



What to expect when someone important to you is dying

A guide for carers, families and
friends of dying people

About this booklet

If you are caring for someone who is in the last stages of life, or who may be soon, this booklet is for you.

It is designed to help prepare you for what to expect in the very last days and hours of a person's life.

It will help to answer three questions that you may have already asked, or are likely to ask at some point:

- 1. What happens when someone is dying? (page 3)**
- 2. What kind of care can a dying person expect to receive, and what kind of support can I, as someone important to the dying person, expect to receive? (page 11)**
- 3. Where can I turn for help if I am concerned about someone who is dying? (page 18)**

This booklet covers the main things you should know on these questions, and aims to point you in the right direction.

The final days of life are precious days, often remembered in detail by those who live on, and the priority is to ensure a peaceful and comfortable death with the right level of support for you and the person you are caring for.

Symptoms and emotions in the final days are often similar whatever the underlying illness – whether it is cancer, heart disease, lung disease or any other chronic condition.

If you have been involved in care up until the final days, then you may want to stay involved or you may want to step back and let others perform the physical care. You are part of the caring team and your voice should always be heard, and decisions shared.

What happens when someone is dying?

You may wonder what the dying process involves – what actually happens in the very last days and hours of a person's life?

This process is unique to every single person. It is not always possible to:

- know for sure that a person is in the last days of life
- predict exactly when a person will die
- know exactly what changes the person you are caring for will experience when they are dying.

There are certain bodily changes that signify a person is likely to be close to death. It is normal for these signs to come and go over a period of days, and if they do go, this does not usually mean that the person is recovering.

Some of these changes may be distressing, but the information below may reassure you that many of these changes are not unusual, and suggest how you can help or seek guidance. As a carer, if any of these signs do start to overwhelm or distress you, you may wish to take a break and leave the bedside for a period.

It's important to think about your own feelings as well as those of the person you are caring for.

Changes in the last days of life

Signs that a person may be dying

The person's appetite is likely to be very reduced

They may no longer wish to eat or drink anything. This could be because they find the effort of eating or drinking to be too much. It may also be because they have little or no need or desire for food or drink.

Eventually, the person will stop eating and drinking, and will not be able to swallow tablets.

Should I be worried?

If a person stops eating or drinking because of their reduced appetite, this may be hard to accept, but it is a normal part of the dying process.

If they stop drinking, their mouth may look dry, but this does not always mean they are dehydrated.

It is normal for all dying people eventually to stop eating and drinking.

Is there anything I can do to help?

If the person is conscious and they want something to eat or drink, you can offer sips, provided they can still swallow.

You can give some comfort to a person with a dry mouth by:

- offering a drink through a straw (or from a teaspoon or syringe)
- moistening the mouth with a damp sponge – special kinds of sponge are available for this purpose (the person may bite on this at first, but keep holding it, as they will let go)
- placing ice chips in the mouth
- applying lip balm.

The person's breathing may change

As a person's body becomes less active in the final stages of life, they need less oxygen, and their breathing may become shallower. There may be long pauses between their breaths.

Sometimes the person's breathing may also make a noise, commonly known as "death rattle". This is likely to be because they are not able to re-absorb or swallow the normal fluids in their chest or throat, which can cause a rattling sound.

In the very last moments of life, the person's breathing pattern may change. Breaths may become much slower and quieter before they stop altogether.

Should I be worried?

A change in the breathing pattern is a normal part of the dying process. If the person is anxious, their breath rate may increase a little.

The rattling sound may be upsetting to hear, but it does not seem to cause any distress to the dying person. It can be a bit like snoring – which affects those who hear it more than the person who is making the sound. The person does not usually need extra oxygen at this stage.

Is there anything I can do to help?

If the person is anxious, sitting with them so that they know you are there may help to reduce their anxiety. Breathlessness can be frightening – a small fan and an open window can help.

If the breathing is very rattly, it may be helpful to change the person's position so that they are on their side if they agree or do not seem too disturbed by being moved. You can ask to be shown the best way to move the person – ask about sliding sheets.

