

CHRONIC OBSTRUCTIVE PULMONARY DISEASE

Contents

What is COPD?	4	
What causes COPD?	7	
What are the symptoms of COPD?	8	
Emphysema	10	
Chronic bronchitis	12	
Severe COPD	13	
How is COPD diagnosed?	17	
What are the treatments for COPD?	20	
What can you do to manage your COPD?		
Managing COPD flare-ups		

We feature real life stories in this booklet. Some names have been changed and some pictures are posed by models. The information in this booklet has been reviewed by independent experts. We have made every effort to ensure that the information provided is correct. Asthma + Lung UK cannot accept liability for any errors or omissions, and policy, practice or medical research may change. If you are concerned about your health, you should consult a doctor.

In this booklet, you can find out about chronic obstructive pulmonary disease or COPD. There's information about what it is, the symptoms you might get, 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 the airways have become 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, also called exacerbations.

We've written this information 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 and air gets trapped in your chest
- pulmonary = it affects your lungs
- disease = it's a medical condition

What is COPD?

Chronic obstructive pulmonary disease (COPD) is where air cannot get out of the lungs easily (the airflow is obstructed). COPD is a common condition that mainly affects middle-aged or older adults who smoke or have smoked. Jobs where people are exposed to dust fumes and chemicals also increase the risk of COPD, as well as having chest trouble or asthma in childhood.

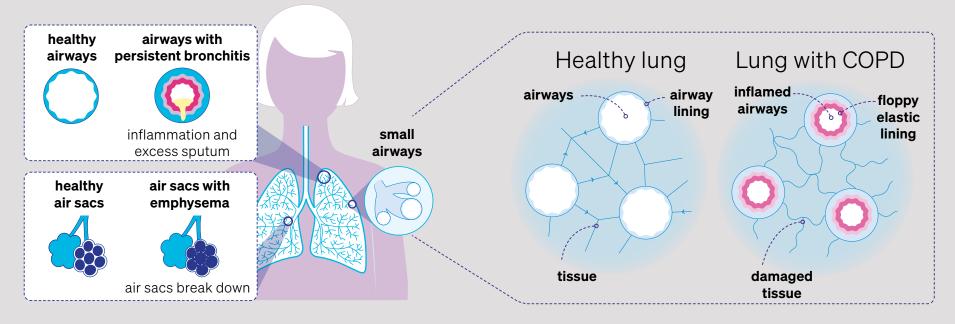
COPD includes long-term (chronic) bronchitis and emphysema:

- **Bronchitis** means the airways are inflamed and narrowed. People with bronchitis often cough up phlegm (mucus). Bronchitis can be a short-term (acute) infection, but for people with COPD, bronchitis is long-term (chronic).
- **Emphysema** affects the tiny air sacs at the end of the airways in your lungs, where oxygen is taken up into your bloodstream. These air sacs break down and the lungs become baggy and full of bigger holes which trap air, making it harder to breathe.

These conditions can often occur together. In both conditions the airways become narrowed. 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.

Your airways are lined by muscle and elastic tissue. In a healthy lung, the springy tissue between the airways pulls on the airways to keep them open. In a lung with COPD, the airways are narrowed because:

- the lung tissue is damaged so there is less pull on the airways
- mucus blocks part of the airway
- the airway lining becomes inflamed and swollen.



COPD is a long-term condition with no current cure. However, there are treatments and medications to help you breathe more easily and help keep you active. There are also things you can do to self-manage your condition at home.

COPD affects people in different ways. Some people with the condition have only mild lung damage and few symptoms. Other people have very damaged lungs and can feel very breathless and limited in what they're able to do – these people would be considered to have a severe case of COPD.

What's the difference between COPD and asthma?

With COPD, your airways have become narrowed permanently – inhaled medication can help to open them up, but only to some extent.

With asthma, the narrowing of your airways comes and goes. It often happens when you're exposed to a trigger – something that irritates your airways – such as dust, pollen or tobacco smoke. Inhaled medication can open your airways fully and relieve symptoms by relaxing your airways.

So, if you have symptoms like feeling breathless, cough, wheeze or a tight chest and these are much better on some days than others, or if you often wake up in the night with symptoms, it could be that you have asthma.

Because the symptoms are similar and because people who have asthma can go on to develop COPD in later life, it is sometimes difficult to distinguish the two conditions.

Additionally, some people have both COPD and asthma.

What causes COPD?

