



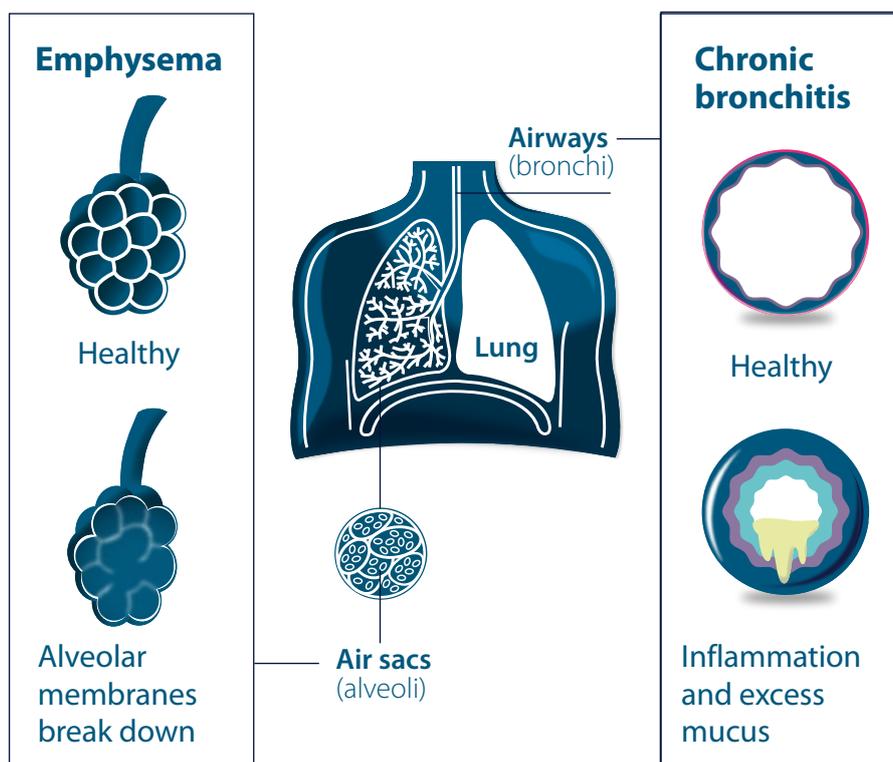
# Living with COPD

This information is for people with chronic obstructive pulmonary disease (COPD), their families, friends and carers. It provides advice and information about COPD, including what the symptoms are, how it can be treated and what steps you can take to manage your condition and look after yourself. It also offers advice on how to take care of your emotional well-being and where you can turn for further information and support.

## What is COPD?

COPD stands for chronic obstructive pulmonary disease. This is the name used to describe a number of conditions including emphysema and chronic bronchitis. Emphysema affects the air sacs in your lungs (alveoli), and chronic bronchitis affects your airways (bronchi). If you have COPD, you might have just one of these conditions, or you might have more than one.

COPD is a condition where the airways become inflamed and the air sacs in your lungs are damaged. This causes your airways to become narrower, which makes it harder to breathe in and out. Therefore, people with COPD have breathing difficulties, and this can affect many aspects of your day-to-day life. Unfortunately, there is no cure for COPD, but there are lots of treatments available to help you manage your condition, improve your symptoms and live an active life.



## What causes COPD?

The main cause of COPD is smoking – the condition usually affects people over the age of 35 and who are, or have been, heavy smokers.

People who don't smoke but have long-term severe asthma can get COPD. It can also be caused by long-term exposure to air pollution, fumes and dust from the environment or your place of work. You can inherit COPD, but this is very unusual. There is a genetic condition called Alpha-1 antitrypsin deficiency that causes damage to your lungs. This condition can lead to a particular type of COPD (emphysema), especially in people who smoke.

## What are the symptoms of COPD?

The symptoms of COPD include:

- wheezing, particularly breathing out;
- breathlessness when resting or active;
- tight chest;
- cough; and
- producing more mucus or phlegm than usual.

