



COPD: Living with chronic obstructive pulmonary disease

In this booklet, you can find out about chronic obstructive pulmonary disease or COPD. There's information about what it is, what the symptoms are, and how it's diagnosed and treated.

COPD describes a group of lung conditions that make it difficult to empty air out of the lungs because your airways have been narrowed.

There are treatments to help you breathe more easily and there are lots of ways you can manage your condition yourself.

We give tips about controlling your breathing and how to manage flare-ups.

We've put this information together for you, your family carers and friends.

- Chronic** = it's a long term condition and does not go away
- Obstructive** = your airways are narrowed, so it's harder to breathe out quickly
- Pulmonary** = it affects your lungs
- Disease** = it's a medical condition

What is COPD?

Chronic obstructive pulmonary disease, or COPD, describes a group of lung conditions that make it difficult to empty air out of the lungs because your airways have been narrowed.

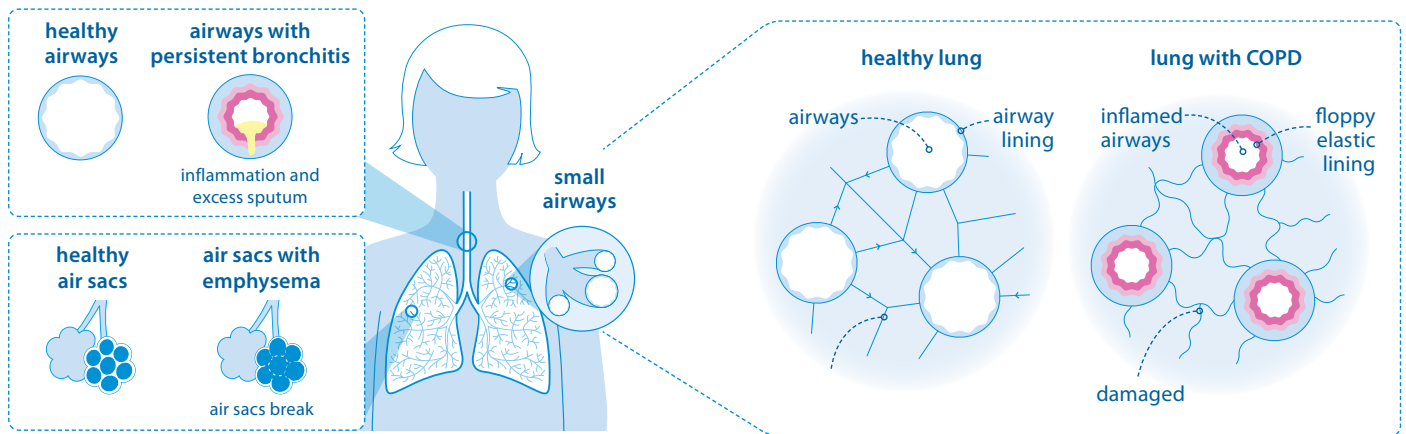
Two of these lung conditions are persistent bronchitis and emphysema, which can also occur together.

- Bronchitis means the **airways** are inflamed and narrowed. People with bronchitis often produce sputum, or phlegm.
- Emphysema affects the **air sacs** at the end of the airways in your lungs. They break down and the lungs become baggy and full of holes which trap air.

These processes narrow the airways. This makes it harder to move air in and out as you breathe, and your lungs are less able to take in oxygen and get rid of carbon dioxide.

The airways are lined by muscle and elastic tissue. In a **healthy lung**, the tissue between the airways acts as packing and pulls on the airways to keep them open. **With COPD**, the airways are narrowed because:

- the lung tissue is damaged so there is less pull on the airways
- the elastic lining of the airways flops
- the airway lining is inflamed



There are treatments to help you breathe more easily, but they can't reverse the damage to your lungs – so it's important to get an early diagnosis.

What causes COPD?

COPD usually develops because of long-term damage to your lungs from breathing in a harmful substance, usually cigarette smoke, as well as smoke from other sources and air pollution. Jobs where people are exposed to dust, fumes and chemicals can also contribute to developing COPD.