The doctor or nurse may also suggest medication which may help to reduce the fluids in their chest and throat. This is not always needed, and it does not always make a difference.

The person may become much sleepier

The person is likely to spend more time sleeping, and will often be drowsy even when they are awake.

They may also drift in and out of consciousness. Some people become completely unconscious for a period of time before they die – this could be short, or as long as several days.

Should I be worried?

It is normal for a dying person to sleep more. They may generally become less interested in what is going on around them, and have less energy to take part, but this does not necessarily mean they are no longer hearing what you say to them.

Is there anything I can do to help?

It is important to remember that, even when the person is or appears to be sleeping or resting, they may still be able to hear you. Do not feel that you need to stop communicating with the person. You might want to carry on speaking quietly and calmly to them. You could also try letting them know you are there in other ways. For instance: holding their hand, reading to them, or playing their favourite music.

The person may become more restless and agitated

This may happen in the last few days of life, though the person may become more peaceful again before they die.

Sometimes they may appear confused and may not recognise familiar faces. They may hallucinate, and see or hear people or things that are not actually there – for instance, they may see pets or people who have died.

Should I be worried?

Restlessness and agitation can be caused by many things. It may be manageable by quiet reassurance and the comfort of people like you who are close to the person, though it may still be distressing for you to see.

Agitation could also be caused by physical problems, like constipation or difficulty passing urine – ask the doctor or nurse caring for the person if you are concerned about this.

If the dying person does not recognise you, this may be distressing for you but it is not a sign that they feel differently about you. More likely, it is that they are unable to clearly distinguish between what is real and what is not – especially if they are a bit sleepy and drifting in and out of full consciousness, rather like what can happen when we are half-awake or half-asleep.

Is there anything I can do to help?

Simply sitting with the person may often help to calm them down.

Keeping things as normal as possible may help comfort the person.

You can also talk to the doctor or nurse, as they can check if there is any treatable reason for this or may be able to offer medication to help settle the person's anxiety.

You can help by:

- speaking clearly and audibly to the person
- telling/reminding them who you are (and being prepared to do so repeatedly)
- keeping their surroundings calm with minimal changes in noise level
- trying not to correct them if they say something wrong, or insist on them getting things accurate, as this may be upsetting for you and for them.

The person's skin may feel cold and change colour

The person's hands, feet, ears and nose may feel cold to the touch (this is due to reduced circulation). Occasionally, a person's hands or other parts of the body may swell a little.

Their skin may also become mottled and blue or patchy and uneven in colour.

Should I be worried?

These changes are all normal parts of the dying process.

If the person's hands swell, please be assured that swelling is not usually painful or uncomfortable.

Is there anything I can do to help?

It may be comforting to put gloves or socks on the person. You do not need to warm them up – but doing so may help you to feel more comfortable.

Gentle massage may help – the nurses may show you how.

The person may lose control of their bladder or bowels

This happens because the muscles in these areas relax and don't work as they did. The person may also have fewer bowel movements as they eat less, and their urine may get darker as they drink less.

Should I be worried?

This may be distressing to see, and you may worry that the person may feel embarrassed.

Is there anything I can do to help?

You can ask a nurse to help by showing you how to:

- keep the person clean and comfortable
- protect the bed.

You can also ask the nurse or doctor for equipment that may be able to help with this, such as incontinence pads or a catheter (a long thin tube that can be put into the person's bladder to drain urine).

The person's eyes are closed

It is important to know that in these final stages, the person may close their eyes often. At some point, they may not open them again. Their eyes may often be half-open, which can be distressing to see.

Is there anything I can do to help?

As they may still be able to hear you, take the opportunity to say the things that are important to you both.

The person's final moments

Particularly in the last few minutes, the person's face muscles may relax and they may become very pale. Their jaw may drop and their eyes may become less clear.

The person's breathing will eventually stop. Often, the person's body will completely relax.