COPD usually develops because of long-term damage to your lungs from breathing in a harmful substance. This is usually cigarette smoke.

But COPD can also be caused from exposure to 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
- you are, or have been, a smoker, or
- you had chest problems as a child.

Some people are more affected than others by breathing in harmful substances. 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 much more likely to develop COPD at a young age.

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
- coughing up more phlegm (mucus) than usual.

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

If you have COPD that makes breathing very difficult, you could lose your appetite and notice you've lost weight. You may also find that your ankles swell because of a build-up of fluid (oedema). These are both symptoms of advanced COPD.

What's the outlook for people with COPD?

With COPD, you might experience flare-ups of your condition (these are also called acute exacerbations). This is where breathing and other symptoms get worse suddenly over a short period of time. As the underlying COPD gets more severe, some people may not be able to cope with this at home and may need to go to hospital for treatment. Sadly, despite treatment, a severe flare-up can be fatal. It's thought that around 4% of people admitted to hospital with an acute COPD exacerbation will die.

In the UK there are 1.3 million people with a diagnosis of COPD. And each year, around 30,000 people die in the UK from COPD.

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.



Emphysema

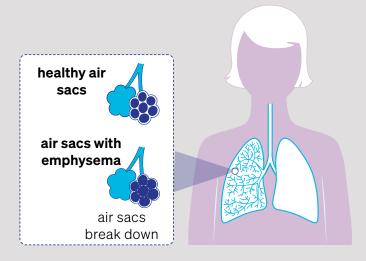
Emphysema causes breathing difficulties. This and chronic (long-term) bronchitis are the two main conditions of chronic obstructive pulmonary disease (COPD).

Healthy lungs are made up of millions of tiny air sacs (alveoli) with elastic walls. These are where oxygen is taken into the body and the waste gas, carbon dioxide, is expelled. Cigarette smoke and other particles you breathe in can damage the walls of these air sacs.

If you have emphysema, the walls of the air sacs in your lungs are damaged. The sacs break apart and merge into each other, creating holes in the lung.

If you have emphysema, you can find it uncomfortable to breathe as your chest becomes hyperinflated. This is when the damaged parts of the lung become baggy and trap air. This means when you breathe in, the damaged part of your lung inflates more and can get in the way of the healthier parts of your lung. This increase in the amount of air inside your chest is called hyperinflation.

For some people with emphysema, lung volume reduction procedures can be a very effective form of treatment.



What are the different types of emphysema?

If emphysema has caused extensive damage, it is sometimes called bullous emphysema. This is because a hole in the lung bigger than 1cm is called a bulla.

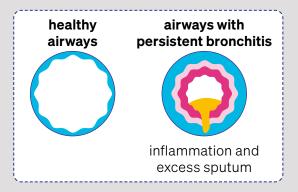
If the pattern of damage is fairly even throughout the lung, it is sometimes called **homogenous emphysema**.

Where the pattern of damage is uneven, it's called **heterogeneous emphysema**.



Chronic bronchitis

If you have chronic bronchitis, your airways are inflamed and narrowed. The narrowing of the airways affects how well and how easily air is emptied out of your lungs.



Bronchitis can be short-term (acute) and long-term (chronic). In COPD, bronchitis is chronic.

Symptoms of chronic bronchitis include:

- a continuous cough that produces phlegm (mucus) according to the NHS, this is defined as a daily cough for three months of the year, for two or more years in a row
- breathlessness
- wheezing.

People with chronic bronchitis often develop emphysema – when the air sacs in the lungs are damaged.

Severe COPD

Chronic obstructive pulmonary disease (COPD) affects different people in different ways. Some people with the condition have only mild lung damage and few symptoms. Others have very damaged lungs and can be especially limited by breathlessness – these people would be considered to have a severe case of COPD.

Over time COPD does tend to get worse – how fast this happens varies from person to person. If you smoke, quitting is the main thing that can slow this progress down.

The most common use of the term severe COPD is if:

■ You have severe or very severe airflow obstruction. This is measured using a breathing test called spirometry where you blow out as hard and as fast as you can. If the lung damage means that the amount of air you can blow out in one second is less than 50% of what it should be, it is classed as 'severe'. If it less than 30% that is classed as 'very severe'. Severe or very severe airflow obstruction is sometimes described as GOLD grade 3 or GOLD grade 4.

