearing you can use textphone 0808 808 0121, or Text Relay. Or you can visit **macmillan.org.uk**

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How you may feel

Hearing the news that you may be reaching the end of your life can be very difficult. You may have many different feelings. You may feel it is very unfair that this is happening. You may fear what the future will bring. You may also find yourself tearful and sad and not sure of how to cope with these feelings.

It can help to tell your family and friends how you are feeling. You could also talk to your doctor or nurse. Or you can speak to one of Macmillan's cancer support specialists.

You will probably have good days when you feel well and bad days when you have less energy. For many people it's important to plan ahead and make the most of the days when you feel well. You may want to do some nice things with your family or friends. You may also want to do 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 very helpful. Others may question their faith or start to think about whether there is a life after death.

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

You can talk to a chaplain, minister, priest, rabbi or other religious leader even if you're not sure about what you believe. Spiritual and religious leaders are used to helping, and you may find peace of mind.

Planning ahead

Making a will If you haven't made a will it's important to make one. A will is the only way to make sure that your belongings and property go to the people you choose.

Your will is a legal document and you must write it properly. It's usually best to use a solicitor when writing your will. They will make sure your wishes are clear and that they are carried out as you wish. If you need help finding a solicitor you can contact the Law Society (see the end of the fact sheet).

Planning your funeral You may want to plan your own funeral. You can think about whether you want a burial or cremation, what type of service you want, what songs you'd like, and what clothes you want to wear.

It's helpful to talk about your funeral wishes with your family and friends. They may also have ideas that will help them to say goodbye. Once you've decided what you want, write down your wishes so that family and friends can carry them out.

Who can look after you at home

Caring can be hard work, so it's important that you and your carers have the support you need. There are many people who can help.

Your GP

While you're at home, your GP (family doctor) is in charge of your medical care. They can help if you:

- are worried about any changes in your symptoms
- want to talk about what may happen as you become less well
- need advice about how to access nursing care or other help in the home.

District nurses

District nurses (DNs) work closely with GPs. They will visit you at home and manage your nursing needs. They can help you by:

- managing your care – if you need help from other people your DN can contact them
- keeping an eye on and treating any symptoms you may have
- giving injections and changing dressings
- giving advice on how to stop your skin getting sore
- giving advice about toilet problems, such as incontinence and constipation
- supplying equipment, such as a chair cushion or special mattress to help stop your skin getting sore, or a commode, urinal or bedpan
- showing your relatives or carers how to move you and take care of you.

District nurses often work with specialist palliative care nurses (see pages below). They can support you and your carers so that you can stay at home.

Marie Curie Nursing Service

Marie Curie nurses care for people who are nearing the end of their life. They visit people in their home and can provide care overnight, or for part of the day. This allows your carers to have a good night's sleep or a break during the day. The nurses also help you cope with your feelings.

Marie Curie nurses are free. But there is usually a limit to how often you can have one. Your district nurse or GP will arrange a Marie Curie nurse for you.

Community specialist palliative care teams

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

You may be referred to a palliative care team if you need specialist support or care, for example if you have symptoms that you need help with. They can visit you at home.

Hospice at Home care teams

If you wish to die at home, some hospices have nurses and carers who can help care for you in your home. This care is usually provided in the last few weeks of your life. Your community specialist palliative care nurse will arrange it for you.

Social workers/care managers

Social workers can organise help with housework, shopping and cooking, or someone to help with jobs like washing and dressing. If you need this sort of help, they can arrange people to do these jobs for you. You or your doctor or district nurse can contact a social worker to ask them to look at your needs. If you can afford it, you may be asked to pay towards the cost of this help.

Occupational therapists

Occupational therapists can provide you with equipment to help you move around and do things for yourself. They will visit your home to see what equipment you need. This may include stair rails, grab rails and equipment for your shower or bath.

Occupational therapists can also give advice on small gadgets and where you can buy them. For example, things like two-handled mugs and special cutlery.