You're most likely to develop COPD if you're over 35 and are, or have been, a smoker.

Some people are more affected than others by breathing in noxious materials. COPD does seem to run in families, so if your parents had chest problems then your own risk is higher. A rare genetic condition called alpha-1-antitrypsin deficiency makes people very susceptible to develop COPD at a young age. There is more information about this at blf.org.uk/aatd or call our helpline.

What's the difference between COPD and asthma?

With COPD, your airways have become narrowed permanently – inhaled medication can help to open them up to some extent. With asthma, the narrowing of your airways comes and goes, often when you're exposed to a trigger – something that irritates your airways – such as tobacco smoke, dust or pollen. Inhaled medication can open your airways fully, prevent symptoms and relieve symptoms by relaxing your airways.

So, if your breathlessness and other symptoms are much better on some days than others, or if you often wake up in the night feeling wheezy, it's more likely you have asthma.

What are the symptoms of COPD?

Symptoms include:

- getting short of breath easily when you do everyday things such as going for a walk or doing housework
- having a cough that lasts a long time
- wheezing in cold weather
- producing more sputum or phlegm than usual

You might get these symptoms all the time, or they might appear or get worse when you have an infection or breathe in smoke or fumes.

If you have severe COPD, you can lose your appetite, lose weight and find that your ankles swell.

How is COPD diagnosed?

Your doctor will ask if your breathlessness is brought on by anything, how your daily life is affected and other questions about your general health.

They'll ask you about your smoking history and any other exposure to dust, fumes or chemicals.

Your doctor can check how well your lungs work by arranging a simple test called spirometry. This involves blowing hard into a machine which measures your lung capacity and how quickly you can empty your lungs. This is called the forced expiratory volume in one second, often shortened to FEV1.

Your doctor will use spirometry to measure how narrow your airways are. But this only covers one aspect. Someone with slightly narrowed airways can be more breathless than someone with very narrow airways depending on their level of fitness and the exact way COPD has damaged their lungs.

Your doctor should arrange for you to have a blood test and a chest X-ray to rule out other causes of your symptoms. Your doctor will calculate your body mass index (BMI) to find out if you're a healthy weight for your height. This is important because you can deal with your COPD better if you're not underweight or overweight.

You may do more tests to give a better picture of your condition, covering:

- how well your lungs are functioning
- how often you have symptom flare-ups or chest infections
- how short of breath you feel during everyday activities
- whether your oxygen level is significantly lower

You may be referred to see a specialist doctor or a specialist nurse to confirm the diagnosis or to work out the right treatment for you. You may also see other health care professionals who can help you to manage your condition:

- physiotherapists – to help you deal with your sputum, control your breathing and keep active
- dieticians – to help you manage your weight
- occupational therapists – to help make your daily living easier

What treatments work?

Your health care professional can prescribe several types of medicine or combinations of medications to improve symptoms like breathlessness and to help prevent a flare-up.

You can also do things to help manage your condition yourself. Keeping active and doing exercise can make a big difference – many people find this helps them more than inhaled drugs.

Don't smoke

If you smoke, the most effective treatment for COPD is to stop. Your health care professional and pharmacist can help you find ways that make it easier for you. You're four times as likely to quit with help from support services and medication. Have a look at [nhs/smokefree](https://www.nhs.uk/smokefree) to find out more.

Have a plan

It's important you have a plan to help you manage your COPD that's agreed with your doctor or nurse. You can get one from [blf.org.uk/self-help](https://www.blf.org.uk/self-help)

You should also have regular check-ups with your health care professional – at least once a year.

Medications

Your doctor will decide with you which medications to use depending on how severe your COPD is, how it affects your everyday life, and any side effects that you may have experienced.

Bronchodilators are a type of medicine that open up your airways to help you breathe more easily.