You might experience 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 (see below), you might experience loss of appetite, weight loss or ankle swelling.

## How is COPD diagnosed?

If you have some or all of the symptoms mentioned above, your doctor will want to do some tests to see if you have COPD. You might be asked if you have a history of smoking, long-term asthma or if you have been exposed to other dusts and fumes that could have damaged your lungs.

To confirm that you have COPD, you will need to take a breathing test to measure the size of your lungs, and to measure the amount of air flowing in and out of your lungs. This is called a spirometry test.

Your doctor can find out how severe your condition is by looking at how narrow your airways are, how often your symptoms flare up and how breathless you feel during everyday activities.

This will help him or her to decide on the right treatment options for you.

## What treatments are available?

### Don't smoke

If you smoke, the single most important treatment for COPD is to stop smoking. Giving up will stop the on-going damage to your airways caused by cigarette smoke. It is the most important treatment to reduce the chance of your condition becoming worse. It also means the tiny hairs in your airways can work properly, clearing mucus, bacteria and poisonous chemicals that accumulate in your lungs.

Giving up smoking is never easy, but there is plenty of help available. For example, stop smoking

services are provided by the NHS across the UK. Nicotine replacement therapies and stop smoking medications can also be very effective in helping you give up for good. It is never too late to stop smoking and support is available from your local stop smoking service or your GP.

For more information on stopping smoking, go to [www.blf.org.uk/Page/Stopping-smoking](http://www.blf.org.uk/Page/Stopping-smoking) or order out free booklet, Smoking and your lungs: why it's never too late to give up, through the BLF website or by calling the BLF Helpline on **03000 030 555**.

## **Diet**

When you have a lung condition, it is important to eat well to prevent infections and keep your lungs healthy. It is also essential to make sure you are the correct weight. Your doctor can help you to work out what your healthy weight should be. If you are overweight it will be harder for you to breathe and move around. However, some people with COPD can lose too much weight because eating makes them feel breathless, or it becomes more difficult to shop and prepare meals. If you are underweight, or you are putting on too much weight, speak to your GP who can give you advice or refer you to a dietician for more support.

For information on eating well, maintaining a healthy weight how your diet can affect your symptoms, go to [www.blf.org.uk/Page/Eating-well-for-healthier-lungs](http://www.blf.org.uk/Page/Eating-well-for-healthier-lungs)

## **Pulmonary rehabilitation**

When you have a lung condition, it is important to be as active as you can and to exercise safely. In some areas, you can attend pulmonary rehabilitation – a programme of exercise that helps with breathlessness by improving your muscle strength and lung fitness. This makes it easier for you to carry out everyday activities.

Pulmonary rehabilitation usually involves a six to eight-week course of group exercise classes. It also offers education on nutrition, living with COPD, financial help, social services and emotional support, as well as information on the medications used to manage COPD and treat flare-ups. The programme will be tailored to your specific needs or goals.

For more information on pulmonary rehabilitation, go to [www.blf.org.uk/Page/Pulmonary-rehab](http://www.blf.org.uk/Page/Pulmonary-rehab) Once you have completed pulmonary rehabilitation, it is important to continue exercising at the right level for you. For more information on how to access exercise, go to [www.blf.org.uk/Page/How-to-get-active](http://www.blf.org.uk/Page/How-to-get-active)

You can also find out more about the BLF Exercise handbook, available to purchase from our website.

## **Medications**

If you experience mild symptoms now and then, your doctor might prescribe a short-acting bronchodilator inhaler. This relaxes the muscles in your airways to keep them as open as possible and relieves breathlessness. If your symptoms occur every day, you might be given a long-acting bronchodilator inhaler. This works in the same way as a short-acting inhaler, but the effects of the medication last for at least 12 hours.

There are different types of bronchodilator, but the most common types used to treat COPD are anticholinergics and beta-2 agonists.

