



Planning for the final stages

There will come a time when you need to think about the last years, months, weeks, or days of life. Thinking and talking about the end of life can be difficult, so take your time reading this information.

This information is for people with a long-term lung condition who are coming to the end of their life. It's also for those who are close to them, including carers, family, and friends.

If you have more questions or just want to chat, our friends at Marie Curie (www.mariecurie.org.uk/help/support/marie-curie-support-line) provide information and emotional support if you're living with or caring for someone who has a terminal illness. You can also call our helpline on 03000 030 555.

Thinking and planning ahead

Thinking and planning ahead is also called advance care planning. How you plan ahead will be personal to you. But there are some things you may want to consider, particularly regarding how you want to be cared for in the future.

What can I do to prepare for the end of life?

It's important to think about, discuss, decide, and write down your decisions in advance. This is so people know your thoughts and decisions about what you do or don't want. It might be that sometime in the future, you can't tell them yourself.

Talking about these things can be stressful, upsetting or tiring. Don't feel you have to do it all at once. Advance care planning is an ongoing activity that can take time.

Talk to your family and friends, your nurse, your hospice and health care teams and a solicitor if you need to. Set aside time to have these conversations with those close to you. The things that are important to you are more likely to happen if you share your ideas and thoughts.

It can be difficult to know where to start. Here are some questions that you might want to discuss with your family, carers, and health care professionals:

- What matters to me most now?
- What can be done to help me if I get more out of breath?
- Do I want to be admitted to hospital if I get really ill, even if I then die in hospital?
- If possible, where would I wish to die?
- What can be done to support my family and friends?

- Is there anything else I need to do about my will and financial affairs?
- What can be done to reduce any suffering I might experience?
- Are there any specific treatments I don't want?
- How do I feel about organ donation?

We have more guidance on talking to loved ones about death further on in this information.

Palliative care

Palliative care isn't only for those who have cancer – it's available for anyone with a life-threatening illness. Palliative care is not just for the end of life. You can receive palliative care at any stage in your illness. You can have palliative care alongside other therapies, treatments and medicines aimed at controlling your illness.

This care is designed to improve the quality of your life and the lives of those who are close to you. This includes controlling symptoms, such as fatigue, anxiety and breathlessness.

Palliative care also aims to support you and your loved ones emotionally, spiritually and practically before and after death. Talk to your doctor and nurse about your local services that could help you (www.nhs.uk/service-search/other-services/Palliative-care/LocationSearch/1822).

Advance care planning

What's the difference between an advance care plan and advance care planning?

Advance care planning is the umbrella term that encompasses legal documents surrounding your care. It includes an advance decision to refuse treatment (ADRT), lasting power of attorney (LPA) and practical issues, such as your will or plans you have for your funeral.

An advance care plan is a way of expressing your preferences and wishes about care, environment and spirituality. It can be written or verbal, often changes as time goes on and isn't legally binding.

Your advance care planning may include one or more of the following:

- an advance care plan
- an advance decision to refuse treatment (ADRT)
- a lasting power of attorney (LPA)
- practical issues such as your will or plans you have for your funeral.

The next three terms (advance care plan, advance decision to refuse treatment and lasting power of attorney) are used in England and Wales. In Scotland and Northern Ireland, advance decisions are governed by common law. In Scotland, the equivalent of an LPA is a continuing power of attorney, and in Northern Ireland an enduring power of attorney.

At all times your current wishes and decisions about care and treatment overrule any previous documents or decisions. But considering, discussing, deciding and documenting your current wishes is very helpful to make the best decision for those times when you can't say so yourself.

An advance care plan

This is a way for you to write down and tell those who are important to you, including health and social care teams, what you know about your illness, and what is important to you about your care and treatment. It's sometimes called an advance statement or preferred priorities of care (PPC).

It can be used to share your wishes and preferences, as well as help make 'best interests' decisions on your behalf in the future if you are unable to say so yourself. Talk to your doctor or nurse and ask for examples of documents that you can use.

You might wish to ask your doctor, nurse or hospice team to keep a copy of this for their records. You can change your mind at any time and any wishes you write down aren't legally binding.

An advance care plan is different to a will. A will is a legal document used after your death to dictate who inherits your money, property and possessions. An advance care plan isn't a legal document – it's a place to record your wishes and preferences as you become less well.

An advance decision to refuse treatment (ADRT)

This is a decision you can make now to say treatments you do not want under any circumstances in the future. It's sometimes called an advance decision, or a living will.

For example, you may not wish to have a tube feeding you if you have a stroke, even if you may die as a result, or you may not want to be put on a breathing machine called a ventilator. This document is legally binding and is only used if you can't express your wishes yourself and only for decisions about treatments that you describe in the document.

Your ADRT must comply with the legal specifications outlined in the 2005 Mental Capacity Act. Your doctor or nurse should have examples of documents you can use while completing it together. The charity Compassion in Dying has an example form you can fill out online, with suggestions of things to think about (www.compassionindying.org.uk/choose-a-way-to-make-an-advance-decision-living-will)

An ADRT is not the same as an advance care plan. The NHS has more information about ADRT on their website, including the criteria an ADRT must meet to be valid (www.nhs.uk/conditions/end-of-life-care/advance-decision-to-refuse-treatment).

