



# Planning for the final stages of a long-term lung condition

There will come a time when you need to think about the last years, months, weeks or days of life. It could be your own life or the life of someone you know and love.

This booklet 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 their carers, family and friends.

This information answers questions such as

- How can I plan for the end of life?
- What are the signs and symptoms of the end of life?
- What care will be provided?

It also explores emotional and spiritual questions.

Thinking and talking about the end of life can be difficult. Take your time reading this booklet. Talk to your family, friends, health and social care professionals. Think about and discuss what's most important to you and decide who you want to talk things through with.

## 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.

"Over the past few days I have been doing a great deal of thinking, such as making sure that I am listed as DNR [do not resuscitate], you even have an opportunity to put, in writing, your preferences for care and where it should be for each stage. For example my own is going to be that while I am mobile and not bed ridden I will stay at home. However the minute I am confined to my bed and unable to do much for myself, I have requested the final stages should be in hospital or hospice. It also gives me time to sort out all the internet stuff, my wife is not computer literate so my son is going to have to take it all over.....banking, repeat meds and so on.....keeps you busy just thinking!"

**Alan, from our web community, has chronic obstructive pulmonary disease (COPD)**

## What can you do?

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.

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

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Talk to your family and friends, your favourite nurse, a doctor, or your hospice, and health care teams. Give yourself 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.

"This week the doctor, the nurse, the oxygen supplier and my carer have all talked about the days to the end and how it will be managed. The drugs are in place and regimes agreed upon that will hold me secure through the difficult days leading to those final moments."

David was in the final stages of idiopathic pulmonary fibrosis (IPF)

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?
- Would I agree to resuscitation if my heart or lungs stopped working?
- Where would I like to be cared for towards the end of my life?
- 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?

You can record your choices in your advance care plan.

## Palliative and hospice care

Palliative and hospice care are not only for those who have cancer – they're available for anyone with a life-shortening 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.

## Your advance care plan

An advance care plan is different to a will. It's a way to tell others what's important to you and how you would like to be cared for if you're unable to tell them yourself.

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.

**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.

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

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

- an advance statement\*: 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 can be used to share your wishes and thoughts, 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.

- an advance decision to refuse treatment (ADRT)\*: This is a document where you write down in advance your decisions about any treatments you wish to refuse in the future. For example, you may not want to be given antibiotics for an infection if you are only expected to live for a few days. Or if you are being fed through a tube or drip, you may not want this to continue if your condition got worse. This document will only be used if you can't express your wishes yourself and only for decisions about treatments that you describe in the document.
- It is helpful for those who are important to you, including health and social care teams, in order to make the 'best interests' decisions on your behalf in the future (if you are unable to say so yourself at the time). Your ADRT must comply with the legal specifications outlined in the 2005 Mental Capacity Act. Talk to your doctor or nurse and ask for examples of documents that you can use.
- 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:
  - 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.
  - 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'.

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

\*These terms 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.

- do not attempt cardiopulmonary resuscitation (DNACPR): If your heart stops, what decision should be made about trying to restart it? Talk to your doctor or nurse about what this means and ask for examples of documents that are used.
- 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.

The term 'living will' doesn't have a legal meaning, and can be used to refer to either an advance statement or an advance decision.

"A month or so after my husband was told he probably had up to a year left, a doctor from the local hospice came to see us at home. Our son, who was on a visit from Canada, and our daughter were also there. My husband discussed his wishes. He was clear he wanted to die at home and 'not know anything about it'.

The doctor helped him make out an advance decision which set out what he didn't want in way of intervention, and agreed a Do Not Resuscitate Notice. We also kept medication in the house that doctors could give my husband to ensure he would not be in pain or distressed at the end.

I arranged a lasting power of attorney covering health and welfare so that either I or my daughter could make decisions about his care if he could not tell us his wishes himself. We told relatives and friends the situation and their support was invaluable."

**Gill's husband died a few years ago**

## 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. You may want to think about:

### Making a will

By making a will, you decide what happens to everything you own. 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. Contact your local Citizens Advice 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, that unmarried partners, including same-sex couples who don't have a civil partnership, have no right to inherit if there is no will.