But COPD affects different people in different ways and the link between lung function test results and how you feel doesn't always match up. So, you might have 'severe COPD' if:

- You have been **admitted to hospital in the past** because of an acute flare-up (exacerbation) of your lung condition.
- You are **very limited by breathlessness** this means that even walking normally at your own pace you have to stop after 100 yards or a few minutes on level ground. Health care professionals sometimes use a measure called the MRC score to assess a person's breathlessness.
- You have **multiple medical conditions** many people with COPD have other medical conditions, such as heart disease.

- You need to use oxygen therapy at home.
- You need to use **non-invasive ventilation at home** this is usually a mask connected to a machine, sometimes called BiPAP, to support your breathing at night.

What makes a person have a severe case of COPD?

The severity of your COPD can depend on a number of factors:

- **If you smoke** quitting smoking is the most important thing you can do to slow the progress of your COPD.
- The type of COPD you have some people with COPD have mostly got airway disease (bronchitis), some have damage to the lung tissue (emphysema), and many have both.
- Your overall fitness the fitter a person is, the better they can cope with having a lung problem. Pulmonary rehabilitation (PR) can help with this.
- If you have other medical conditions for example, many people with COPD also have heart disease. Heart disease can also cause breathlessness, so someone with both conditions may have more challenges.
- If you experience anxiety or other mental health conditions

 anxiety can make breathlessness worse, so it is important to seek help for your mental health.

How can I cope with severe COPD?

The key things you can do are:

- Get help to quit smoking if you are a smoker. We have more support at blf.org.uk/smoking
- Ask your health care professional to refer you to pulmonary rehabilitation (PR)

- Complete our COPD Passport checklist to **make sure** you're getting the correct COPD care you're entitled to at passport.blf.org.uk
- Make sure you take your medication regularly and correctly
- If you're having frequent chest infections, tell your health care professional to see if they can do anything to help
- Be prescribed oxygen therapy if your blood oxygen levels are low
- Be prescribed non-invasive ventilation at home, this helps if you have breathing problems at night (obstructive sleep apnoea) or too much carbon dioxide in your bloodstream (hypercapnia)
- Ask about lung volume reduction procedures which can be very effective if you have emphysema
- Talk to your health care professional about ways to **look after your mental wellbeing** anxiety and depression can be common in people with long-term conditions, like COPD but there is support and treatment available to help.



How is COPD diagnosed?

What will the doctor ask me?

Your health care professional will ask:

- if you cough
- if you have a lot of phlegm (mucus)
- if your breathlessness is brought on by anything
- how your daily life is affected
- other questions about your general health and medical problems you have had in the past
- if you smoke or if you've ever smoked
- about your work history, and if you've been exposed to dust, fumes or chemicals through your work
- about childhood chest problems.

What tests will I have?

Spirometry

To get an accurate diagnosis of COPD, you should have a simple test called spirometry. This involves blowing hard and fast into a machine that measures your lung capacity. This is the total amount of air you can breathe out, and also how quickly you can empty your lungs. Healthy people can empty at least 70% of the air from their lungs in the first second of a hard blow out.

Spirometry only covers one aspect of your lung function. People with the same spirometry result may be more, or less, breathless depending on their level of fitness, any other medical conditions and the exact way COPD has damaged their lungs.

Chest X-ray and blood test

For most people, a firm diagnosis of COPD can only be confirmed by spirometry. It will not be made with a chest X-ray on its own. However, your health care professional should arrange for you to have a chest X-ray or scan and a blood test to rule out other causes of your symptoms.

BMI calculation

Your doctor will calculate your body mass index (BMI) to find out if you're a healthy weight. This is important because you can manage your COPD better if you're not underweight or overweight.

Other tests

Your health care professional may want to get a better picture of your condition and how it affects you, including:

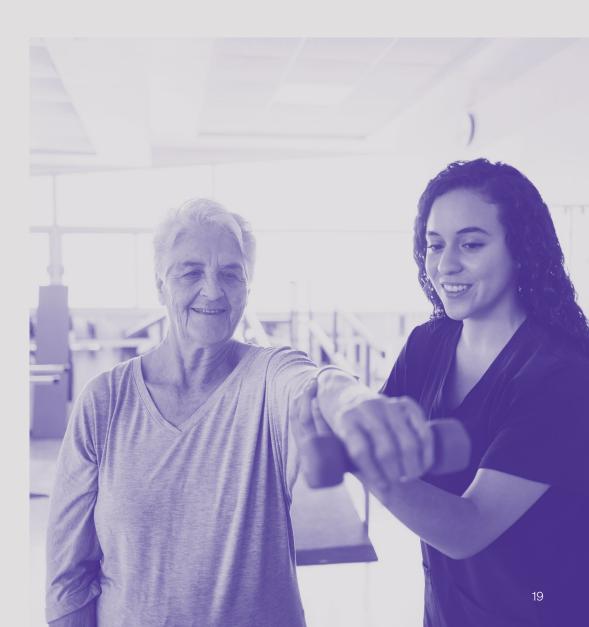
- tests to find out how well your lungs are functioning
- tests to see if the oxygen level in your blood is significantly reduced
- carrying out general tests, including measuring heart rate, blood pressure, and temperature
- asking how often you have symptom flare-ups or chest infections
- finding out how short of breath you feel during everyday activities.

Specialist care and support

You may also see a specialist doctor or nurse to confirm the diagnosis or to work out the right treatment for you:

- physiotherapists to help you deal with your phlegm (mucus), control your breathing and keep active
- dieticians to help you manage your weight

- occupational therapists to help make your daily living easier
- counsellors or talking therapists to help your mental wellbeing
- if you smoke, stop smoking advisors to help you quit.



What are the treatments for COPD?

Remember: you should have regular check-ups with your health care professional – at least once a year.

Check you're getting the best COPD care with our COPD passport checklist at **passport.blf.org.uk**

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 to make it easier for you. You're around three times more likely to quit with help from support services and medication.

Find out more about quitting smoking at blf.org.uk/smoking.

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. Vaccination reduces your risk of developing serious complications if you are exposed to flu, such as pneumonia and heart problems. The NHS offers it for free to people living with long-term conditions like COPD.

You should also make sure you're up to date on your coronavirus vaccinations.

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

Pulmonary rehabilitation

Pulmonary rehabilitation (PR for short) is a programme of exercise and education designed for people living with COPD. It's one of the best treatments available for COPD. Ask your doctor or nurse to refer you.

A course lasts about six to eight weeks and you'll be part of a group.

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 a treatment, not a cure, but you'll feel better, more confident, and in control.

After you've completed your course, it's important to carry on exercising regularly, stay active and use the techniques you've learned. Read our information on keeping active at **blf.org.uk/keep-active** or call our helpline to find out more.

Remember: it's not harmful to make yourself breathless when you're physically active.

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.

Have a self-management plan

It's important you have a plan to help you manage your COPD that's agreed with your doctor or nurse and reviewed every year. You can download a free copy on our website at **blf.org.uk/support-for-you/copd/your-copd-self-management-plan**

Look after other medical conditions

Most people with COPD have one or more other long-term health conditions. Examples include heart disease, diabetes, osteoporosis, muscle and joint problems as well as anxiety and depression. This can happen because:

- people with COPD may have smoked, and smoking causes other health problems, especially heart disease
- long-term medical conditions are more common as people get older and COPD tends to occur in older people
- COPD makes people breathless and less physically active which increases the risk of other health problems.

It's important to make sure all your health conditions are well managed, and all your symptoms are properly treated. For example, heart disease is common in people with COPD and can be another cause of breathlessness. Having anxiety can make it harder to cope with feeling short of breath and worsen your breathlessness.

Oxygen therapy

Your health care team may send you to a specialist to see if oxygen therapy can help you. Oxygen is only useful as a treatment for people with a low oxygen level. It doesn't help breathlessness in people whose oxygen level is not low. 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.

Non-invasive ventilation (NIV)

Sometimes, people who have severe COPD are unable to clear the waste gas carbon dioxide from their lungs, which can cause you to become very unwell. If you are admitted to hospital with a severe flare-up of your condition and high carbon dioxide levels, you may be offered non-invasive ventilation (NIV). This involves wearing a snug-fitting mask over your nose, or over your nose and mouth, connected to a machine that helps air get into your lungs. NIV supports your breathing to give your muscles a rest and helps you breathe out carbon dioxide.

NIV is also occasionally given at home to people with severe, but stable, COPD, who have too much carbon dioxide in their bloodstream (hypercapnia). 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. If you are found to have high carbon dioxide levels, then you might be assessed to see if this would be a helpful treatment for you.

Lung volume reduction procedures

Lung volume reduction procedures reduce the amount of air trapped in the lungs. The procedures are a suitable treatment for only 1-2% of people with COPD and only effective for people with emphysema. Lung volume reduction may involve an operation

to remove damaged parts of the lung or putting valves into the airways to block off the most emphysematous part.