Sometimes it can be difficult to identify the exact moment when the person died. There may be one or two last gasps a minute or so after what seemed like the last breath. However, you should note down the time as close as possible to the moment they died. This is always a profound moment, even when death has been expected for days. You may suddenly feel overwhelmed with sadness; you may want to be alone, or you may want to ring family and friends.

By this time you may be exhausted with the caring and the waiting, and the relief and finality of the moment of death can take you by surprise.

What happens after the person has died?

Once the person has died and you have noted the time of death, you may wish to respond in a way which is appropriate to you at the time. This could be by:

- carrying out a particular ritual or ceremony, if there is one that is important to you or the person who has died, and your culture or beliefs
- simply sitting and being with the person.

After this, there are practical steps you can take. For useful information on these, you could look at 'What to do after someone dies' pages on the GOV.UK website. It covers the key steps you need to take, especially:

- contacting a member of nursing or medical staff (if they died in a hospice or hospital), or their GP, if they died in their home or care home
- registering the death (which must be done within 5 days, or 8 days if you are in Scotland)
- arranging a funeral.

What kind of care can a dying person expect to receive? What kind of support can I, as someone important to them, expect to receive?

Dying people have a right to the same high quality of care as people who have illnesses that are curable. The NHS is intended to be there to support us **“when we cannot fully recover, to stay as well as we can to the end of our lives”**. (a quote from the NHS Constitution).

There are likely to be lots of different people involved in the person’s care. Some of these will be NHS health and care staff, whilst others may be from separate organisations like social care agencies, hospices, or other charities.

When somebody is at home, often the people most involved in their care will be their family, friends and others who are close to them. Their GP has overall responsibility and district or community nurses are usually involved.

There are five important priorities for the care and support that dying people and their carers can expect. They apply wherever the dying person is being cared for – whether this is at home, in a hospice or care home, or in hospital.

1. The person’s situation must be recognised, and reviewed regularly.

The person must be seen by a doctor if their condition gets worse unexpectedly. The doctor must judge whether anything can be done to improve the person’s condition. If it can, and the person wants such attempts to be made, they must make sure that this is done quickly.

When the doctor believes that the person will die very soon, they must communicate this to the person if appropriate, as well as anyone that the person has said is important to them. This is likely to include you.

It is important to remember that the doctor may not be able to be sure that the person will die very soon, and they cannot know exactly when this will happen, but they must judge the situation to the best of their ability and communicate this judgement.

2. There should be sensitive communication between the dying person, those close to them, and the staff involved in their care.

The staff involved in the person's care must make time to talk to them, and to you. You can expect them to be open and honest, and clear in what they say.

Some members of staff find it difficult to be open and honest when talking about the care of dying people. If this happens, you could help them by saying what it is you already know and what else you want to know now.

Try asking specific questions that are on your mind. For example: "I'd like to know if my wife is going to be in more pain, and if there's anything you can do to reduce that

3. The dying person and those important to them should be involved in the decisions about how they are treated and cared for, to the extent that the dying person wants.

Staff who are caring for the dying person should find out what the person wants, as far as possible, when it comes to their treatment and their care. For example, they may have written down their wishes ahead of time (sometimes called a 'living will' or 'advance statement').

There may be a document called an Advance Decision to Refuse Treatment (ADRT), a legally binding document made in advance to say what treatments the person does not want. Hopefully the question of whether to restart the heart once it has stopped (resuscitation) will have been discussed, and a form will have been completed to stop this from happening. This is often called Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR).

Staff should also find out who the person wants to be involved in decisions about their care and to what extent. They may want you as their carer, for instance, to help decide about day-to-day things, like their food and drink, and/or their treatment.

The doctor responsible for the person's care must make sure these wishes are noted. If he or she decides that the person is not mentally capable of making such a decision at the time, a decision must be taken in their best interests – consulting people that the dying person has identified as important to them and other members of the care team. If the person has an advance statement in place, this should also be consulted to make a decision which takes into account the wishes and preferences they previously stated.