Your nurse, doctor or pharmacist should teach you to use your inhaler properly to make sure your medication is effective. Lots of people don't use their inhaler correctly, so ask your doctor or nurse to check your technique, and make sure you follow their instructions.

If you are still struggling with your symptoms or experiencing regular flare-ups your COPD team or GP might prescribe a steroid inhaler. This will help to reduce the swelling in your airways. This type of medication is usually given as part of a combination inhaler – when two medicines are given together in one inhaler. These long-term medications will help to reduce breathlessness and exacerbations. Steroid tablets are also available to reduce the swelling in your airways.

Your doctor might give you a medication called a mutolytic to reduce the thickness of your phlegm. You may also need to take antibiotics to prevent getting infections.

It's very important to use your medications regularly and correctly.

### **Possible side-effects:**

Side-effects from inhaler medicines are not common, since the dose is usually very small. Steroid inhalers can sometimes cause hoarseness or thrush in the mouth. To reduce the risk of this, make sure you use your inhaler correctly (see above), and rinse your mouth and gargle after using it.

### **Get vaccinated**

Make sure you get vaccinations against flu and pneumonia to avoid getting infections in winter. You should get a flu vaccination every year, but the pneumonia vaccination is given just 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 to prevent further lung damage.

### **Oxygen**

If the level of oxygen in your blood is too low when you are resting, or if the level drops when you are active, you might need oxygen treatment. This is used to increase the amount of oxygen that flows into your lungs and bloodstream. There are two types of oxygen treatment that are suitable for people with COPD:

- **Long term oxygen therapy:** if the level of oxygen in your blood falls below a certain amount when you are resting, you might need to use an oxygen machine for 15-16 hours each day. The tubes from the machine are long so you can move around your home, and portable oxygen tanks are available if you are away from home.
- **Ambulatory oxygen:** if your oxygen levels drop when you are active, you might be given ambulatory oxygen. This is a small, portable oxygen cylinder, which can also help reduce breathlessness when you exercise.

You should be given a full assessment by your health care professional before using either of these types of oxygen treatment.

For more information on oxygen treatment, go to [www.blf.org.uk/Page/Oxygen](http://www.blf.org.uk/Page/Oxygen)

### **Non-invasive ventilation**

If an infection is making your breathing too difficult, you might need the support of a breathing machine. This is known as non-invasive ventilation (NIV) and is usually provided in hospital. It can also be given at home if your condition is very severe. This treatment involves a mask that covers either your nose or face and is connected to a machine that pushes air into your lungs. The aim of NIV is to increase your oxygen levels and to help you breathe out more carbon dioxide. It also takes some of the effort out of breathing because your chest muscles don't have to work as hard, so it helps to ease the feeling of breathlessness.

## Surgery

A small number of people with whose airways are very narrow might be offered surgery to remove badly damaged areas of the lung. This is called lung volume reduction surgery and allows the less damaged areas to work more effectively.

If you have very severe COPD and have not got better with treatment, you might be a candidate for a lung transplant. However, due to the lack of suitable organ donors and the significant risk of the operation, transplants are only considered in very unusual circumstances.

You can find more information on lung surgery at [www.blf.org.uk](http://www.blf.org.uk)

What else can I do to manage my COPD better?

- Dress warmly if going out in cold weather.
- If you work in a smoky or dusty environment this can continue to damage your lungs. You might need to change your job or speak to your employer about changing your place of work. For more advice on this issue, call the BLF Helpline on **03000 030 555**.
- Make sure you sleep well and get enough rest every day. This will help with your energy levels. If you are having trouble sleeping, try to take some exercise each day and don't have tea, coffee or alcohol before bed time. If you are still having problems, talk to your doctor.
- 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.
- A chest physiotherapist and your doctor can help to reduce severe breathlessness. You should always inform them if you are having breathing problems. There are breathing techniques and medications that can help to make you feel more comfortable.
- If you have ankle swelling, there are medicines that can reduce this. Ask your doctor for more information.
- It's important to talk to your doctor or nurse about longer-term treatments and advanced 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.