If you have emphysema and you've had pulmonary rehabilitation and are still limited by breathlessness, ask your doctor if you might be suitable for a lung volume reduction procedure. This procedure is part of normal NHS care and your GP can refer you to a specialist centre if appropriate.

Lung transplant

A lung transplant is a high-risk major operation and is only suitable for a small number of people. Currently, there are not enough donor lungs available to meet demand.

Whether you can be considered for a lung transplant depends on factors that influence the chance of a successful outcome. These include your general health and fitness, other medical conditions that mean that you would not be able to cope with the procedure and whether you are over- or under-weight. You will also need to have not smoked for at least six months. There is no strict age cut-off, but it's unusual for people with COPD to have a transplant much over 60 years old. Ask your doctor if you think you might be suitable.

Medications

You and your doctor will decide together which medications you should use. This will depend on how severe your COPD is, how it affects your everyday life, and any side effects you may have had from previous medications.

Bronchodilators

Bronchodilators are a type of medicine you inhale, usually with an inhaler. They make breathing easier by relaxing the muscles in your airways helping them to open up.

Short-acting bronchodilator

■ If you only get short of breath when you're active, your doctor may give you a short-acting bronchodilator. This will help your breathing quickly and the effects last for four to six hours.

Long-acting bronchodilator

- If you're breathless every day, 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. They are called long-acting anti-muscarinic (LAMA) and long-acting beta agonist (LABA). Most people with COPD who are breathless will benefit from taking both kinds. Sometimes they come in separate inhalers and sometimes in combinations. You may get on better with one or another combination, but in general they are all thought to be equally effective.

Steroid inhalers

If you have more than one or two flare-ups (exacerbations) of your COPD requiring treatment, you may also be given an inhaler with a small dose of steroid in it. This can help reduce inflammation and swelling in your airways. You'll usually be given a combination inhaler – two or three medicines in one inhaler – with one or two bronchodilators and a steroid.

Steroid inhalers are also useful for people with COPD whose condition has asthma-like features: this includes varying day-to-day symptoms, a history of asthma or allergies, or higher levels of a type of white blood cell called eosinophils picked up as part of routine blood tests.

If you're prescribed steroids for your COPD you should always take them as prescribed. Do not stop taking your steroid inhalers just because you feel well. Not everybody with COPD needs to use inhaled steroids. Your health care professional should be able to explain to you why you are on them.

Steroid cards

If you are on a high dose of steroids, you should be given a steroid card from your GP. This is a card that lets health care professionals know you take steroids at a high dose.

For inhaled steroids a high dose is defined as more than 1000 micrograms of beclomethasone (a steroid medicine) or equivalent. Most people, even if they are on inhaled steroids, do not require such a high dose. Ask your health care professional if you are unsure what dose you're on.

Make sure you always carry your steroid card with you. If you have a carer, make sure they know you have a steroid card. If you lose it, you can get a replacement from your pharmacy or GP. It's useful in emergency situations, as your body may not produce enough natural steroids to help you deal with illness or injury. In this situation, doctors will need to give you extra steroids when treating you.

Taking your inhalers

If you're given inhaled medicine to take regularly, it's important you take it as prescribed, even if you feel well. This can also reduce the risks of a flare-up.

Inhaled medicine can be taken in different ways:

- dry powder inhalers (DPIs) breathe in as hard as you can then hold your breath for ten seconds
- soft mist inhalers these produce an aerosol but use spring power instead of propellant
- pressurised metered dose inhalers (pMDIs) they produce a puff of medication like an aerosol – use a slow deep breath in and hold your breath for up to ten seconds
- with a spacer these attach to pressurised metered dose inhalers (pMDIs) 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 normally only used in an emergency when you need large doses of inhaled medicine, such as during a flare-up.

Do you know how to use your inhaler?

Your inhaler will only help if you use it correctly. Ask your pharmacist, nurse or doctor to show you how to use each type of inhaler you have and make sure they review your technique at least every year.

We have videos showing how to use your inhaler properly at asthma.org.uk/advice/inhaler-videos

Treating COPD flare-ups (exacerbations)

It's normal for COPD symptoms to vary a bit from day to day. But if you notice your symptoms are worse for two or more days, you're having a flare-up (an acute exacerbation).

