

Caring for someone with a lung condition



This information gives practical help if you're caring for someone with a lung condition and tips for caring from past and present carers.

You might also want to read about help and welfare benefits for carers at [blf.org.uk/support-for-you/welfare-benefits/carers](https://www.blf.org.uk/support-for-you/welfare-benefits/carers)

Who is a carer?

You're a carer if you give unpaid care for a loved one or friend who could not manage without this help. You could look after someone who becomes ill, frail or disabled.

Anyone can become a carer. You may feel helping someone who is close to you is part and parcel of life. You may not think of yourself – or want to think of yourself – as a carer.

Caring for someone can start gradually and creep up on you or start overnight. But the help you provide is important. It can bring rewards – and challenges.

What does a carer do?

The help you provide is unique to your circumstances. You might:

- **do everyday jobs around the house** – cleaning, cooking, washing
- **give personal care** – helping with washing and dressing, medication, eating
- **emotional support** – companionship, lending a friendly ear
- **help with admin and finances** – reading or writing letters, paying bills

It may also involve taking the person you care for to health appointments and being their advocate, encouraging them to keep active and helping them to socialise.

How do I find out more about COPD, IPF or another lung condition?

If you care for someone with a lung condition, make sure you're clear about the condition they have, how it is treated and the best ways they can manage their condition.

Over time, carers often become experts in the health conditions of the people they look after, and can understand their needs very well.

Learn about specific lung diseases

Find out more:

- if you care for someone with bronchiectasis: [blf.org.uk/bronchiectasis](https://www.blf.org.uk/bronchiectasis)
- if you care for someone with COPD: [blf.org.uk/copd](https://www.blf.org.uk/copd)
- if you care for someone with IPF: [blf.org.uk/ipf](https://www.blf.org.uk/ipf)
- if you care for someone with mesothelioma: [blf.org.uk/mesothelioma](https://www.blf.org.uk/mesothelioma)
- if you care for someone with pneumonia: [blf.org.uk/pneumonia](https://www.blf.org.uk/pneumonia)
- if you care for someone with pulmonary fibrosis: [blf.org.uk/pulmonary-fibrosis](https://www.blf.org.uk/pulmonary-fibrosis)

Or search for another other lung condition at [blf.org.uk/support-for-you](https://www.blf.org.uk/support-for-you)

How can I help someone to manage their condition?

Make sure you are both clear about the **medication** they take, why they take it and how and when it's best to take it.

Inhaled medicines work best if the inhaler is used in the right way

There are lots of different inhalers and it can be hard to use them correctly. Ask your doctor, nurse or pharmacist to demonstrate the right way to use the inhaler. You can also check the technique by watching a short video on [asthma.org.uk/advice/inhaler-videos/](https://www.asthma.org.uk/advice/inhaler-videos/)

Talk to health care professionals about the best ways you can work together to manage the condition. This may involve agreeing a plan with health care professionals about what to do if their symptoms flare up and, sometimes, keeping rescue medications at home.

You can help by encouraging the person you care for to do things to help themselves.

These include:

- stopping smoking
- learning how to control breathing
- keeping active
- eating well and keeping a healthy weight
- having an annual flu jab and the one-off pneumonia vaccine
- looking after mental health

Watch out for weight loss

The person you look after may eat less because eating makes them breathless.

Check out our diet tips at [blf.org.uk/support-for-you/eating-well/diet-and-my-symptoms#breathlessness](https://www.blf.org.uk/support-for-you/eating-well/diet-and-my-symptoms#breathlessness)

If you care for someone who is losing weight without planning to, it's very important to tell their health care professional. They may be at risk of malnutrition, which can weaken their breathing muscles and lead to chest infections. The doctor may be able to prescribe a nutritional supplement or refer them to a dietitian. Find out more at [blf.org.uk/support-for-you/eating-well/maintain-a-healthy-weight#weight-loss](https://www.blf.org.uk/support-for-you/eating-well/maintain-a-healthy-weight#weight-loss)

How do I care for someone who gets breathless?

It can be distressing seeing someone you care for struggling to breathe. And when they feel breathless, it can be hard to do everyday things and to keep active.

"He runs out of breath so easily. Even getting dressed is a major production."

Monika

It can help to think ahead. For example:

- agree which activities are priorities and plan the day so there is time to rest before and after them
- suggest they do things in ways that affect their breathing less like sitting down to wash or prepare meals, or using a towelling robe after a shower to dry off

The person you care for can also learn ways to feel more in control of their breathing:

- Ask a health care professional if pulmonary rehabilitation could help the person you look after. This is a course for people with lung conditions to help them keep active and learn more about their condition, including coping with feeling short of breath. If they are referred you can go along too!
- They could also ask to see a respiratory physiotherapist to learn:
 - breathing techniques to help them breathe more efficiently and to feel more in control
 - positions which help to recover from breathlessness
 - ways to clear their airways of mucus

To understand more, have a look at [blf.org.uk/breathlessness](https://www.blf.org.uk/breathlessness)

Getting out of breath when you're active helps

If someone avoids activities that make them breathless, their muscles will get weaker. Weaker muscles need more oxygen to work. The good news is that it's possible to break this vicious cycle of inactivity. By becoming more active muscles get stronger, including breathing muscles. This will help people feel less out of breath as they do everyday things.