- If you only get short of breath when you're active, your doctor will give you a **short-acting bronchodilator**. This will help your breathing quickly and the effects last for four to six hours.
- If you're breathless daily, you'll be prescribed a **long-acting bronchodilator**. This may take longer to have an effect, but the effects last longer – 12 to 24 hours. There are two main types of long-acting drugs: anti-muscarinic or beta agonist. You may be started on one of each or on both. Sometimes they come in separate inhalers and sometimes in combinations. You may get on better with one or another version, but in general they are all thought to be equally effective.

If you have regular flare-ups or exacerbations of your COPD, you may also be given a **steroid inhaler**. This can help reduce inflammation and swelling in your airways. This sort of drug is usually given with a long-acting bronchodilator in a combination inhaler – two medicines given in one inhaler.

Steroid inhalers are also useful in people whose condition is an overlap of asthma and COPD.

If you cough up a lot of sputum, you may be given a drug called a **mucoytic as a tablet or syrup**. This makes your sputum thinner and easier to cough up.

Side effects

It's not common to get side effects from inhaled drugs, as the dose is usually very small. Steroids can sometimes make your voice hoarse or give you a fungal infection, called thrush, in your mouth. This is easy to treat. You can reduce the risk by using your inhaler correctly and rinsing your mouth out after every time you use it.

Taking your medicine

If you take inhaled medicine every day, take it as prescribed, even if you feel well. This can also reduce the risks of a flare-up. You can take your inhaled medicine in different ways. These include different sorts of inhalers:

- dry powder inhalers – suck in as hard as you can
- metered dose inhalers – they produce a puff of medication like an aerosol – use a slow deep breath in
- spacers – these attach to some inhalers to help you breathe in the drug more effectively
- nebulisers – these devices turn the medicine into a mist that you can breathe in. They're used in an emergency when you need large doses of inhaled medicine, such as during a flare-up. Most people don't need such a big dose and get as much benefit from normal inhalers as long as they use them correctly with a spacer device

Your inhaler will only help if you use it correctly. Ask your doctor, nurse or pharmacist to show you how.

Answer a few questions to check you're getting the best COPD care – and find out what to do if not – at [blf.org.uk/passport](https://www.blf.org.uk/passport)

Oxygen

Your health care team may send you to a specialist to see if oxygen can help you. Oxygen is only useful as a treatment for people with a low oxygen level. It's not a treatment for breathlessness, which in COPD is usually caused by difficulty moving air in and out as you breathe, rather than by a low oxygen level.

Don't worry about becoming dependent or hooked on oxygen.

- If your oxygen levels drop when you are active, you might be given **ambulatory oxygen**. This is a small, portable oxygen cylinder, which helps improve how far you can walk and how much you can exercise.
- If you have low levels of oxygen in your blood when you're resting, you may be offered **long-term oxygen therapy**. To get the benefits of this, you should breathe it for at least 15 hours a day. You breathe oxygen in through a small plastic tube that fits just inside your nostrils or a mask connected to an oxygen supply. You will get an oxygen concentrator in your home, with long tubes so you move around and portable oxygen tanks when you're away from your home.

People using oxygen while they still smoke are a danger to themselves and other people because of the fire risk. There's more information about oxygen treatment at [blf.org.uk/oxygen](https://www.blf.org.uk/oxygen)

Non-invasive ventilation

If you're admitted to hospital with a severe flare-up of your condition, you may be offered non-invasive ventilation. This involves wearing a nasal cannula (a soft tube inserted into your nose) or face mask connected to a machine that pushes air into your lungs. Non-invasive ventilation supports your breathing to give your muscles a rest and gently helps with each breathe you take. This increases your oxygen level and helps you breathe out more carbon dioxide.

If you regularly wake up with a headache, tell your doctor. It can be a sign your breathing is shallow at night and you might benefit from non-invasive ventilation at home.

Surgery

Lung volume reduction surgery

Some people with emphysema may benefit from surgery to remove the worst affected areas of the lung. This allows the remaining healthier parts of your lung to work better. If you've been through a pulmonary rehabilitation programme and are still limited by breathlessness, ask your doctor if you might be eligible for this sort of treatment. Bronchoscopic techniques for lung volume reduction are also becoming available. You may be considered for these instead of surgery as part of the assessment process for surgery.