Your doctor may prescribe a rescue pack of drugs to keep at home in case you need them to treat a flare-up. Rescue packs include:

Steroid tablets

Steroid tablets can help you get better quickly during a flare-up but can cause side effects if taken at a high dose or for a long time. A supply of steroid tablets will normally last for five days, with the aim to reduce the inflammation in your airways.

Antibiotics

Antibiotics usually help if you have signs of a bacterial chest infection. This could be:

- becoming more breathless than normal
- coughing more than normal
- a change in colour or consistency in your phlegm (mucus).

Antibiotics won't help if your chest infection is caused by a virus. It's very important to only take antibiotics appropriately and when necessary. It's usually a five-day course.

Mucolytics

If you cough up a lot of phlegm (mucus), you may be given a drug called a mucolytic as a tablet or syrup. This may make your phlegm thinner and easier to cough up.

Side effects from medications

Steroid inhalers can sometimes make your voice hoarse or give you a fungal infection, called thrush, in your mouth.

You can reduce the risk of side effects from inhalers by:

- using your inhaler correctly
- using a spacer with your pMDI inhaler
- rinsing your mouth out after every time you use your inhaler.

Steroid tablets can help during flare-ups but cause side effects if taken at a high dose or for a long time. Longer courses of steroids should only be prescribed by a COPD specialist. You should be given the lowest effective dose and be closely monitored for side effects. Side effects of steroid tablets include increased appetite, difficulty sleeping, diabetes, weakening of the bones (osteoporosis), thin skin that bruises easily, cataracts and severe mood changes.

You and your doctor will decide together which medications you should use. If you're concerned about side effects, or want to know more about your medication, ask your pharmacist, doctor or nurse.

What can you do to manage your COPD?

You can do a lot to help manage your condition yourself. 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.

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

Keeping active

If you have COPD, being active and exercising can help you to improve your breathing, fitness and quality of life. It can also make you feel better, by improving symptoms of anxiety and depression. Keeping active can make a big difference – many people find this helps them more than inhaled drugs.

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.

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).

There is strong evidence that people with COPD benefit from PR and exercise more generally.

Remember: it's not harmful to get breathless when you're exercising!

There are lots of ways to be active – find one you might enjoy! We have ideas in our keep active information, as well as our Stay Active, Stay Well exercise videos, and our exercise handbook. Find out more at **blf.org.uk/keep-active**

Controlling your breathing

There are techniques and positions that can help you feel more in control of your breathing and cope when you get out of breath.

If you practise breathing techniques and use them every day, they'll help you when you're active or if you suddenly feel short of breath. Try different breathing techniques to find what helps you. There are also positions that can help you to practise breathing control or to control your breathing when you get breathless. Talk to your respiratory physiotherapist or nurse to find out what works for you. We have plenty of information on how to manage and live well with www.blf.org.uk/support-for-you/breathlessness

Some people with COPD who joined a singing group said singing helped them to manage their breathing and other symptoms better. Read our information on singing for lung health at **blf.org.uk/singing**

Have a self-management plan

Self-managing your condition – with support from others – helps to give you control. It helps to know all about your condition, your

symptoms, your medication and how to cope with flare-ups. It also makes your day-to-day life easier and could reduce the risk of needing to go into hospital.

It's important you have a plan to help you manage your COPD that's agreed with your doctor or nurse and reviewed every year. You can download a free copy of a self-management plan on our website at blf.org.uk/support-for-you/copd/your-copd-self-management-plan

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 necessary.

- 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 you find it difficult to shop and prepare meals, try to eat little and often. Ask your doctor or nurse about nutritional supplements.

Read more information on eating well at **blf.org.uk/eating-well** and find out about maintaining a healthy weight and how your diet can affect your symptoms.

Take care of your emotional wellbeing

Living with a long-term condition can affect many aspects of your life. Physical symptoms such as breathlessness and coughing, feeling more tired and being less active can mean you feel stressed, anxious, or depressed.

The risk of anxiety and depression is greater in people with more severe COPD, people who have been admitted to hospital, and those with low oxygen levels. Treatment and support are available to help you. Anxiety and depression are both understandable reactions to living with a long-term condition like COPD. Talk to your health care professional about counselling and medications.

Don't bottle things up – talking to someone you trust, including your 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 support group to meet others going through a similar experience, or join our online community.

Have a look at our information about looking after your mental health at **blf.org.uk/mental-health**

Our support groups are for people living with a lung condition and their families. It's a great way to get more information and make new friends. To find your local group, go to **blf.org.uk/support-for-you/breathe-easy** or call our helpline on **0300 222 5800**

"The idea of managing a long-term condition was very new to me."