"Sometimes I see people in the exercise class who are scared of getting breathless. But it's important they keep exercising – and their carers encourage them to."

Dave

How can I help someone I care for to keep active?

For many people with a long-term lung condition, exercise can help them manage their condition, boost their confidence and improve their mood. Research has shown it can reduce the number of flare-ups of conditions like chronic obstructive pulmonary disease.

If you care for someone who gets breathless, ask about getting pulmonary rehabilitation. It's important to keep exercising after the course finishes.

There are lots of other ways to be active. Choose ones the person you look after enjoys – or that you enjoy doing together. As well as everyday activities like walking or gardening, they could take up activities like an exercise class, yoga, dancing and tai chi.

How can I help someone avoid infections that make their condition worse?

If you look after someone with lung condition like bronchiectasis, COPD and pulmonary fibrosis, you'll want to lower their chances of getting a chest infection or their symptoms getting suddenly worse – called a flare-up or an exacerbation.

If a flare-up makes them feel a lot more breathless than usual, they may also get anxious. Being anxious will, in turn, make them feel even more breathless. Have a look at how to cope with anxiety, panic attacks and breathlessness at [blf.org.uk/support-for-you/breathlessness/causes#anxiety](https://www.blf.org.uk/support-for-you/breathlessness/causes#anxiety)

Colds and flu spread very easily. Particularly during colder months, think about:

- the benefits of going out and meeting other people against the risk of getting an infection
- avoiding contact with anyone who you know has a cold or another illness. Your friends will understand
- getting a flu jab
- using an antibiotic gel
- making sure you and everyone else covers their nose and mouth with a tissue when they sneeze

“My first mission is to keep him clear of colds.”

Maxine

What can I do if the person I care for suddenly gets worse?

A lot of carers remember a time when the symptoms of the person they care for got worse suddenly and they couldn't find a health care professional to ask what to do. It's a good idea to ask 'what if?' before that happens to you, and also to watch for signs that a flare-up is on its way.

Whatever the condition of the person you care for, make sure you talk to their health care professionals about how their symptoms might get worse and what you can do if that happens. Ask about having standby medication at home. Ask what to do in an emergency too.

For some conditions, such as chronic obstructive pulmonary disease (COPD), bronchiectasis and asthma, where it's more usual for symptoms to flare up, UK guidelines recommend the person you care for has a plan, agreed with health care professionals. The plan will set out signs to look out for, what to do and when to get emergency help. Your health care professional may also suggest you keep standby drugs at home, sometimes called a rescue pack.

Guidelines for treating less common conditions, such as idiopathic pulmonary fibrosis, also say specialist teams should give clear information about managing the condition.

Read more:

- what is an asthma action plan: [blf.org.uk/support-for-you/asthma](https://www.blf.org.uk/support-for-you/asthma)
- spotting signs of a flare-up of bronchiectasis: [blf.org.uk/support-for-you/bronchiectasis/coping-with-flare-ups](https://www.blf.org.uk/support-for-you/bronchiectasis/coping-with-flare-ups)
- our COPD flare-up checklist: [blf.org.uk/support-for-you/copd/flare-ups](https://www.blf.org.uk/support-for-you/copd/flare-ups). You can also get COPD a self-management plan here: [blf.org.uk/your-copd-self-management-plan](https://www.blf.org.uk/your-copd-self-management-plan)
- our pulmonary fibrosis organiser includes a downloadable flare-up plan: [blf.org.uk/support-for-you/pulmonary-fibrosis/my-personal-organiser](https://www.blf.org.uk/support-for-you/pulmonary-fibrosis/my-personal-organiser)

“One point we always worried over was when Ron should take standby antibiotics when he had a cold. We've since been advised to take them at the first sign of a cold. In the early days, I felt unsure about pestering health care professionals for what seemed trivial things, but please never hesitate to ask. Ron nearly ended up with pneumonia as he didn't take antibiotics soon enough.”

Maxine

How can I give emotional support as a carer?

As a carer you give both practical support and emotional support, like being a good listener.

“We’ve always talked – we’ve become even closer after the diagnosis. It’s very important that we both talk about how we feel and what’s happening.”

Sita

Living with a lung condition can affect mental as well as physical health. This goes for carers too. It’s common to feel anxious or have symptoms of depression.