There's more information at blf.org.uk/lvrs

Lung transplant

If you have very severe COPD and have not got better with treatment, you might be a candidate for a lung transplant depending on your age, other illnesses and test findings. Lung transplant is a high-risk operation and is only suitable for a small number of people. There are also few suitable organ donors.

What you can do to manage your COPD

If you have a long-term condition like COPD, you'll feel better if you self-manage your condition and take some control of your life. Knowing all you can about your condition, your symptoms, your medications and how to cope with flare-ups will make your day-to-day life easier.

This section explains the benefits of:

- exercise and pulmonary rehabilitation
- learning how to control your breathing
- eating well and keeping a healthy weight
- getting vaccinated
- taking care of your feelings

Remember, if you smoke, stopping smoking is the best thing you can do.

"If you have a lung condition, you can't sit around and wait for other people to take care of you – you need to take care of yourself! I fully believe you get out of it what you put in"
Peter

Exercise and pulmonary rehabilitation

If you have COPD, being active and exercising can help you to improve your breathing, your fitness and your quality of life. Don't avoid activities that make you breathless: you'll get less fit and out of breath more easily. Regular exercise can help reverse this by strengthening your muscles. Exercise also benefits your heart and blood pressure, and makes you less likely to develop conditions such as diabetes and osteoporosis (fragile bone disease).

The best way to learn how to exercise at the right level for you is to take part in pulmonary rehabilitation. Ask your doctor to refer you.

Pulmonary rehabilitation or PR is a programme of exercise and education designed for people living with COPD. It combines physical exercise sessions with advice and discussions about your lung health.

A course lasts about six to eight weeks and you'll be part of a group. The sessions are designed to be enjoyable and fun.

At each session, you'll spend about half the time on physical exercise. This will be carefully designed to provide the right level of activity for you. You'll also get information and tips about things like:

- breathing techniques and positions to help you when you're out of breath
- how to manage stress
- healthy eating
- how to use your inhalers and other medicines
- what to do when you're unwell

PR is about helping you manage your COPD better. It's not a cure, but you'll feel better – more confident and in control.

There is strong evidence that people with COPD benefit from PR and exercise more generally. Most people find PR improves their ability to exercise and their quality of life. The impact of PR is often bigger than the impact of taking inhaled medications. By combining the two approaches, you're likely to get the most benefit.

Controlling your breathing

Breathing techniques

There are techniques to help you reduce breathlessness. Try to practise them every day. They can also help if you get out of breath suddenly. Being in control of your breathing means breathing gently, using the least effort, with your shoulders supported and relaxed. Different things work best for different people but these are all techniques to try:

- **relaxed slow deep breathing:** breathe in gently through your nose and breathe out through your nose and mouth. Try to feel relaxed and calm each time you breathe out.
- **pursed-lips breathing:** breathe in gently through your nose and breathe out with your lips pursed as if you are whistling.
- **blow as you go:** use this when you're doing something that makes you breathless, such as standing up. Breathe in before you make the effort. Then breathe out while making the effort. Try using pursed lips as you breathe out.
- **paced breathing:** this is useful when you're active, such as climbing stairs. You pace your steps to your breathing. For example, breathe in when on the stair, and breathe out as you go up a stair.

Your physiotherapist can help you find what works best for you.

There's more detail in patient information developed by the Association of Chartered Physiotherapists in Respiratory Care at www.acprc.uk/publications

Helpful positions

Use these positions to help you practise your breathing control, or to recover your breath when you get breathless. Your physiotherapist will help you find positions that work for you.