The term 'living will' doesn't have a legal meaning and can be used to refer to either an advance care plan or an advance decision to refuse treatment.

A lasting power of attorney (LPA)

This enables you to give another person the right to make decisions on your behalf. There are two types of LPA:

- Health and welfare - It only comes into force if you lose the ability to tell those who are important to you your preferences and wishes. Anything done under the authority of the LPA must be in your 'best interests'. If you have an LPA for health and welfare an ADRT usually isn't needed, as your LPA can decline treatments on your behalf if they know your wishes.
- Property and financial affairs - With your permission, it can be used as soon as it is registered. The person you nominate will need to show the document, stamped 'validated' on each page, when they act on your behalf.

You have to be over 18 to make an LPA. There are special rules about appointing someone as your LPA, and you must register the forms with the Office of the Public Guardian (www.gov.uk/government/organisations/office-of-the-public-guardian). You can create an LPA online at www.lastingpowerofattorney.service.gov.uk/home. It takes up to ten weeks to register an LPA.

Do not attempt cardiopulmonary resuscitation (DNACPR)

A do not attempt CPR (DNACPR) decision provides immediate guidance to health care professionals about the best action to take should your heart stop.

Talk to your doctor or nurse about what this means. You might find these FAQs from the Resuscitation Council UK useful to read through: www.resus.org.uk/home/faqs/faqs-decision-making-cpr

You could also talk to your health care professional about the ReSPECT process. It's a form that allows for a person's care and treatment preferences known, in the event of a future emergency where they're unable to make or express a wish or concern. You can read more about the ReSPECT form and see an example copy on the Resuscitation Council UK website (www.resus.org.uk/respect). If you live in London, you'll have access to a different system called CMC (Coordinate My Care): www.coordinatemycare.co.uk

Practical issues such as your will or plans you have for your funeral

Your will is usually made through your solicitor, who can also help with completing and registering your LPA. Some people also decide to spend time planning their funeral, such as the music and readings they want to be included.

Does my advance care planning need to be in writing?

Advance care planning doesn't need to be in writing – unless you are making an ADRT or appointing an LPA. However, your family or people who are caring for you might find it helpful if your wishes or preferences are in writing, signed and dated. It's a good idea to give a copy of your wishes to everyone who needs to know, keeping a copy for yourself as well. If you make any changes make sure you tell those who need to know.

Best interests: The 2005 Mental Capacity Act outlines the process of how to make 'best interests' decisions about your care and treatment if you lack the capacity to decide or are unable to say yourself. It applies to all professions – doctors, nurses, social workers, occupational therapists, health care assistants and support staff.

Working out what is in your 'best interests' means taking into account:

- the views of your family, key professional carers and other people you have chosen to act for you
- any information about what your views might have been about the issue at hand, including your earlier advance care planning.

You can read more about the Mental Capacity Act on the NHS website at www.nhs.uk/conditions/social-care-and-support-guide/making-decisions-for-someone-else/mental-capacity-act/

What practical things should I think about?

Practical issues might be the last thing you want to think about towards the end of a life. But you may find it helpful to sort things out, knowing that your family and friends don't have to have the responsibility of making major decisions for you later.

Making a will

A will is a legal document that sets out instructions for who will inherit your money, possessions and property after you die. You can draw up a will yourself, but it is best to get legal help because there are certain rules to follow when writing it. Have a look at our free will guide or contact your local Citizens Advice (www.citizensadvice.org.uk) for a list of solicitors who can help by either writing the will for you, or checking one that you have written. Bear in mind, if you haven't made a will and you and your partner aren't married or in a civil partnership, they won't have an automatic right to inherit. This applies even if you've been together a long time or have children together.

We run a free will writing service (www.blf.org.uk/legacies/use-our-free-will-writing-service) for people in England and Wales, where you can get a basic will written for free by a participating solicitor in your area. There is also the option of writing your will from the comfort of your home - this is also free and online: farewill.com/partner-blf100

Before making your will, it's important to think about:

- what money, possessions and property you have (this is called your estate)
- who you want to give your estate to
- who you want to take care of any children who are under 18
- any wishes you may have about your burial or cremation
- who you want to carry out your wishes and sort out your estate (they are known as the executor of your will).

Putting your affairs in order

It can be helpful to let your family and executor know where they can find:

- your financial records such as your bank, building society, credit card and pension details. You might find it useful to set up a joint bank account with your partner or next of kin to move important direct debit payments onto, so they won't stop when you die.
- important documents such as your passport, insurance details and house deeds.
- how they can access important information stored on your computer or phone. You might want to share your usernames and passwords with one trusted person. The Digital Legacy Association (digitallegacyassociation.org/resources-2) has useful free resources to help you sort out your online assets, like social media, online subscriptions and photos you might have saved on the computer. We have information about staying safe online on our technology for lung health hub at www.blf.org.uk/technology-for-lung-health/technology-guide/the-importance-of-talking-to-others#staying-safe
- details of your gas, water, electricity suppliers and phone contracts as well as any hire or credit agreements.
- funeral plans, including any pre-paid plans. You might have thoughts about how you want your funeral to be. If so, don't be afraid to write them down or let someone know what is important to you.