Remember that family, friends and other carers can also play their part. If you can get out to meet others at groups and activities the person enjoys, that will help the person you care for – and you too.

“Keep as social as you can, go to groups, coffee mornings, dancing, anything to meet other people. I reckon a lot of the benefits of our exercise group come from socialising.”

Dave

Find out more about things you can do and the help available at **blf.org.uk/support-for-you/dealing-with-your-mental-health**.

Tips from other carers

These tips come from people who are, or have been, carers. They wanted to share their experiences and to pass on things they would have liked to have known as they started to care for someone.

They know looking after someone can affect you emotionally, physically and financially. And that it’s important to look after yourself to help you care, maintain your relationship with the person you care for and your work life, if you’re working.

Look for help and build a support network

Carers told us they had found practical help – in different ways and from different sources. They are always on the lookout for what will help them in their situation.

“Chat to everyone locally and ask people for help. Try your GP practice nurse and local carers’ organisations.”

John

Remember you may be able to get financial and other help from the government or your local council. Make sure you tell your council you are a carer.

Sometimes, you might want to find additional carers. For example, if the person you care for has money which means the local council won't help with the costs of care even if they agree it's needed. Carers UK has advice about finding the sort of help you're after at [carersuk.org/help-and-advice/practical-support/getting-care-and-support/finding-homecare](https://www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/finding-homecare)

Also think how doing tasks in other ways could make your life easier. For example, you can book GP appointments and order repeat prescriptions online.

"Getting our groceries delivered makes a big difference."

Monika

Building up a support network can make a big difference. Think about the kind of help you might need from your family, friends and neighbours. And involve the person you care for in thinking about who can help.

Get the right advice and information quickly

Caring can be very complicated – finding out about a specific lung condition, how it's treated and managed and what help you can get - as well as looking after yourself. You ask other carers – in person or in online carers forums.

"I talk to fellow carers at support groups. I talk to others and get support from the carers Facebook group. That is carers sharing their experiences and giving information."

Maxine

Ask about local support groups. Our breathe easy and pulmonary fibrosis support groups are spread across the UK.

Remember, our website is packed with reliable lung health information and our helpline team are there to help you too. You can also join our web community which can be found at [blf.org.uk/web-community](https://www.blf.org.uk/web-community)

Remember our friendly helpline team are there to help you. Call them on **03000 030 555** or email helpline@blf.org.uk

Don't be afraid to stand up for yourself

Looking after someone often means dealing with lots of different professionals and organisations. As a carer, you can go along to appointments and ask health care professionals what you want to know. It can be hard to speak up if you feel the professional has not explained things clearly, has not understood the whole situation or has not told you where to get more help. But this is also an important part of caring for someone.

"Go with a list of questions and wait for answers."

Kasim

Tip

Agree a written plan with a health care professional about how to manage the condition of the person you care for and how to deal with flare-ups of their symptoms. Ask if you can have medication to keep at home for an emergency.

You may want to be referred to more specialist help too. You may want help from:

- physiotherapists to help with breathing control and ways to keep active
- dieticians to help with eating well and keeping a healthy weight
- oxygen nurses, if the person you look after has oxygen therapy
- palliative care specialists to focus on controlling symptoms and improving the quality of life for the person, their family and carers at any stage of their condition
- occupational therapists to make sure the person you care for is safe and comfortable at home

Occupational therapists can make minor changes to your home. They can also arrange equipment such as a wheelchair.

"Sue used a wheeled trolley to help her carry things round the house. We got reclining chairs too."

John

Carers told us that some equipment can make a big difference. Often they had to buy it themselves. But there may be grants and other help available. Have a look at Carers UK's website about equipment and how to get it at [carersuk.org/help-and-advice/11-help-advice/4821-equipment-and-how-to-get-it](https://www.carersuk.org/help-and-advice/11-help-advice/4821-equipment-and-how-to-get-it)

Coping with your feelings

When you look after someone, you will need to adapt and make changes to your life. It's hard to watch someone close struggle with shortness of breath or other symptoms. You may feel your life is no longer your own, and frustrated that disease controls your life. It's normal to feel a lot of different emotions, including worry, guilt and frustration. **You have these feelings because you care.**

"Sometimes my difficulties seem unimportant compared to what he's going through. It's all strange. Guilt can be a big part of my feelings, as sometimes I feel torn between caring for him, being there for the rest of my family and keeping on top of my work. I've had counselling and that helped."

Sita

It's important to talk to people who understand what you're going through about how you can handle these feelings. Some people find it helps to talk to family and friends. Some use online forums, like our web community which can be found at **blf.org.uk/web-community**

But it can also be useful to talk to someone outside your family or support network. Ask your GP, who should be able to refer you to counselling or therapy. You may have to wait for free services.