Chris helped set up his local support group

I was diagnosed with COPD quite late on, after I was admitted to hospital with a flare-up. For the past 10 years I'd had a cough, and I remember running for a train with some friends and noticing that I was very, very breathless.

I had no idea what COPD was or what the doctors were telling me. The idea of managing a long-term condition was very new to me. We have an extremely good COPD service at my local hospital. They spent a lot of time explaining things to me and telling me what was going on.

I've had some serious flare-ups and been referred to pulmonary rehabilitation. I loved it and I've been doing follow-up exercise classes. Socially it's very important. I also use oxygen, which has given me a lot more confidence to go out and do different things. My wife and my daughter are a great support, as are my friends and family.

I set up my local Breathe Easy group because when things get hard it's easy to feel isolated. So it's good to remember you're not the only one who feels that way. Talking to other people going through the same thing is so comforting.

What else can I do to manage my COPD better? Sleep and rest

Make sure you sleep well and get enough rest every day. This will help with your energy levels. Talk to your doctor about how to get a good night's sleep.

Ask for help if you need it

Ask your health care professional 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.

Know your symptoms

Be aware of your regular symptoms and what is normal for you.

If your ankles swell, tell your health care professional as this could be a sign of advancing COPD. Medicines can help reduce this, as well as things that you can do at home. But many people with COPD have other conditions, and leg swelling or a rapid heartbeat can be a sign of a heart condition.

Sex and COPD

Having an illness like COPD can affect your relationships. 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 phlegm (mucus).

Your doctor, nurse or physiotherapist can help you to manage this. Read more about sex and breathlessness at **blf.org.uk/sex**.

Financial help

Just having a long-term lung condition, like COPD, doesn't entitle you to benefits. However, you may still be eligible to claim financial support. Or, if you have a carer, they may be able to claim benefits like respite care. Find out more in our welfare benefits information at www.blf.org.uk/support-for-you/welfare-benefits

Plan ahead

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. Read more information on advance care planning and taking control of your choices at **blf.org.uk/end-of-life**.

Looking after someone with COPD

When someone close to you has COPD and needs your support, it is natural to want to help them. If you look after someone you might feel anxious, frustrated or stressed. These emotions are normal. Talk about your worries with the person you care for, with their COPD specialist team, or family and friends.

If you care for a family member or partner, it is important to continue to enjoy things together and for the person with COPD to keep as active and independent as they can. Read our more detailed information for carers at **blf.org.uk/carers**.



Ian was diagnosed with COPD over 12 years ago

Early on, I relied on my GP and practice nurse entirely. But as time went on, I realised I wanted to understand my condition better to help manage it.

Now I keep a detailed twice-daily record of wellness and ambient conditions, my medication, my coughing and breathlessness and even things like sleep. With this evidence, my health care professional and I can decide what works best for me.

Several times a year I get extra breathless. But is it an infection, or a flare-up? It's good to ask because taking antibiotics and steroids unnecessarily isn't a good thing. But not taking them and letting the flare-up set in is also not good care.

When I was first diagnosed, I was reluctant to start my rescue pack. By the time I was sure it was an infection, it was three days in, and the damage to lungs and airways can be irreversible.

Often it's my wife who spots the signs first – she notices my change of mood and temper! Symptoms creep up on us and when I realise she's right – I'm not feeling my usual self – it's time to think.

I look at my notes, including my peak flow, check my temperature and think if anything's different: am I wheezing? has air quality been bad? have I forgotten to exercise? have I missed my meds? I'll take my relievers and see if my symptoms pass. It might have been a reaction to something like the weather or pollen.

Next day, if I feel worse and the signs are going downhill, I'll start my rescue pack. And of course, my GP is a phone call away.

I realise living with COPD is different for each person. So this is very personal to me. But I'd encourage everyone to start a diary of evidence, it takes just minutes each day. It doesn't need to be as detailed as mine but being in touch with changes in how you feel and your symptoms is important to get the right care for you. Also find out all you can about your diagnosis. Both will help you to manage your COPD with your GP and nurse.

Managing COPD flare-ups

A flare-up – sometimes called an acute exacerbation – is when your COPD symptoms become particularly severe.

Call 999 if you're struggling to breathe or have sudden shortness of breath and:

- · your chest feels tight or heavy
- you have a pain that spreads to your arms, back, neck and jaw
- you feel or are being sick.