If your condition is at the later stages, you can find more information on advanced care planning and taking control of your choices in the later stages of COPD on the BLF website. You can order a copy of our booklet, *Coping with the final stages of chronic lung disease*, online or by calling the helpline.

## Managing exacerbations

An exacerbation happens when you experience any two of the following symptoms:

- worsening breathlessness
- increased phlegm
- discoloured phlegm

This is also known as a flare-up, when your symptoms suddenly get worse. You might feel unwell, or have a fever. A flare-up might be triggered by an infection or other causes such as weather changes or stress. When you have a flare-up, it is very important to start taking antibiotics early to prevent your symptoms from getting worse. If you have a history of winter infections or flare-ups, your doctor might give you emergency antibiotics to keep at home in case of an exacerbation. These should be used as soon as your symptoms change.

If you have more than two flare-ups in one year, that need more than two courses of antibiotics, you should contact your GP or nurse. They might give you preventative antibiotics. If you are also having breathing difficulties, you might be given steroids in the form of tablets.

You should keep the contact details of your COPD service, GP or nurse nearby at all times. This is so you can arrange an emergency appointment or prescription if you have a flare-up that is getting worse, even when taking your emergency antibiotics at home.

### **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 about your options.

### **Hospital admission:**

If you feel very breathless or unwell and need to go to hospital, this should not be delayed. If you need to use the ambulance services, make sure you tell the emergency staff that you have COPD. This will ensure you get the right oxygen treatment to improve your condition.

## **Dealing with breathlessness**

### **Pulmonary Rehabilitation**

Attending a course of pulmonary rehabilitation is one of the best ways to reduce your breathlessness. You can find out more about pulmonary rehabilitation on page 3.

### **Breathing control techniques**

A lot of the techniques below are taught as part of pulmonary rehabilitation and can be very helpful in reducing breathlessness if you practice them every day. They also help if you get breathless suddenly. Breathing control means breathing gently, using the least effort, with your shoulders supported and relaxed. You can see some positions to help ease breathlessness on page 7.

- Relaxed, slow, deep breathing: in a comfortable, supported position, relax your shoulders, arms and hands. 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 out with your lips pursed as if you are whistling. This slows your breathing down and helps to make your breathing more effective.
- 'Blow as you go': breathe out when you are making a big effort, for example, when stretching your arms above your head, reaching for something on a shelf, bending down, going up steps or standing up. During the hardest part of any action, blow as you go! If you become breathless suddenly when resting, it can help to remember, 'If in doubt, breathe out!'
- Paced breathing: this is useful when climbing the stairs or walking. Breathe in, in time with the steps you take. Do this in a rhythm that suits you and how breathless you are. For example, you should:
  - Breathe in when on the stair, and breathe out as you go up a stair (blow as you go); Breathe in for one stair and out for one stair;
  - Breathe in for one stair and out for two; or
  - Breathe in for two stairs and out for three.

## Other methods of dealing with breathlessness include:

- lose weight if you are overweight, or put on weight if you are underweight;
- arrange the things you use every day to make sure they are easy to reach;
- use your inhalers correctly and regularly;
- sit down and take things slowly when you're not active, to save energy;
- avoid bending down by wearing slip-on shoes or using long-handled tools in the garden;
- when you're breathless, take a rest and then start again; and
- ask for help when you need it.

Your doctor might also recommend medications to reduce breathlessness, if appropriate.

## Positions to help ease breathlessness

The best positions are the ones that need the least energy or effort.

If you tense your shoulders and grip onto things when you are breathless, you're wasting energy (and oxygen).