Organ and body donation

In England, Wales and Scotland, if you haven't registered that you do not wish to be an organ donor, you will be considered to have no objections to becoming an organ donor when you die.

You still have a choice and can register if you do not wish to be an organ donor. When the time comes your family will always be asked, so whatever you decide it's important you let them know. You can find out more about organ donation on the NHS website at www.organdonation.nhs.uk

In Northern Ireland, the current legislation is that a person becomes an organ donor by joining the NHS Organ Donor Register and sharing the decision with their family: www.organdonationni.info/register/online

Deciding to become an organ donor is a personal choice. It's a good idea to take some time to think about what is right for you and tell your loved ones your decision. Having a medical condition doesn't necessarily prevent a person from becoming an organ donor. Even if you are unable to donate some organs, tissue and corneal donation is possible for almost anyone. Read more about who can donate on the NHS website at www.organdonation.nhs.uk/helping-you-to-decide/about-organ-donation/who-can-donate

You might be interested in donating your body for medical purposes when you die. The Human Tissue Authority (HTA) has a useful FAQ page on body donation where you can read more about what this means, how it affects funeral or memorial services and the conditions of body donation: www.hta.gov.uk/faqs/body-donation

Emotions and sharing your thoughts

We know from research and people's personal stories that when approaching death, feelings can range from anger, despair, denial, bargaining, fear and anxiety to peace, acceptance and tranquillity. We don't all feel the same way – you might experience lots of different emotions at different times.

There are different experiences, feelings and emotions you might go through. Some might be comforting, for example finding peace or accepting a situation. But others might be difficult or hard to process, like resolving a conflict. Marie Curie has more information on emotional experiences and concerns on their website you might find useful to read through at www.mariecurie.org.uk/help/support/terminal-illness/preparing/end-of-life-experiences

What can I do to cope?

Everybody has their own way of coping with difficult emotions. Many people find that talking and sharing their feelings and emotions helps. When you talk about how you feel, you may find that you can identify what matters most to you, what your usual coping mechanisms are, and what decisions you might need to make about future. We have more information on talking to loved ones about death further on in this information.

Finding practical ways to cope with how you're feeling might help you in the final stages, to help bring focus and structure into your day. This could be something simple, like writing in a diary or making a list of things you enjoy. You don't necessarily have to do them, just thinking about happy memories could help.

Marie Curie has more information and advice on things you can do to help with emotional pain during the end of life on their website at www.mariecurie.org.uk/help/support/terminal-illness/wellbeing/emotional-spiritual-pain

Dealing with spiritual needs at the end of life

We all have our own traditions, beliefs or questions about our lives. This can be broader than the rituals of specific religions or churches. Towards the end of life, you may become more aware of these feelings, or your beliefs might change. You might want to think and talk about them.

What can you do?

If you have a specific belief system, then the traditions of your religion or faith system can offer support. Talking about your beliefs and thoughts with your faith leader or friends and family might bring a lot of comfort. Your religious advisor may be able to visit you if you're in hospital or in a hospice.

Spirituality might involve thinking and talking about your past and the future, or carrying out personal traditions. You may want to think about and discuss questions such as "Why has this happened to me?" or "What happens next?" Talking about these questions can be very helpful. It's important you can explore your spiritual needs in the last few weeks of your life, if you want to.

If you have specific needs relating to your spiritual or religious beliefs, it's important the people caring for you know. For example, if you have any specific requests about how you'd like your body to be handled after you die.

Talking to loved ones about death

It's not easy to know how to talk about dying and death with your loved ones. These topics can naturally bring up upsetting or uncomfortable emotions, and so it's easy to avoid them.

But it is important to talk about your preferences while you're able to. You might want to discuss what's happening or how your loved ones will cope after you've gone. Or, if someone close to you is dying, you may be struggling to know how to talk about it. This section aims to help you start to have these sorts of conversations with your loved ones.

Age UK has a booklet on talking about death and dying you might find useful to read through and share with loved ones: www.ageuk.org.uk/information-advice/health-wellbeing/relationships-family/end-of-life-issues/talking-death-dying

Talking to loved ones about your death

Whether you have a terminal illness or simply want to start to having conversations about the end of your life, it can be difficult to know how to broach the subject with your loved ones.

It can be useful to have some conversation starters in mind, relevant to what you'd like to talk about. For example:

- "I think I've decided what I'd like to happen to my body after I'm gone. Would you be happy to have a conversation with me about this, so you understand my wishes?"
- "I have some ideas about what I'd like my funeral to be like. Can we have a conversation about my preferences on this?"
- "I think it would be a good idea for me to make a will, so it's ready when the time comes."
- "I've been reading about advance care planning and think it would be a good idea for me to start putting some things in writing. Would you be happy to talk with me about this?"