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

- what money, possessions and property you have, 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
- important documents such as your passport, insurance details and house deeds
- important documents such as your passport, insurance details and house deeds
- 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

## Become an organ donor

You may wish to donate your organs to someone who really needs them. You can give advance consent by joining the organ donor register. Even if you have a lung condition, you could still be eligible to donate certain organs.

Register in:

England at [organdonation.nhs.uk](https://organdonation.nhs.uk)

Scotland at [organdonationscotland.org](https://organdonationscotland.org)

Northern Ireland at [organdonationni.info](https://organdonationni.info)

Wales has an opt-in system, which means that if you haven't registered your decision at [organdonationwales.org](https://organdonationwales.org), you will be treated as having no objection to being an organ donor.

## Emotions and sharing your thoughts

It's normal to experience many emotions in the final stages of a long-term lung disease. Your family and friends may also experience similar emotions.

We know from research and people's personal stories that 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.

"No two people are the same and for each of us our experience is individual. Anxiety is one of the final problems I face. I do feel anxious. Boy and how! It's the feeling that bounces around like a naughty child and gets in the way."

David described what it was like for him in the final stages of idiopathic pulmonary fibrosis (IPF)

## What can you do?

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 medical care.

You might find it helpful to talk to family and friends. Or you might prefer to talk to a doctor, nurse, or counsellor. You might like to talk in depth, to talk a little or not at all. 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.

## How do I talk to children and young people?

It can be difficult to know how to talk about the end of life with children or grandchildren. Some people worry that they may frighten or upset them.

### What can you do?

Young people and children may have questions about what is happening and want to express their thoughts and feelings. 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. There are a lots of books and resources for children experiencing loss before and after a loved one dies. You might also have access to local childhood bereavement services.

Marie Curie has suggestions for both children and teenagers of books that deal with death and grief. See their reading lists at: [mariecurie.org.uk/help/support/bereaved-family-friends](http://mariecurie.org.uk/help/support/bereaved-family-friends)

“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.”

**Gill's husband died a few years ago**

## How we make sense of the meaning of our lives

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 beliefs, and you may wish to think and talk about them.

### What can you do?

If you have a specific belief system, then the traditions of your church 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.

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.

You might also want to tell someone, such as a health care professional, trusted friend or religious leader, something that you have never told anyone before, but feel that you need to share before you die.

## What are the physical signs and care 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? 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. Also, the presence of one or more of these symptoms doesn't necessarily mean someone is close to death. They might have been part of your life for months or years before.

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
- 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

- Breathing 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](http://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 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.

If your mood improves, your breathing and mobility can often improve too.

Sometimes, simple relaxation can help when you feel anxious or frightened. You could try thinking of a place that makes you feel happy or practising new ways to control your breathing. Your nurse or physiotherapist can help you with this. We also have information on breathing techniques at [blf.org.uk/breathlessness](http://blf.org.uk/breathlessness)

- Fluid retention can be treated with water tablets called diuretics. These reduce swelling. 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.
- Loss of appetite is a common issue. As your breathing gets worse, you can lose weight as your breathlessness makes swallowing difficult.

A little of what you fancy can help increase the amount you eat. 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.

You can also add extra calories to food by:

- adding sugar to hot drinks and cereals
- adding butter to vegetables
- pouring custard and cream over fruit
- adding cream to breakfast cereals, mashed potatoes, scrambled eggs, puddings and soups
- using more butter or mayonnaise in sandwiches

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](http://blf.org.uk/eating-well)

## Top tips If you care 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 size meals 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 cup with a big mouth opening, so the drinker doesn't have to tilt their head back.
- Don't rush the meal, this could increase the risk of food entering the 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.
- 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 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 distressing and embarrassing incontinence. This can be managed by reducing drinks containing caffeine such as tea and coffee, and alcohol. 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 how to get them.
- Chest pain is usually less common with lung diseases but can be treated with painkillers. For severe pain or breathlessness that do not respond to other measures, a syringe pump that gives a constant dose of strong painkillers under the skin can be useful.
- 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. Talk to your health care professional about the possible causes and how to deal with them.