Staff must make it clear to you whether they need you to help make a decision about the person's care, or are simply informing you of the situation. If the person is not able to make or express a decision for themselves, and has identified you in an official 'Lasting Power of Attorney' (LPA) document, you will be able to make most decisions which are in their best interests on their behalf (this is an LPA for health decisions – which is separate from the LPA they may have completed for financial decisions).

They will need to have made this arrangement whilst they still have mental capacity to do so (please note that the processes and terminology used in Scotland and Northern Ireland are different, you can find more information about these by visiting www.gov.uk/power-of-attorney)

If there is no LPA, you can still expect that staff will discuss decisions with you and use your views to help inform the decision, but they themselves will carry the responsibility for making the decision in the best interests of the person. In that situation, you will not be responsible for making the decision.

4. The needs of the person's family and those important to them should also be met – as far as this is possible.

It is important not to forget about your own needs. Staff should ask you about these, and try to find ways of addressing these needs if possible. You should feel able to tell staff how you are – you may, for example, be feeling sad or tired. Staff should listen to you and let you know where you can access support, or tell you about things that might make it easier for you. This may include information about how you can get bereavement support for you and others (including children) before and after the person has died.

If you are having emotional or psychological difficulties, you may be able to find a support group for carers or family members. You could also ask the doctor (or your own GP) or nurse about counselling or other forms of support that may be available if you think you would find this helpful. Your local hospice may offer carer support, practical advice and bereavement care even if they are not directly involved in caring for the dying person. If you are having difficulty looking after dependents or other family members, you may want to talk to your doctor or nurse who may arrange for you to speak to a social worker.

If a person is dying in hospital, you may want to request a side room to make it easier for you to stay overnight.

5. An individualised plan of care should be agreed and delivered with compassion

An individualised plan should be made (and regularly reviewed) for the care of the dying person. The plan should be consistent with the person's wishes, as far as this is possible.

The plan must pay attention to all of the needs they have and the choices they have expressed, including:

How they are feeling, physically

This includes control of symptoms, including eating and drinking:

- The dying person has a right to food and drink, if they would like this.
- They may decide not to have it, as they may not feel like eating or drinking, or because they are struggling to swallow.
- If the person wishes and would benefit from other ways of receiving food and fluids, this can be discussed with the staff who are caring for them.
- However, these are not usually considered when a person is in the very final stages of life, as the body does not require food or extra fluid at this time. You could also try the suggestions for moistening their mouth on page 4.

If the person is being cared for at home, their GP will be responsible for prescribing their medication. The GP can also advise if there are other ways of giving the person alternative fluids safely if there is a real need.

It is usually helpful to have emergency medications in the house to help with symptoms in the final days. These are often called Just in Case medications and your GP can prescribe these.

How they are feeling, emotionally

- The person's mood or feelings may be affected by their condition.
- They may feel anxious or depressed, for instance, or become angry or upset. They may struggle to come to terms with their condition, or the reality that they are dying.
- Talking to you, or having you talk to them, may be comforting.
- If for any reason this is difficult for you or the person you are caring for, or the person needs further support, their doctor or nurse can help to make sure they receive support.

How they are making sense of the situation

- The person may be asking difficult questions about meaning, belief and faith, and may need support or comfort – whether they would consider themselves to be 'religious' or not. They may be asking questions about the meaning of life or past events, or what is going to happen after they die.
- Many hospitals, hospices and care homes have someone responsible for making sure people's spiritual needs are met. In some places there may be a chaplain or a spiritual care coordinator. Whoever is in either of these roles must be available to anyone who is being cared for, whether they have a religious belief or not.
- The person may have specific needs based on their culture and/or their religion, when it comes to their care in the last days of life. These may be about, for example, how they are cared for or how they would like their body to be cared for when they die.
- These specific needs (if the person has any) should be put into their individual care plan, and should be communicated to care staff as early as possible. Staff should attempt to meet these needs as far as they can.

Plans often also include information about where the person would prefer to die – for example at home – or where they would not want to be. As far as possible, their wishes should be met. However, sometimes things change unexpectedly and make it impossible to fulfil the person’s wishes, or mean that it would be more appropriate to their needs not to do so. For instance, they may have said that they would like to die at home, but their needs could become so complex that a hospice or hospital would be better able to meet them.