Your nurse or doctor can refer you to others if you need help. They will also tell you about the types of help available in your area.

The last few weeks of life

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

Emotional changes

You may have different emotions that include worry, anxiety, panic, anger, sadness and depression. It is normal to be worried or anxious when you are facing death. 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 refer you to one.

Physical changes and symptoms

Tiredness and lack of energy It's usual to lack energy and not be able to do things for yourself. You may need to rest a lot during the day. Pace yourself and get help with tasks that tire you out, such as washing and dressing. Don't skip meals. Try to eat small amounts of food regularly.

Sleep disturbance Some people find they can't sleep well at night. There may be many reasons for this. For example, you may be worried or you may have symptoms that

are bothering you. Tell your doctor or nurse if you're not sleeping well so that they can help.

To help you sleep:

- reduce light and noise, and make sure you're not too hot or cold
- have a hot drink before going to bed, but avoid caffeine and alcohol
- avoid using any screen, such as a TV screen or computer screen, for one hour before going to bed
- use a relaxation CD or DVD, or listen to some soothing music before you go to bed.

Pain Tell your doctor or nurse if you have pain. They will help you 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 your pain. Different types of painkiller include:

- simple painkillers, such as paracetamol
- moderately strong painkillers, such as codeine and tramadol
- strong painkillers, such as morphine, oxycodone, fentanyl and diamorphine
- anti-inflammatory drugs, such as ibuprofen
- painkillers for nerve pain, such as gabapentin and pregabalin.

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

Painkillers are usually given as tablets, liquid medicines, or patches stuck onto the skin. If you aren't able to swallow or are being sick, you may be given them by injection or by a small portable pump called a syringe driver. Your nurse or doctor can explain more about this.

Moderately strong and strong painkillers can cause drowsiness, sickness and constipation. Drowsiness usually wears off after a few days. If you feel sick, anti-sickness medicines can help. Sickness usually gets better in a few days. Constipation is common. Most people taking moderately strong or strong painkillers need to take a laxative regularly. Your doctor, nurse or pharmacist can tell you more about this.

There may be simple things you can do to reduce your pain. For example, you can sit or lie in a comfortable position. You can also use warmth or cold on the area of pain.

Feeling sick and vomiting Your illness, and sometimes your medicines, may make you feel or be sick. If this happens, your doctor or nurse can give you anti-sickness drugs. You can take these as tablets, but if you can't swallow tablets you can try other ways. Your doctor or nurse will tell you more about this. If you feel sick try ginger tea, ginger beer or ginger biscuits. Sip fizzy drinks and eat little but often.

Weight loss and loss of appetite You may lose weight, and this can be upsetting for you and your relatives.

As time goes on, you may not feel like eating. Try eating smaller, high-calorie meals more often and nibble on snacks.

As you near the end of your life, you may not feel like eating anything. Don't force yourself to eat. Have small amounts of things you enjoy. You may find nourishing drinks such as Build Up® and Complan® easier to take. You can buy these from chemists and some supermarkets.

Constipation Many people get constipated. This is because they aren't moving around or eating and drinking as much. Some medicines also cause constipation. Tell your doctor or nurse if you feel constipated. They can give you laxatives to help. Drink plenty of fluid.

Breathlessness Tell your doctor or nurse if you are short of breath.

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 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/alarm so that you don't need to 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 Your mouth may become dry or you may get ulcers or an infection. These problems can sometimes be made worse by the medications you're taking. Tell your nurse or doctor if you have mouth problems so that they can treat them.

You can help by keeping your mouth clean. Brush your teeth twice a day using a fluoride toothpaste. Use a soft baby toothbrush if your mouth is sore. If you have been prescribed a mouthwash, use it as directed. Cut down on things that can dry or irritate your mouth, such as caffeine, alcohol or smoking. 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 they may need to be treated in a hospice or hospital. Your nurse or GP will talk to you about this. Once you are feeling a little better, you can usually go home again.