It can be useful to remember that people might be worried about upsetting you or making you feel uncomfortable, or asking you questions you don't know the answer to. Setting boundaries is important: there may be topics you don't want to talk about with certain people, and that's fine.

There is no right or wrong when it comes to talking about illness and end of life. Some people find it helpful to talk to family and friends. Others prefer to talk to a doctor, nurse, or counsellor. You might like to talk in depth, a little or not at all. Discussing difficult topics helps us to be better prepared for when those things happen. Talking to those closest to us can seem scary, but it's an important way to help process and understand what's happening.

If you don't like to talk about these things, you might want to express yourself in a different way. You could write a diary, blog, story or letter, record a message, or share time with family and friends. The important thing is to identify what helps you most. We have a list of organisations that offer emotional support in our help and support section at [blf.org.uk/support-for-you/end-of-life/further-information](https://www.blf.org.uk/support-for-you/end-of-life/further-information)

You might be worried about how your loved ones will cope after you've gone, but it can be useful or comforting to talk about the future with them. We have more information about the different stages of mourning and life after the death of a loved one further on in this information.

Talking to someone who is in the final stages

Talking about death with loved ones can be difficult, but it's important to have these conversations. By talking about death and dying, you can find out what's important and talk about any worries or concerns. It also helps you and the people around you accept and understand the situation and allows people to feel part of the discussion.

It's also important to understand a person's preferences and discuss practical issues, like wills and organ donation.

It can be extremely difficult to see death approaching for someone you love or care about. But it can be helpful to talk about what is important to your loved one about how they are cared for. We have more information on how to care for someone in the final stages further on in this information.

It can be difficult for the person who is dying to talk openly about it. You may need to wait for signs they want to talk. For example, they might mention things feeling final, or coming to an end. It can be easy to change the subject. But it's important to allow the person who is dying to talk about how they're feeling. Or to let them know you are there and ready to listen, should they wish to talk.

You might be worried you won't know what to say, or that you'll say the wrong thing. So, it can be a good idea to have a conversation starter in mind, such as:

- "I know this is difficult, but I think it might help if we talk about what is happening and how we both feel."
- "Just to let you know, I am here if you ever want to talk."

You may find that they don't want to talk, or that there are things they don't want to talk about with you. Try to not be offended by this – they are likely to be going through a range of emotions.

It's important to remember that sometimes people would prefer not to think or talk about the future. All you can do is your best to make sure the person knows that when they're ready to talk, you'll be there to listen.

How do I talk to children and young people?

Talking to children about death and dying

Young people and children may have questions about what is happening and want to express their thoughts and feelings. Some children, particularly young ones, will need adults to prompt conversations around death and dying. You could do this by talking openly about the person who is dying and if they want to know more about it. Marie Curie has useful page of starting point questions children may ask and suggestions for how you could answer them at www.mariecurie.org.uk/help/support/bereaved-family-friends/supporting-grieving-child/questions-children-ask

They may also have questions about the future. Who will look after them? What will happen at the funeral and can they be involved? Take time to reassure them and offer any emotional support they need.

Don't be afraid to ask for help from your doctor, nurse, or social worker. Schools often have counsellors who can help children who are likely to experience bereavement or who have experienced bereavement. You might also have access to local childhood bereavement services at www.nhs.uk/Service-Search/other-services/Bereavement%20support/LocationSearch/314

It can be important for children to see their loved one after death as it helps them understand the person is now gone. You can address this by asking the child if they would want to see the person after they have died, when the time is felt to be close. This can help with later grieving.

There are lots of books and resources for children experiencing loss before and after a loved one dies. Marie Curie has suggestions for both children and teenagers of books that deal with death and grief at www.mariecurie.org.uk/help/support/bereaved-family-friends/supporting-grieving-child/books-about-death

"My daughter and her family visited us every Sunday. Maggie was 13 and Tom was 9 when granddad died. We had told them that granddad was very ill and that he might not be with us much longer. We also explained he might suddenly have a problem. They were involved in his care - Maggie was in charge of hugs for granddad and Tom turned the oxygen concentrator up and down as asked. They both reminded him very loudly to take his pills at mealtimes.

They visited on the last morning of granddad's life. They both coped well and came to the funeral. Tom did say a year later that he didn't really believe granddad was dead until the funeral. There don't seem to be any long-lasting effects, perhaps because we were so open about what was happening. There are photos of granddad around the house and we often discuss whether he would have liked something and how proud he was of his grandchildren."

What are the physical signs in the last weeks or days?

How can you tell when someone with a long-term lung condition is entering the last stage of life? In this section, we explain the physical signs of the final stages and ways these symptoms can be controlled. We also explain what to expect in the final days.

What are the signs someone is approaching end of life?

As people reach the final stages of long-term lung disease there are often typical physical changes. But it's not always easy to predict when life will come to an end.

Each person's experience at the end of life is different. Experiencing these symptoms doesn't necessarily mean someone is close to death.

Most long-term lung conditions get gradually worse over several years. The most common symptom is feeling increasingly out of breath. Some people's breathing might get worse much more quickly, over weeks or months. This is particularly true of interstitial lung diseases, such as IPF.