- 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 short of breath. 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 but sometimes you can stay at home supported by specialist respiratory teams. If the flare-up is severe, hospital patients may need non-invasive ventilation to help improve the level of oxygen taken into the 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. There may also be an increase in chesty or respiratory secretions and noisy, moist breathing because of a build-up of phlegm that can't be coughed up. Remember, this might be more distressing for others than for the person affected. Medication is available that can help to dry up the phlegm
- 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
- 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

Your health care professional can also prescribe 'just in case' medicines to keep at home. 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?

It can be difficult to see death approaching for someone you love or care about. During this time, 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.

“She required more and more care, help and support. This was given willingly; indeed it made us closer and was a privilege. But it was challenging, frightening, exhausting and isolating.

She became ever more frail and, in the final two weeks, bed-bound. She was comfortable in her own bed surrounded by me, her youngest sister and her cats. She would listen to her Kindle and complete crosswords. She wanted minimal interference from anyone, her wishes were respected. The intermediate care team, particularly the physiotherapist, was a support for us more than my mum.”

**Penny cared for her mother**

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.

We think that 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
- listening to their worries and concerns
- 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
- 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 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.

## Sarah, a palliative care nurse, gives her perspective:

I know that thinking and talking about the end of your life, or the life of someone dear to you, can be really difficult. In this booklet, Alan, David, Gill and Penny tell us a lot about what is most important. Nurses, doctors, physiotherapists and the whole team are there to help you and your family to discuss and plan for possible future situations.

These are the things that I think about in such conversations:

- What do you know, or want to know, about what might happen in the future?
- What is most important to you now, or in the future?
- Is there anything that you are worried or scared of?
- What have you discussed with your family or friends?
- What help do you want in discussions, decisions or preparing documents?
- What support would be helpful for your family?
- Is there anything that you want to do or achieve before becoming more ill?
- How else can we help?

Most importantly, I think: what do I know, or have to find out, about what matters to you?

## What do I do at the time of death?

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

## Deaths from mesothelioma

Doctors must report some deaths, including mesothelioma, to the coroner.

In England and Wales, the coroner will decide whether a post mortem or inquest is needed and sign the death certificate. Procedures in Scotland and Northern Ireland are different. For more information, call our helpline on 03000 030 555 or visit [blf.org.uk/mesothelioma-end-of-life](http://blf.org.uk/mesothelioma-end-of-life)

What to do after a death In England or Wales, a booklet produced by the Department for Work and Pensions, is useful and can be found at [gov.uk/government/publications/what-to-do-after-a-death-in-england-or-wales-leaflet](http://gov.uk/government/publications/what-to-do-after-a-death-in-england-or-wales-leaflet). What to do after a death in Scotland is available at [scotland.gov.uk](http://scotland.gov.uk) and there is a checklist relating to deaths in Northern Ireland at [nidirect.gov.uk](http://nidirect.gov.uk).

Tell Us Once is a service that lets you report a death to most government organisations in one go. The registrar will give you details when you register a death.

The service is not available in Northern Ireland.

## How do I arrange the funeral?

Arranging a funeral, either for yourself or a loved one, may be upsetting, but some people find it plays an important role in adjusting to the end of life and finding closure. Maybe you have already had 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.

There are many options that include both religious and non-religious ceremonies. The funeral director can guide you through the practical and legal arrangements.

Some people may have taken out a pre-paid funeral plan, or may be entitled to a funeral payment from the Department for Work and Pensions. Similar arrangements apply in Scotland and Northern Ireland.

## Life after the death of a loved one

It is 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.

“Although the death of my mum was inevitable it still came as a shock to me. Despite everyone around me trying to say that her time was nearing the end it still shook me to the very core, and I struggled to make sense of events.

After my mum's death I experienced tiredness like no other, it's not like after a day's hard work, or a late night but an ongoing indescribable tiredness which sometimes makes living life a struggle. You compensate by trying to become overtly organised but struggle to maintain this. I became forgetful and found maintaining focus difficult.

Small steps - taking an hour, a day, a week and a month at a time - that's the way forward. Bad days, better days, go with flow of how you feel. Talking about events over and over again is helpful - her final days, the funeral - that is important – it helps make sense of events.”