The last few days of life

People will 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 and need help getting from your bed to a chair

- need to spend most or all of the day in bed
- lose interest in things around you and people you care about, such as your close family
- sleep a lot and feel drowsy when you are awake
- feel confused and unsure whether you are dreaming.

Physical care

The people looking after you will need to give you a lot of care. If your family are looking after you and they need help to wash you, your nurse can arrange this. They can also show your family how to move you safely.

Your mouth may become dry and will need to be moistened regularly. Your nurse can get mouthcare sticks (like big cotton buds) and show your carers how to use them. They can also put lip balm on your lips to stop them getting dry and cracked.

To stop your skin getting sore, your carers will need to moisturise it and help you change your position regularly. The nurses can show your carers how to make you comfortable when you can't move yourself.

There may be a lot of time when you don't need to have anything done. You can just 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 be started on new ones.

If you have problems swallowing, your medicines can be given either by injection, by patches stuck on to the skin, or by using a small portable pump (see the section about pain). Your specialist nurse or doctor may arrange for you to have injections of some medicines at home. Your district nurse will give you these if you need them.

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

Breathing changes Fluid can sometimes collect in your breathing passages. This may make your breathing noisy but it won't usually cause you any distress. Your doctor or nurse can give you medicines to help this.

Restlessness Some people become restless. This often happens if they are worried. Medicines can be given to help you relax and sleep. Having a close family member or a religious leader sit, talk or pray with you can also help

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 (catheter) into your bladder to drain away the 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 practices carried out, or prayers read, as you near death. You may also want a spiritual or religious leader with you. Tell your relatives what you would like so that they can make sure this happens.

What happens

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

Usually you become so deeply asleep you can not be woken. You may still be able to hear and know that family and friends are close by. Some people have times when they are awake and can talk, and then 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 and your skin may turn slightly blue. This is normal. Your breathing may also change. It may become slower with longer gaps between each breath. Finally your breathing will completely stop.

In some cultures, there is a belief that the person's mind or soul stays around the body for some time after death. Other people feel that the mind or soul moves on quickly to another place. Some people believe that life just ends and nothing is left of the person's mind or soul.

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. Many people feel relieved that their relative or friend can now be at peace.

Most cultures and religions have practices that they carry out at the time of death. Take your time to carry these out. It may also be important for you to have a spiritual or religious leader with you to help with these.

If you want, you can spend time with the person who has died. Many people like to sit and talk or hold hands, and see the person at peace. You may want to have a relative or friend there to support you.

What your GP will do

If your relative died at home you will need to let their GP or district nurse know. The GP or nurse will come to the house to confirm their death. If your GP comes, they will also give you a medical certificate for the cause of death and a form called 'Notice to informant'. This tells you how to register the death (see below). If a nurse or an 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 your funeral director will do

Once the death has been confirmed, you can contact the funeral director (undertaker). They provide a 24-hour service and can tell you what to do next. Details of funeral directors are in your local phone book or on the internet.

The funeral director will come as soon as you want them to. Let them know if you would like them to help you look after your relative's body at home until the funeral. Or they can take the body to the funeral director's chapel of rest. You can visit the chapel to be with your relative's body if you would like to.

The funeral director will take care of your relative's or friend's body. How this is done may vary for different religions and cultures. It usually involves washing and drying the body, and closing the eyelids and mouth. The funeral director will ask you what clothes you would like them to wear.

Some people want to be embalmed. This is when blood is drained out of the body and replaced with embalming fluid. This preserves the body. It is done at the funeral directors.

Registering the death

Before the funeral happens you need to register the death at your local registrar's office. This has to be done within five days (eight days in Scotland). Details of your local registrar's office are in your phone book. They may also be on the envelope containing the death certificate. Telephone the registrar's office before going to register the death, as you may need to make an appointment.