For those in the final stages of a lung condition, breathing becomes noticeably worse. After each flare-up, or exacerbation, their lung function doesn't quite get back to the level it was before and breathing becomes more difficult.

Your lungs become less efficient as long-term lung disease develops. Any exertion, even just changing your position, talking, or eating, might make you feel out of breath. It can become uncomfortable to breathe if you lie flat, so you could try sleeping in a fairly upright position. Reduced lung function may result in low levels of oxygen in the blood. This can cause fluid retention in your legs and tummy, which can be uncomfortable. Flare-ups usually reduce oxygen in your blood further and can make these symptoms worse.

Other symptoms might include a troublesome cough, poor appetite, chest pain and disturbed sleep patterns. The most common physical symptoms are:

- feeling more severely out of breath
- reducing lung function making breathing harder
- having frequent flare-ups
- finding it difficult to maintain a healthy body weight due to loss of appetite
- feeling more anxious and depressed.

You, your family, and carers can ask your health care team for more advice and information about what to expect in your particular circumstances.

Controlling symptoms at the end of life

Pain

Pain is a common symptom in any advanced physical disease and can be part of the normal dying process. It can usually be well controlled using the right medications. These medications may include opioids (morphine-like pain killers). You might be worried about having opioids if you or a loved one has a respiratory condition, but they are safe for people with lung disease to use.

You'll be given drugs in a way that causes the least amount of discomfort, pain, or stress. Your doctor may suggest trying a low dose of liquid morphine that is short-acting. This is to see initially how much you need help with your symptoms. If it helps, your doctor might suggest you have a longer acting morphine pill or morphine-like patch.

Breathlessness

Breathlessness might be improved by using inhalers, tablets and occasionally nebulisers. It can be helpful to use a hand-held fan when you feel breathless. The feeling of air on your face can make it feel easier to breathe. But if your breathlessness is more severe and blood oxygen is low, long-term oxygen might improve your breathing and quality of life.

Long-term home oxygen is needed when your lungs can no longer maintain enough oxygen in your blood. This oxygen is normally delivered from a machine that concentrates the oxygen from the air called an oxygen concentrator. You need to use this machine for at least 15 hours a day. The amount of oxygen needed is carefully assessed and monitored and may need to be increased over time. Read more about oxygen therapy at blf.org.uk/oxygen

Oxygen is only available by prescription and is provided by a local oxygen supplier. Normally, your local respiratory team will assess your need for oxygen. Portable oxygen, usually from small cylinders, is also available and allows you to travel and go on outings.

Your GP can only prescribe palliative oxygen. This is for people who are reaching the end stage of life and have low blood oxygen levels.

Oxygen therapy used to treat low blood oxygen may not always relieve breathlessness. If your breathlessness becomes very distressing despite using oxygen, a number of medications are available to reduce the feeling of breathlessness. These include low doses of sedatives such as diazepam or lorazepam, as well as painkillers called opioids such as morphine.

Anxiety and depression

Anxiety and depression can be common if your breathing gets more difficult and can make it feel worse. Loneliness and isolation are also common problems if you are housebound with a long-term lung condition.

If you struggle to leave the house because of breathing difficulties, ask for support from a health care professional. Anxiety and depression may become so severe that they require treatment in their own right.

You may also find relaxation or breathing techniques help to ease your feelings of tension and anxiety. We have more information on breathing techniques online at blf.org.uk/how-to-manage-breathlessness

Fluid retention

Fluid retention can be treated with water tablets called diuretics. Frequent trips to the toilet may become a problem if you feel breathless and have difficulty moving about. Ask your health care professional about using a urinal or commode. Catheters are tubes that allow urine to pass from the bladder out of the body. They can be useful in end of life care, but there are risks of complications including infection and discomfort.

Loss of appetite

Loss of appetite is a common issue and is often a natural part of the disease process. A little of what you fancy can help increase the amount you eat, bring you pleasure and ultimately boost quality of life. If you find swallowing difficult, choose softer, moister foods.

Sometimes, smaller meals plus snacks throughout the day work well. Higher calorie snacks can include cakes and biscuits, cheese, and full-cream yoghurts. Choose nourishing drinks such as full-fat milk, hot chocolate, malted drinks, smoothies, fruit juice and fortified soups. Over-the-counter fortified soups and milkshakes are available in most supermarkets and pharmacies.

If you use oxygen, try using a nasal cannula when you eat. If you use a face mask, remember to replace it between mouthfuls so your oxygen levels don't drop as you eat.