**Penny's mother died a few years ago**

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.

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. 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 a little bit more support.

## Glossary of terms

Below we explain some words used in this information.

**Advance care planning:** Thinking about, and planning for, how you want to be cared for at the end of life.

**Advance decision to refuse treatment (ADRT):** A written document that states any treatments you want 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 future care and treatment. This can include where you would like to die and where you would like to be cared for.

**Do not attempt cardiopulmonary resuscitation (DNACPR):** This states your wish to not have doctors attempt cardiopulmonary resuscitation if your heart stops.

**'Just in case' medicines:** These are medicines your health care professional prescribes 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 where a cure is no longer possible. It is care designed to improve the quality of the person's life and the lives of those who are close to them.

## Further information

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 booklet. These organisations give you further help and information.

**Age UK** – produces a range of information about the end of life  
0800 169 6565  
[ageuk.org.uk](http://ageuk.org.uk)

**British Association for Counselling and Psychotherapy (BACP)** – provides a list of qualified psychotherapists and counsellors  
01455 883300  
[bacp.co.uk](http://bacp.co.uk)

**Carers UK** – provides support for carers  
020 7378 4999  
[carersuk.org](http://carersuk.org)

**Cinnamon Trust** – a network of volunteers that provides dog walking and pet fostering while owners are in hospital  
01736 757900  
[cinnamon.org.uk](http://cinnamon.org.uk)

**Citizens Advice** – provides free advice on benefits, legal rights and NHS services  
[citizensadvice.org.uk](http://citizensadvice.org.uk)

**Cruse Bereavement Care** – information and support for bereaved people  
0844 477 9400  
[cruse.org.uk](http://cruse.org.uk)

**Child Bereavement UK** – support for bereaved families  
0800 02 888 40  
[childbereavementuk.org](http://childbereavementuk.org)

**Dying Matters** – helps people talk more openly about death, dying and bereavement, and make plans for the end of life  
08000214466  
[dyingmatters.org](http://dyingmatters.org)

**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 [gov.uk/after-a-death](http://gov.uk/after-a-death) for deaths in England or Wales

[scotland.gov.uk](http://scotland.gov.uk) for a booklet What to do after a death in Scotland.

[nidirect.gv.uk/articles/what-to-do-when-someone-dies-checklist](http://nidirect.gv.uk/articles/what-to-do-when-someone-dies-checklist) for deaths in Northern Ireland

**Hospice UK** –for information about local hospice care  
020 7520 8200  
[hospice.org](http://hospice.org)

**The Law Society** – a guide to writing a will and specialist solicitors in your area  
020 7242 1222  
[lawsociety.org.uk](http://lawsociety.org.uk)

**Macmillan Cancer Support** – provides information, advice and support for people with cancer and their families  
0808 808 00 00  
[macmillan.org.uk](http://macmillan.org.uk)

**National Council for Palliative Care** – promotes the extension and improvement of palliative care services  
020 7697 1520  
[ncpc.org.uk](http://ncpc.org.uk)

Get in touch with us to find support near you.

Helpline: 03000 030 555

Monday to Friday, 9am-5pm

Ringling our helpline never costs more than a local call and is usually free, even from a mobile.

[helpline@blf.org.uk](mailto:helpline@blf.org.uk)

[blf.org.uk](http://blf.org.uk)

**Natural Death Centre** – support for those dying at home

01962 712 690

[naturaldeath.org.uk](http://naturaldeath.org.uk)

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  
[gov.uk/government/organisations/office-of-the-public-guardian](http://gov.uk/government/organisations/office-of-the-public-guardian)

Scotland  
01324 678300  
[publicguardian-scotland.gov.uk](http://publicguardian-scotland.gov.uk)

Northern Ireland  
028 9072 5953  
[courtsni.gov.uk](http://courtsni.gov.uk)

**Samaritans** - provides emotional support to anyone who is going through emotional distress or struggling to cope  
Call: 116 123  
[samaritans.org](http://samaritans.org)

British Lung Foundation  
73-75 Goswell Road  
London EC1V 7ER

Registered charity in England and Wales (326730), Scotland (038415) and the Isle of Man (1177)



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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](http://blf.org.uk)