This is sometimes inevitable and it is important to try not to feel guilty – the most important thing is that the person is cared for well and with compassion.

It is also important to remember that the person’s wishes may change, especially as they become more unwell. This, again, is normal for people in the last stages of life.

This can be upsetting, but you and the person should be communicated with as much as possible in any situation like this to explain why it might be necessary or more beneficial to do something different to what the person had said they wanted.

Where can I turn for help if I am concerned about someone who is dying?

The information in this guide so far will hopefully help you to feel less worried and more prepared for what to expect when someone is dying.

However, if you have concerns or unanswered questions about the person's care, there are a number of ways you can get help:

People involved in care

Staff who are involved can help you. They have a responsibility to help in lots of different ways, and you should feel able to approach them if you are at all concerned.

Either contact your GP or use the telephone number you have been given by your health care team. Try to find out which services are available during the night in your area.

Practical help

- You may be entitled to some financial support. If this would help, you should enquire at your local Citizens' Advice Bureau or ask the staff where the person is being cared for.
- Carers' organisations (which are available locally in most towns) are also a useful source of information.
- Practical help in caring, such as advice on how to move a person or how to give medication or injections is really important to help your confidence to care. District nurses or palliative nurses can train you in these tasks.
- It might be difficult for the person to get out of bed or stand up, so they might need equipment that will make it more comfortable and safe. There are supplies of equipment such as adjustable beds, commodes or incontinence aids that can be made available urgently – district nurses and hospice teams can advise on these.

Talk to an occupational therapist about what equipment the person needs. A physiotherapist or occupational therapist can also help with the person's breathing.

You do not need to face your concerns alone. You should expect the staff to ask you about your needs and those of the dying person, and to do their best to get you the care and support to meet these needs, or direct you to other people or organisations that can help.

- The way care is provided at evenings, weekends and on bank holidays varies depending on the area where you live. For example, support and care services might include a 24-hour telephone helpline or night-sitting service.
- In particular, it's helpful to know what number you should ring, and what information you should be ready to provide over the phone – for example:
 - » what stage the person is at in their illness (or what you have been told about this)
 - » what medication they have recently taken
 - » when they were last seen by a doctor or nurse
 - » whether they are known to the local hospice service
 - » whether they have an advance care plan and had made prior decisions about treatment, or future admission to hospital.

Where the 'doctor' is referenced here, this means the doctor looking after the person if they are in a hospice or hospital, or the person's GP if they are at home (including care homes).

What are you concerned about?

Does the person I am caring for need medication? If so, which medication, and how do I get hold of it?

- Your GP can give information about this, and prescribe it. If the person is in hospital or a hospice, the doctor looking after them can discuss medication with you.
- The pharmacist can also give information about different medications.
- The person's doctor can also suggest using alternative ways of giving the medicine if the person has difficulty swallowing or keeping it down.

The person has experienced some kind of physical change

- Look at pages 4 – 9 of this booklet.
- Talk to the nurse or doctor looking after the person to find out what they think is happening.

The person feels sick or is vomiting

- The doctor or nurse will be able to give some anti-sickness (or 'anti-emetic') medication. Sometimes these medications may have to be given as injections under the skin, often using a machine called a 'syringe driver'.
- Apply a cool, damp cloth to the person's forehead.
- Avoid strong smells, such as air freshener, aftershave/ perfume, or smells from cooking.
- Give the person smaller amounts of food rather than large meals.

Will the person's pain get worse as they get closer to dying?

- Not necessarily. You can look out for body language which may tell you if a person is in pain, such as wincing, flinching, clenching their teeth, stiffening of the body or a scrunched up forehead. The person may moan occasionally but this could be just an involuntary sound or caused by a change in breathing rather than because they are in pain.
- You can help by letting the doctor or nurse know as they will be able to check the person and give extra medication to help if needed. If the person had been taking pain killers, usually this will need to be continued. If they cannot swallow, they may need this to be given by injection, possibly using a syringe driver (or pump) described above.