If eating is really difficult, nutritional supplements might help and can be prescribed by your doctor or nurse. You could also be referred to a dietician. You can buy some nutritional supplements over-the-counter but always ask for advice to find the best one for you. Read more about eating well with a lung condition at blf.org.uk/eating-well

Top tips for caring for someone who needs help eating:

- Face the person so they can see you and their food.
- If the person normally wears glasses or hearing aids, help them to put them on. This will help them to see what you're doing and to hear what you're saying.
- Offer smaller meals or portions that don't overwhelm the person.
- Let the person eat slowly. Allow plenty of time for them to chew their food and swallow it. They might need to catch their breath before each mouthful.
- Watch for clues to help you tell when they have finished swallowing. If it's hard to tell, ask the person if they've finished or to open their mouth to see if there is any food left inside.
- For drinks, use a wide cup or glass, so the drinker doesn't have to tilt their head back. You could also use a straw, for cold drinks.
- Don't rush the meal. This could increase the risk of food entering the person's airways.
- Look out for signs of tiredness. If the person is getting sleepy, it is best for them to stop eating even if they haven't finished their meal. This is because people are more likely to cough or choke on food.
- If possible, try and make sure the person waits at least 15 minutes before going back to bed or lying down. This reduces the chances of food and drink coming back up the throat and causing them to choke.

Coughing

Coughing could be a problem. Sit as upright as possible, supported by pillows. There are medicines that can help stop a distressing cough. Your health care team can prescribe them. Coughing attacks and severe breathlessness may also produce incontinence. This can be managed by reducing drinks containing caffeine such as tea and coffee, and also reducing alcohol intake. There are also a number of continence products that can help, including a bladder tube and bag called a urinary catheter. Speak to your health care team about whether this may help.

Hiccups, indigestion and reflux can be difficult to manage if you have a terminal illness. Treatment is available to help manage these symptoms and there are things you or your carer can do to help you feel more comfortable. Marie Curie has more information about this on their website at www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/symptom-control/hiccups-dyspepsia-and-reflux

Fatigue (tiredness) and disturbed sleep

Fatigue (tiredness) and disturbed sleep are common as lung disease progresses. Fatigue may be due to a combination of anxiety, depression, poor sleep, and low-calorie intake. Lack of sleep may also be caused by symptoms, such as breathlessness, pain, and coughing, which disturbs sleep. Napping during the day may also make it difficult to sleep at night. Fatigue may never fully resolve but there are techniques that can help you to manage it and sometimes medications that can help with some of the causes. Talk to your health care professional about the possible causes and how to deal with them.

Flare-ups (exacerbations)

A flare-up may occur if you catch a chest infection. Having a chest infection means you will have a worse cough with discoloured, yellow, or green phlegm and you will feel more breathless. This should be treated promptly and usually improves with antibiotics and a short course of steroids.

If you have severe flare-ups you might be admitted to hospital and may need non-invasive ventilation to help improve the level of oxygen taken into your lungs. This is delivered by a mask and a portable machine that supports breathing by providing air or oxygen under slight pressure.

What should I expect in the last few days?

As the end of life approaches, you might experience a number of physical and emotional changes. These are different for everyone. You might notice changes over weeks, days or even hours. Some of the changes might be the same as signs of a flare-up, so discuss them with your doctor or nurse.

Signs to look out for include:

- Not wanting to eat or drink very much or at all. Swallowing may become difficult
- Losing physical energy, the ability or desire to talk and signs of withdrawing from family and friends.
- Feeling sleepy or drowsy most of the time, being very inactive and eventually becoming unconscious. It is not unusual to stay in bed or a comfortable chair rather than getting up.
- Changes in breathing rate or pattern. As the body becomes less active, the need for oxygen reduces. There may be long pauses between breaths and the tummy may move up and down more than the chest. Breathing in and out might cause gurgling or rattling sounds, because of a build-up of phlegm that can't be coughed up. Remember, this noisy, moist breathing might be more distressing for others than for the person affected. Medication is available that can help to dry up the phlegm.
- Changes in skin colour and temperature. Skin may become pale, moist, and slightly cooler just before death.
- Involuntary twitches. These are normal and don't mean that someone is distressed or uncomfortable. If you notice these it's best to mention them to whichever health care professional is involved at the time.
- Needing oxygen, if it's not already being used, and the support of other medical equipment. This doesn't need to get in the way of physical contact. Don't be afraid to touch and be close to each other.

Use of medical equipment in the final stages

Oxygen therapy might become burdensome in the final days and hours of life. This is because the blowing in the airways can cause soreness and as the person become less aware of their surroundings it can cause distress. If this happens, oxygen therapy can be removed, even if oxygen levels are low. This is with the knowledge that doing so will help relieve discomfort in the person who is dying, rather than contribute towards death.

Overall, the use of medical equipment in the final stages of is focused on comforting the person who is dying and is minimised as much as possible, to disturb them as little as possible.

Your health care professional can also prescribe 'just in case' medicines to keep at home. These are generally injectable medications a community nurse will give you if needed for symptoms like pain or breathlessness, where oral medications aren't the best choice. Sometimes it can be difficult to access medicines quickly at night or weekends. Having a box of 'just in case' medicines means your health care professional can quickly control symptoms if you are in pain or start to feel sick.

How do I care for a loved one at the end of life?

At the end of a person's life, it can help to think and talk about what is important to you and your loved one about how they are cared for. Tell their nurses and doctors about their wishes.

Think about what you could or would like to do. Also consider what support you need as a carer. Think how others can help you, such as doing the shopping or walking the dog, or sitting with your loved one when you need to leave them.