1. To ease your breathing when standing up, lean from the hips, with your forearms resting on something at the right height. Chairs, window sills, garden walls or kitchen work surfaces are often suitable (**figure 1**).
2. When you're standing or walking, try putting your hands on your hips or in your pockets, or stick your thumbs into your belt loops to support your arms without gripping. If you carry a shoulder bag, you can rest your arms on it.
3. Sitting uses less energy than standing up. You may find it useful to lean forwards, resting your forearms on your knees, or on the arms of a chair or table (**figure 2**).
4. A walking aid (walking stick or a frame with wheels at the back and front) can help you find one of these comfortable postures when you are out and about. Most people feel better pushing a supermarket trolley – it works the same way.
5. You can rest your head and arms on pillows on a table when you're really short of breath (**figure 3**). Or, try lying on your side, propped up with lots of pillows.

**Try all these positions and decide which ones are best for you. Different positions will suit different situations.**



## Sex and COPD

Having an illness like COPD can affect any relationship. It can make you feel tired, anxious or depressed. If you have COPD you might experience breathlessness during sexual activity. You might worry about sex if you are afraid that you will become too short of breath, or need to cough up phlegm. 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 [www.blf.org.uk/Page/Sex-and-breathlessness](http://www.blf.org.uk/Page/Sex-and-breathlessness) You can also order our leaflet, Sex and breathlessness, via the BLF website or by calling the helpline.

## Taking care of your feelings

Living with a lung condition is not easy. Experiencing physical symptoms such as breathlessness and coughing, feeling more tired and being less active than before are just some of the reasons you might feel stressed, anxious or depressed.

If you are struggling emotionally, talking to your family or a health care professional can help. It is 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. Or, some people with a lung condition find that joining a singing group is helpful for breathing and their general well-being. You can also talk to your doctor about medications or counselling to help you stay positive.

The Breathe Easy group network provides support and information for people living with a lung condition, their friends and family. For more information, or to find your local group, go to [www.blf.org.uk/BreatheEasy](http://www.blf.org.uk/BreatheEasy) or call the BLF Helpline on **03000 030 555**.

## 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 are caring 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. Ask your doctor or COPD service for information about social and financial support.

You can also find lots more information at [www.blf.org.uk/Page/Looking-after-someone-with-lung-disease](http://www.blf.org.uk/Page/Looking-after-someone-with-lung-disease) or by ordering our booklet, Looking after someone with lung disease, through the BLF website or by calling the helpline.

## Financial support

If you have COPD, or you care for someone who does, then you might be entitled to financial support. Help is available and even if you are in work, you might be able to claim financial benefits. For more information on your rights, go to [www.blf.org.uk/Page/Your-rights](http://www.blf.org.uk/Page/Your-rights) or call the BLF Helpline.

## Further information and support

### Disability benefits helpline

Anyone with a disability can get advice on benefits from this government helpline.

**08457 123 456**

### Age UK

Age UK aims to improve later life for everyone, and provides information on health and well-being for older people, as well as information about COPD.

**0800 169 6565**

**[www.ageuk.org.uk](http://www.ageuk.org.uk)**

The BLF has more information and publications about COPD and living with a lung condition. You might find these useful:

- COPD leaflet
- Healthy eating and exercise information
- Going on holiday with a lung condition booklet
- Breathlessness leaflet

The information above is free and available in print and online. You can read and order the information at **[www.blf.org.uk/lung-health](http://www.blf.org.uk/lung-health)** or by calling the helpline.

You may also benefit from our range of self-help tools, including the Living well with COPD DVD and Exercise handbook. For more information go to **[www.blf.org.uk/shop](http://www.blf.org.uk/shop)**

### British Lung Foundation

The specialist team of nurses and advisers on our helpline are dedicated to answering your questions. Whether it's about a visit to the doctor, concerns about your lungs, coping with symptoms or if you just need a chat, they are here for you.

Ringling the BLF Helpline never costs more than a local call and is usually free, even from a mobile.

Lines are open from 9am to 5pm, Monday to Friday.



### British Lung Foundation

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