- **Stand leaning forward (figure 1):** lean from the hips, with your forearms resting on something at the right height, such as a chair or kitchen work surface. When you're out and about, you could lean on a walking stick or a frame with wheels. If you're shopping, use your supermarket trolley.
- **Sit leaning forward (figure 2):** lean resting your elbows on your knees.
- **Sit leaning forward at a table (figure 3):** rest your head and arms on pillows on a table when you're really short of breath.

figure 1

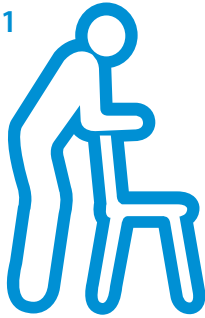


figure 2



figure 3



You can also **stand leaning back** or sideways against a wall. Have your feet apart. Relax your arms down by your sides. If you prefer, rest your hands or thumbs in your waistband or belt loops, or across the shoulder strap of your handbag.

Top tips to manage your breathlessness

- Use a towelling robe after showering or bathing, as you'll use less energy than drying off with a towel.
- Hold a handheld battery fan near your face if it helps you to feel less breathless.
- Plan your day in advance to make sure you have plenty of opportunities to rest.
- Find simple ways to cook, clean and do other chores. You could use a small table or cart with wheels to move things around your home, and a pole or tongs with long handles to reach things.
- Put items that you use frequently in easy-to-reach places.
- Keep your clothes loose, and wear clothes and shoes that are easy to put on and take off.
- Use a wheeled walking frame to help improve your breathlessness.

Eating well and keeping a healthy weight

It's important to eat a balanced diet and maintain a healthy weight. Your doctor or nurse can help you to work out what your healthy weight should be and can refer you to a dietician or local scheme to help you.

- If you're overweight it will be harder for you to breathe and move around.
- If you're losing too much weight because eating makes you feel breathless, or find it difficult to shop and prepare meals, try to eat little and often.

There's information on eating well, maintaining a healthy weight and how your diet can affect your symptoms, at [blf.org.uk/eating-well](https://www.blf.org.uk/eating-well)

Get vaccinated

Make sure you get your flu jab every year to protect you against the flu viruses likely to be going round over the winter. The NHS offers it for free to people living with long-term conditions like COPD.

Your doctor should also offer you a vaccination against pneumococcal infection – a bacterial infection that can cause pneumonia and other illnesses. You only need to have this once.

You can also avoid infections by staying away from people – including babies – who have colds, flu, sinus infections or a sore throat. If you do get an infection, make sure you treat it quickly.

Take care of your feelings

Living with a long-term condition is not easy. Physical symptoms such as breathlessness and coughing, feeling more tired and being less active can mean you feel stressed, anxious or depressed.

It helps to understand your mood and what causes you to feel down. Once you understand it, you can take steps to tackle it and take greater control of your life.

Don't bottle things up – talking to a friend or relative or a health care professional can help. It's very important to stay active and sociable, and to learn more about COPD. This will help you to understand and cope better with your condition. You might want to get involved with a local group to meet others going through a similar experience. You can also talk to your doctor about medications or counselling to help you stay positive.

Our Breathe Easy groups support people living with a lung condition and their family. It's a great way to get more information and make new friends. To find your local group, visit blf.org.uk/breathe-easy or call our helpline on **03000 030 555**

What else can I do to manage my COPD better?

- Make sure you sleep well and get enough rest every day. This will help with your energy levels. If you have trouble sleeping, try to exercise each day and don't have tea, coffee or alcohol before bed time. Talk to your doctor if that doesn't help.
- Ask your doctor about ways you can adapt your home to help you move around more easily. An occupational therapist and your local council can help you with this.
- If your ankles swell, tell your doctor. Medicines can reduce this. But many people with COPD have other conditions, and leg swelling can be a sign of a heart condition.
- It's important to talk to your doctor or nurse about longer-term treatments and advance care planning. This means thinking about what you would like to happen if your condition gets worse, or you experience more severe flare-ups, to help your family and your doctor to understand your wishes. There's more information on advance care planning and taking control of your choices at blf.org.uk/end-of-life or call our helpline.

Singing

Some people with COPD who joined a singing group said singing helped them to manage their symptoms better.

Have a look at blf.org.uk/singing to find out more and find a group near you, or call our helpline.