Your caring role may change if the person you care for moves into permanent residential care or a hospice or has full-time care at home. If you lived together, but their circumstances or health mean that you no longer do, it's important to think about how much time you still spend helping the person you care for, even if you now live apart.

You may still devote much of your time to caring from a distance, managing their affairs, and dealing with health care professionals. If you still fall into the definition of 'carer' you may be entitled to help and benefits (blf.org.uk/support-for-you/welfare-benefits/carers)

If the person you care for moves into residential care or a hospice, you should discuss with them and staff how often you can visit.

What practical things can I do to take for a loved one at the end of life?

It's thought hearing is the last sense to go before death, so you can give care and support to your loved one by:

- spending time together and sharing memories and stories
- talking about people you know
- playing music
- listening to the radio or reading together

There are also practical steps you can take, such as:

- moistening their mouth and lips with water, moisturiser, or lip salve (but if they are on oxygen, don't use any petroleum-based products)
- recognising what keeps them comfortable, such as gently moving their arms and legs to reposition them if that seems to help

It can be very comforting to sit with your loved one and keep them company. Don't be afraid to take turns with your friends and family.

Don't worry if the person you care for doesn't seem to respond very much. As the end of their life approaches, weakness, and lack of consciousness increase. It is this, rather than a lack of appreciation for you, that may stop them responding.

What support can health care professionals give me?

Members of the health care team can give advice and offer help with controlling your loved one's symptoms such as pain, breathlessness, or chesty secretions. Your health care professional can also help to provide practical care with equipment to maintain comfort, such as special beds.

Death and dealing with bereavement

When the person you care for dies, you will probably feel a range of emotions. You may feel a great sense of loss when they pass away.

As well as coping with the loss of the person you cared for, you might need to cope with the loss of your caring role.

It might be when the practical arrangements have been made and the funeral has passed that you start to grieve. However, some people experience strong feelings such as loss, grief and mourning before the person has died.

At this time, and throughout your time as a carer, it is important you take time for yourself and seek the help you need.

You may want to share your feelings with family and friends but, equally, you may not feel comfortable doing this. Some people find it easy to talk to a particular person – don't be afraid to let them know how you feel. We have more information about grieving and life after the death of a loved one you might find useful to read further on in the information.

Adjusting to life when your caring role changes

It can be hard to adjust to life when your caring role alters or comes to an end. You may find you have more time on your hands and decide to spend time with your family and friends, take up a new skill or go back to work. You may find that the exhaustion of having been a carer for a long time catches up with you.

Whatever you do, there are practical issues you should deal with promptly:

- **Central government and local authority support** – if you claim carer's allowance or had a carer's assessment or any other financial help towards your caring role, you must inform the relevant authorities that you are no longer a carer. If you lived with someone whose housing was subsidised or provided by the state, and you no longer live with them, the local authority needs to know.
- **GP** – if you told your doctor about your caring role, tell them about any changes.

Carers UK has advice and suggestions about what you can do and how to cope when your caring role changes or ends. Go to www.carersuk.org/help-and-advice/practical-support/when-caring-ends

What do I do at the time of death?

If death occurs in a hospital, care home or hospice, the staff lets the family know what they need to do. If death occurs at home, then the family must inform the GP, register the death and contact the funeral director.

Tell Us Once is a service that lets you report a death to most government organisations in one go: www.gov.uk/after-a-death/organisations-you-need-to-contact-and-tell-us-once
The registrar will give you details when you register a death. The service is not available in Northern Ireland.

Deaths from mesothelioma

Doctors must report some deaths, including mesothelioma, to the coroner. You can read more about deaths from mesothelioma in our separate information at blf.org.uk/support-for-you/mesothelioma/support/end-of-life#coroner

How do I arrange the funeral?

Arranging a funeral may be upsetting, but some people find it plays an important role in adjusting to the end of life and finding closure. There are many options that include both religious and non-religious ceremonies. The funeral director can guide you through the practical and legal arrangements. You can read more about the practicalities of arranging a funeral on the government website at www.gov.uk/after-a-death/arrange-the-funeral

Some people may have taken out a pre-paid funeral plan. This when a person has put money aside to pay for their own funeral in advance.

You could be entitled for help with costs if you need help to pay for a funeral you're arranging. Find out more about Funeral Payments on the government website at www.gov.uk/funeral-payments

Life after the death of a loved one

It's normal to have many emotions after the death of a loved one. There is no timetable for what you should feel or when. You may have strong emotions immediately after they die, or you may not experience these emotions until much later on. Or you could feel grief and loss before your loved one dies.

You may want to share your feelings with family and friends. But, equally, you may not feel comfortable doing this. Maybe you find it easy to talk to one particular person – don't be afraid to let them know how you feel.

Research has suggested there are different stages a person goes through when grieving the death of a loved one. These are commonly accepted to be:

- accept the reality of the loss
- work through the pain of grief
- adjust to an environment where the deceased isn't there
- find a lasting connection with the deceased while continuing to live.