How can I make the person more comfortable?

- The nurse or doctor can give you advice about this.
 - » They can also help by: arranging an assessment of what equipment the person needs
 - » providing equipment for physical care (eg mouth care sticks)
 - » showing you how to use this equipment.
- Talk to an occupational therapist about what equipment the person needs.
- A physiotherapist or occupational therapist can also help with the person's breathing and movement.

The person seems distressed, or is experiencing difficult emotions: they may be feeling angry, scared, guilty or confused

- A chaplain or spiritual care coordinator is trained to help people who are experiencing such feelings. They can provide support for the person who is dying and those who are important to them, whether or not they hold a religious belief.
- If the person does have religious beliefs, they can also receive a visit from their local faith leader.
- A counsellor, social worker or psychologist, as well as a nurse, may also be able to offer support.

Where else can I turn for help?

- The GP or nurse will know of local services.
- Your local hospice or palliative care team can advise on all aspects of care in the last days of life.
- There are also lots of services that provide support for carers, often run by charities. Please see the next page for help on finding services like these in your area.

Organisations that can help

There are many organisations that provide support for people who are at the end of their life, and the people caring for them. The support that is available to you from different organisations depends on where you are based in the country.

For further information, visit the Dying Matters website:

www.dyingmatters.org/overview/need-support

You can find your local hospice and the services it offers from the Hospice UK website: www.hospiceuk.org/findahospice

You can also find out a lot of information through the NHS website: www.nhs.uk

Marie Curie provides care and support for more than 40,000 terminally ill people and their families in the UK each year:
www.mariecurie.org.uk

Sue Ryder support people who are living with a terminal illness, a neurological condition or who have lost a loved one:
www.sueryder.org

My concerns were not addressed. Is there anything I can do?

If you have discussed your concerns with a member of staff, they have a duty to try to address these. In some cases, these concerns are not something the staff can help with – but even then, they should try to direct you to somebody who can help, or at least listen to you with attention. If they did not do any of this or you are not happy with how they responded, you have the right to complain and to have your complaint dealt with.

In the first instance, you should go back to the organisation concerned. This could be a hospital, hospice or care home. By law, they must have a complaints procedure, so you could ask to see this.

If you do not feel that the concerns were addressed, there are other ways of accessing support and help. The diagram on the following two pages shares possible ways you can do this.

Ask the organisation that provided the care for their complaints procedure



You don't need to take any further action

Yes



Make a complaint to the Parliamentary and Health Service Ombudsman*

Yes



Make a complaint to your local council

Yes



Are you satisfied with how the complaint was dealt with?

NO



Yes

You don't need to take any further action



Raise your complaint with the service provider



Are you satisfied with how your complaint was dealt with?



NO

Was the organisation that provided or funded the care an NHS organisation (eg a GP or a hospital)?



NO

Did the local council pay for this care?



NO



Contact the Local Government Ombudsman
(Tel. 0300 061 0614)

* In England (Tel. 0345 015 4033)

In Northern Ireland – Office of Northern Ireland Public Services Ombudsman
(Freephone 0800 34 34 24)

In Scotland – Scottish Public Services Ombudsman (Freephone 0800 377
7330)

In Wales – Public Services Ombudsman for Wales (Tel. 0300 790 0203)

Things you may wish to record:

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About this booklet

This document was produced by Hospice UK, in collaboration with people with experience of a loved one dying, health and care professionals, and representatives from end of life care charities.

About Hospice UK

Hospice UK is the national charity for hospice and palliative care. We believe that everyone, no matter who they are, where they are or why they are ill, should receive the best possible care at the end of their life.

We work with and support hospice and palliative care providers to grow outstanding care for adults and children across the UK, championing the expert and compassionate care they provide.

Following a merger with the National Council for Palliative Care in 2017, Hospice UK leads the Dying Matters coalition, which encourages people to have more open conversations about death and dying, and also to make advance plans for the end of life.

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