Managing flare-ups

A flare-up – sometimes called an exacerbation – is when your symptoms become particularly severe. Signs are:

- your breathlessness gets worse
- you cough more
- you produce more sputum
- a change in the colour and consistency of your sputum

A flare-up might be triggered by an infection or there may be no apparent reason.









You should have an action plan that you've agreed with your health care professional so you know what to do if you have a flare-up. Your plan may include a rescue pack of drugs (antibiotics and steroid tablets) that you keep at home. Make sure you know when:

- you should start to take steroid tablets
- you should start to take antibiotics. This will usually be if you notice that as well as being more breathless, you're producing more sputum than usual or it has changed colour
- to make changes to how you take your bronchodilator medicine – such as increasing the dose or changing how you take it – to help with your symptoms

Remember to tell your doctor or nurse if things don't improve within two days of starting the drugs you keep at home.

Most people can be treated at home if they have a flare-up, but you may need to go to hospital depending on how severe your symptoms are. If you use the ambulance service, make sure to say you have COPD, so you get the right oxygen treatment.

If you have more than two flare-ups in one year that require your rescue drugs, get a review with your GP or nurse. It may be a good idea to get some specimens of your sputum analysed to see if you have an unusual or resistant infection. Your doctor may order a scan of your chest to see if there is an area of damaged lung that makes you more susceptible to infections. Sometimes people who have frequent chest infections benefit from taking regular antibiotics. This is usually started by specialist teams.

Do I feel worse than usual?			
Symptoms may include:	 Getting more out of breath	 More sputum, change in colour: is it green, brown or yellow?	 Increased chesty cough
What can I do?	 Continue or increase my inhaler or nebuliser treatment	 Start my rescue pack drugs	 Keep calm and do my breathing exercises
I must remember...	Contact my nurse or doctor or the community respiratory team 	If symptoms are severe, call 999 	

Hospital at home schemes

In some areas of the country, people with COPD can be treated at home when they have a flare-up. These local hospital at home schemes provide medication and visits by a specialist team. This means you can recover at home where you might feel more comfortable and can be more active when you feel ready. If you would prefer to be treated at home, speak to your doctor or nurse.

If you're a smoker, stopping smoking will help you to live longer but can also reduce or stop flare-ups completely.

Other areas to think about

COPD is a long-term condition and can affect all areas of your life. We have more information on the areas below – have a look online at blf.org.uk, call our helpline or order our free information:

Sex and COPD

Having an illness like COPD can affect any relationship. It can make you feel tired, anxious or depressed. You might worry about sex if you are afraid that you will become too short of breath, or need to cough up sputum. Your doctor, nurse or physiotherapist can help you to manage this. You can also find more information and tips to help you to enjoy a fulfilling sex life at blf.org.uk/sex-and-breathlessness **carers** or call our helpline.

Looking after someone with COPD

When someone close to you has COPD and needs your support, it is only natural to want to help them. If you look after someone with a lung condition you might feel anxious, frustrated or stressed.

These emotions are normal, and it's important to talk about these worries with the person you care for, and with their COPD specialist team.

If you care for a family member or partner, it is important to continue to enjoy things together and for the person with a lung condition to remain as active and independent as possible.

There is help available for carers. Take a look at blf.org.uk/carers or call our helpline.

Financial help

If you have COPD, or you care for someone who does, then you might be entitled to financial support: go to blf.org.uk/welfare-benefits or call our helpline.

Further information

There's more information developed by the Association of Chartered Physiotherapists in Respiratory Care about breathing control and positions at www.acprc.uk/publications

We've got more free information about COPD and living with a lung condition online and in print:

- **COPD patient passport** – to check you're getting the care you should receive if you're living with COPD
- **Healthy eating and exercise information**
- **Going on holiday with a lung condition**
- **Breathlessness**

You can read and order the information at blf.org.uk/support-for-you or call our helpline.

Take a look at our COPD self-management plan and exercise handbook as well as our DVD: *Living well with COPD*. For more information go to blf.org.uk/shop

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

blf.org.uk

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



Code: BK2 **Version:** 3

Last medically reviewed: September 2016

Due for medical review: September 2019

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