There isn't a particular order you might go through these stages, and you may revisit certain stages over time. The stages will mean different things to different people and it's important to remember that grief is unique for all of us. If you feel you haven't gone through one or more of these stages, it may mean you're still working through the grief process, or that this model of grief isn't right for you.

Your health care team might be able to offer you bereavement support after a loved one's death. Talk to your doctor and nurse about what services and information are available locally at www.nhs.uk/Service-Search/other-services/Bereavement%20support/LocationSearch/314. If you sense that how you are feeling is not right or you are not coping, don't be afraid to talk to your GP. People often need more support.

Glossary

Below are explanations of some of the words used in this information:

Advance care planning:

Thinking about, and planning for, how you wish to be cared for at the end of life.

Advance decision to refuse treatment (ADRT):

This is a written document that states any treatments you wish to refuse in the future. It is only used if you are unable to express your wishes later on.

Advance statement or Preferred Priorities of Care (PPC):

A written document that states what your wishes are for your care and treatment. This can include your preferred place of death and your preferred place of care.

Do not attempt cardiopulmonary resuscitation (DNACPR):

This expresses your wish for doctors to not attempt cardiopulmonary resuscitation if your heart stops.

End of life care:

End of life care is part of palliative care and is for people who are nearing the end of their life. End of life care aims to help you live as comfortably as possible, by managing physical symptoms and getting emotional support for you and those around you.

'Just in case' medicines:

This describes medicines that your health care professional prescribes for you to keep at home so that they can easily be given to you at short notice.

Lasting Power of Attorney (LPA):

This gives another person the right to make certain decisions on your behalf.

Palliative care:

Palliative care is for people living with a terminal illness. It is care designed to improve the quality of the person's life and the lives of those who are close to them. You can receive palliative care at any stage in your illness. You can have palliative care alongside other therapies, treatments and medicines aimed at controlling your illness.

Where can I get more help?

Thinking and talking about the end of life can be difficult. Take your time. You might want to talk to your family, friends, health and social care professionals about what's in this information.

Information, advice, or emotional support

The following organisations provide more information relating to end of life. There's information for people who are approaching end of life, and information for people who are grieving. Some have helplines you can call if you'd like to talk to someone.

Age UK – produces a range of information about the end of life.

www.ageuk.org.uk

0800 678 1602

Carers UK – provides support for carers.

www.carersuk.org

0808 808 7777

Cinnamon Trust – a network of volunteers that provides dog walking and pet fostering while owners are in hospital.

cinnamon.org.uk

01736 757900

Cruse Bereavement Care – information and support for bereaved people.

www.cruse.org.uk

0808 808 1677

Child Bereavement UK – support for bereaved families.

www.childbereavementuk.org

0800 02 888 40

Dying Matters - helps people talk more openly about death, dying and bereavement, and make plans for the end of life.

www.dyingmatters.org

08000214466

Hospice UK –for information about local hospice care.

www.hospiceuk.org

020 7520 8200

Macmillan Cancer Support – provides information, advice, and support for people with cancer and their families.

www.macmillan.org.uk

0808 808 00 00

Marie Curie - provides information and emotional support if you're living with or caring for someone who has a terminal illness.

www.mariecurie.org.uk/help/support/marie-curie-support-line

0800 090 2309

Natural Death Centre – support for those dying at home.

www.naturaldeath.org.uk

01962 712 690

Samaritans - provides emotional support to anyone going through emotional distress or struggling to cope.

www.samaritans.org

116 123

Legal support

Resources and places of support if you need help with legal matters relating to end of life.

Citizens Advice Bureau – provides free advice on benefits, legal rights, and NHS services.

www.citizensadvice.org.uk

GOV.UK – practical help about death and dying, including dealing with a death abroad, registering a death, a guide to sorting out property and death, and bereavement.

- deaths in England or Wales (www.gov.uk/after-a-death)
- deaths in Scotland (www.mygov.scot/when-someone-dies)
- deaths in Northern Ireland (www.nidirect.gov.uk/information-and-services/births-deaths-marriages-and-civil-partnerships/death-and-bereavement)

The Law Society – provides a useful guide to writing a will and lists of specialist solicitors in your area.

www.lawsociety.org.uk

020 7242 1222

Office of the Public Guardian – help for people to plan ahead, and register lasting powers of attorney across the UK.

- England and Wales 0300 456 0300 (www.gov.uk/government/organisations/office-of-the-public-guardian)
- Scotland 01324 678300 (www.publicguardian-scotland.gov.uk)
- Northern Ireland 028 9072 5953 (www.justice-ni.gov.uk/topics/courts-and-tribunals)

British Association for Counselling and Psychotherapy (BACP) – provides a list of qualified psychotherapists and counsellors.

www.bacp.co.uk

01455 883300

Get in touch with us to find support near you.

Helpline: **03000 030 555**

Monday to Friday, 9am-5pm

Ringing our helpline will cost the same as a local call.

helpline@blf.org.uk

blf.org.uk

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blf.org.uk/end-of-life

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We value feedback on our information. To let us know your views, and for the most up to date version of this information and references, call the helpline or visit **blf.org.uk**