Planning the funeral

Funerals are a way of celebrating someone's life and saying goodbye.

Your relative or friend may have told you their funeral wishes or written them in their will. If they have, this will help you plan their funeral. In some cultures and religions it's important to have the funeral soon after the death. Tell the funeral director if this needs to happen.

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

How grief might affect you

Grief is normal after the death of someone close to you. You may feel numbness, denial, anger, guilt, a longing for the dead person or depression. Although these feelings can be very strong at first, with time they slowly lessen.

Talking through your feelings with close family or friends can help. There are also organisations, such as Cruse, that run groups for people who are grieving.

Tell your GP if you are struggling with how you're feeling. They can refer you to someone who can support you.

Contact details of useful organisations

Advanced cancer and end-of-life care

Age UK

Tavis House, 1–6 Tavistock Square, London WC1H 9NA

Tel (England and Wales) 0800 169 6565

Tel (Scotland) 0845 125 9732

Tel (Northern Ireland) 0808 808 7575

(Daily, 8am–7pm)

www.ageuk.org.uk

Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

Dying Matters

Tel 08000 21 44 66

www.dyingmatters.org.uk

Promotes public awareness of dying, death and bereavement.

Marie Curie Cancer Care

89 Albert Embankment, London SE1 7TP

Tel 0800 716 146 (Mon–Fri, 9am–5.30pm)

Email supporter.services@mariecurie.org.uk

www.mariecurie.org.uk

Marie Curie nurses provide free end-of life care to people in their own homes, or in Marie Curie hospices, 24 hours a day, 365 days a year.

Counselling and emotional support

British Association for Counselling and Psychotherapy (BACP)

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

Tel 01455 883 300

Email bacp@bacp.co.uk

www.bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services.

You can search for a qualified counsellor at itsgoodtotalk.org.uk

Support for carers

Carers UK

Tel (England, Scotland, Wales) 0808 808 7777

Tel (Northern Ireland) 028 9043 9843

(Wed–Thu, 10am–12pm and 2–4pm)

Email advice@carersuk.org

www.carersuk.org

Offers information and support to carers across the UK. Can put people in contact with support groups for carers in their area.

Bereavement support

Cruse Bereavement Care

PO Box 800, Richmond, Surrey, TW9 1RG

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

Email: helpline@cruse.org.uk

www.crusebereavementcare.org.uk

Has a UK-wide network of branches that provide bereavement support to anyone who needs it. You can find your local branch on the website, at

crusebereavementcare.org.uk/LocalCruse.html

Finding a solicitor

The Law Society for England and Wales

113 Chancery Lane, London WC2A 1PL

Tel 020 7242 1222

www.lawsociety.org.uk

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

The Law Society of Scotland

26 Drumsheugh Gardens, Edinburgh EH3 7YR

Tel 0131 226 7411

www.lawscot.org.uk

Represents solicitors in Scotland and can provide details of solicitors.

The Law Society of Northern Ireland

96 Victoria Street, Belfast BT1 3GN

Tel 028 9023 1614

www.lawsoc-ni.org

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

Related Macmillan information

- Controlling cancer pain
- Controlling nausea and vomiting
- Coping with fatigue

For copies of this related information call free on **0808 808 00 00**, or see it online at macmillan.org.uk

This fact sheet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Chief Medical Editor Dr Tim Iveson, Consultant Medical Oncologist and Macmillan Chief Medical Editor.

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- Department of Health. End of life care strategy – promoting high quality care for adults at the end of life. July 2008.
- National Institute for Health and Care Excellence (NICE). *Improving Supportive and Palliative Care for Adults. The Manual*. March 2004.
- National Institute for Health and Care Excellence (NICE). Opioids in palliative care: safe and effective prescribing of strong opioids for pain in palliative care of adults. May 2012.
- National Institute for Health and Care Excellence (NICE). Quality standard 13. Quality standard for end of life care for adults. August 2011.

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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