Get in touch with your local Mind at **mind.org.uk/information-support/local-minds**, whose services can include drop-in centres and training, counselling and befriending. Or you can find private counsellors and therapists through the British Association of Counsellors and Psychotherapy.

Look after yourself

Caring always involves an element of putting your own needs aside. But it's important to look after yourself too, so you can keep going as a carer.

Tell your own GP about your caring role and keep up with your own health appointments.

Free flu jab

You and the person you care for will want to avoid flu viruses going around over the winter, so make sure you have a flu jab. Some people with long-term lung conditions, their main carers and people over 65 are entitled to a free flu jab every year.

The NHS also provides a one-off pneumonia vaccination for people with a long-term health condition and people over 65. This protects you from serious forms of pneumococcal infection. Ask your health care professional about this for the person you care for and yourself.

Look after yourself by eating well, keeping active and getting enough sleep. And look after your mental health too – don't ignore signs you're getting stressed. Mind has suggestions about how to cope when you're supporting someone else at **mind.org.uk/information-support/helping-someone-else/carers-friends-family-coping-support/looking-after-yourself**. Don't forget to take a break and make time for yourself.

Take time for yourself

Try to find ways to have time for yourself regularly. Ask a friend or family member to take over for a while. Or you might be able to arrange some help in the home for a couple of hours or for the person you care for to visit a day centre.

Try to find a space in every day to relax or do something you enjoy.

“You need a little something that’s about you. Once a day I go to the sofa in my study, light a couple of candles and sit quietly for 10 or 15 minutes. Sometimes I can feel the tension ebbing away.”

Sita

Tip

You may want to learn relaxation techniques. Try looking online or your local library may have some CDs or DVDs.

Sometimes you might need a longer time to recharge your batteries. There is help available for this at [blf.org.uk/support-for-you/welfare-benefits/carers#respice](https://www.blf.org.uk/support-for-you/welfare-benefits/carers#respice). You may feel that you can no longer go on holiday with the person you care for because of their lung condition. This isn’t always the case. With some forward planning and realistic expectations, you can have a lovely trip. Read our tips at [blf.org.uk/support-for-you/going-on-holiday](https://www.blf.org.uk/support-for-you/going-on-holiday)

Making difficult decisions

If you care for someone, there will be points when you’re faced with particularly difficult or emotional decisions. Thinking about things in advance and talking to the person you care for can help to keep calm when it comes to the crunch. You may want to think about a lasting power of attorney covering health and welfare. If the person you care for nominates you, you will be able to tell their health care professionals about their wishes and be able to make decisions on their behalf if they can’t.

Planning ahead may involve some difficult conversations with the person you look after as well as family and friends.

“His dad couldn’t accept the diagnosis for a long time. And our friends have reacted differently – and sometimes surprisingly. A few of our closest friends couldn’t cope and disappeared, while some people we didn’t know so well have become much closer to us.”

Sita

Planning for the final stages of caring is particularly difficult.

“We have talked about the future and told his health care team what he wants. We’ve also made our wills and talked about his funeral, and we arranged for me to have lasting power of attorney (LPA). This was in the early days when everything felt immediate and dramatic and we felt we had to act very quickly. But it’s been useful as the LPA means that I can talk to medical staff on his behalf now that he is often too fatigued to do it.”

Sita

Have a look at our information of thinking and planning ahead at blf.org.uk/end-of-life. It covers what you can expect if the person you care for is reaching the end of their life, and what you might need to do. This includes planning end of life care and putting affairs in order. You might also want to talk to health care professionals about the options available locally, such as helping you care at home, care in a hospice or hospital.

When caring ends

Your caring role is likely to change over time, and it is hard to adjust when it comes to an end. When the person you care for dies, your feelings and reactions be unique to you but a range of support is available.

Dying matters is an organisation that aims to help people talk more openly about bereavement. dyingmatters.org/page/coping-bereavement

Carers UK has a list of practical things you may need to do. carersuk.org/help-and-advice/practical-support/when-caring-ends/bereavement

Where to get more help

Our helpline **03000 030 555**

Our friendly helpline team can help you with all aspects of caring for someone with a lung condition, including welfare benefits.

Our web community **blf.org.uk/web-community**

Carers UK **www.carersuk.org/**

Gives expert advice and information and has an online forum.

Helpline **0808 808 7777**
Forum **www.carersuk.org/forum**

Carers Trust **www.carers.org**

Works to improve support and services for carers.

Find your local carers' centre at **www.carers.org/carers-services/find-your-local-service**

Carers Trust Wales **0292 009 0087**

Carers Trust Scotland **0300 772 7701**

Carers Northern Ireland **028 9043 9843**

Northern Ireland

Carers Support service **07826 930508**

NHS

Guide to care and support **www.nhs.uk/conditions/social-care-and-support**

Carers Direct helpline **0300 123 1053**

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/carers

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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**