You need to be seen urgently.

What are the signs of a flare-up?

It's normal for your COPD symptoms to vary a bit from day to day. But if your symptoms are worse for two or more days, this is a flare-up (an acute exacerbation).

Signs of a flare-up include:

- feeling a lot more breathless than usual
- you are coughing more
- you are producing more phlegm (mucus)
- your phlegm (mucus) changes colour or gets stickier.

Flare-ups are often triggered by an infection but there may be no apparent trigger. If you get a cold, watch out for any changes in your chest symptoms.

What should I do if I think I'm having a flare-up?

If you think you're having a flare-up, follow your action plan as agreed with your health care professional. Download a copy of our flare-up plan at **blf.org.uk/support-for-you/copd/your-copd-self-management-plan**.

Your flare-up plan may include a rescue pack of drugs (antibiotics or steroid tablets or both) that you keep at home. Make sure you know when:

- **to take steroid tablets** it's important not to use these too frequently, because of potential long-term side effects.
- to take antibiotics this will usually be when you are producing more phlegm (mucus) than usual or it has changed colour, as well as being more breathless for some time despite taking reliever medication.

Your doctor or nurse should discuss this with you at every review appointment.

Make sure you let your doctor or nurse know:

- if you take your rescue pack medication
- if things don't improve within two days of starting the rescue pack.

If your breathlessness gets worse, but you have no fever and your phlegm is normal for you, the first step is usually to use your reliever inhaler more. Make sure you know what to do – such as increasing the dose or changing how you take your bronchodilator medicine – to help with your symptoms. Many milder flare-ups will respond to this.

If your symptoms pass and don't develop into a flare-up, remember to tell your health care professional what happened.

Current guidance says people with COPD using three or more rescue packs in a year should be offered a review of their condition to check everything has been done to reduce the risk of flare ups.

Where will I be treated if I have a flare-up?

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.

Allow yourself some time to recover after a flare-up. Some people find it can take several weeks or even months to feel completely back to normal.

Hospital at home schemes

Most people with COPD who have a flare-up do not need to be admitted to hospital and can stay at home. But in some areas of the country, people who would be admitted to hospital elsewhere, can also be treated at home. 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.

What if I have multiple flare-ups?

If you have more than three flare-ups in one year that require your rescue drugs, ask your GP or nurse for a review.

It may be a good idea to ask for samples of your phlegm (mucus) to be analysed to see if you have an unusual or resistant infection. These can include pseudomonas and atypical mycobacterial infections, such as non-tuberculous mycobacterial infection (NTM).

Your doctor may order a scan of your chest to see if there is an area of damaged lung that makes you more likely to get infections.

If you are more likely to get these infections, make sure you act very quickly when you have a flare-up and be aware your usual rescue drugs may not be effective. Sometimes people who have frequent bacterial chest infections benefit from taking regular antibiotics. This is usually started by specialist teams.

How can I be prepared for flare-ups?

As part of your self-management plan, you should have a plan in place for if your symptoms get worse.

Make sure you 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. Download a copy of our flare-up plan at **blf.org.uk/support-for-you/copd/your-copd-self-management-plan**.

Your flare-up checklist

Do I feel worse than usual?			
If I get:	If I get:	If I get:	If I get:
more out of breath	more out breath despite taking my reliever medicines	more phlegm, change in colour: dark yellow, green	more chesty coughing
I will:	I will:	I will:	I will:
use my reliever inhaler more	start my rescue pack – steroids	start my rescue pack – steroids and antibiotics	keep calm and use ways to control my breathing

Call our helpline on **0300 222 5800**

We are here to help:

- answer your questions, whether that's about coping with symptoms, your rights or finding equipment
- provide clear and trustworthy information about breathing problems and living with a lung condition
- you to get in touch with your local support group

Our friendly team are here Monday to Friday 9am to 5pm. Calling will cost the same as a local call. It's usually free, depending on your call package, even from a mobile.

Or visit **AsthmaAndLung.org.uk** to find support and information or to join our web community

■ Get support and information blf.org.uk/support-for-you

■ Sign up to our newsletter blf.org.uk/signup

■ Find your local support group blf.org.uk/breathe-easy

join our web communityhealthunlocked.com/asthmalunguk-lung

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Each year over 400,000 people rely on our expert advice to make key decisions about their lung health. And today, you were one of them.

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Helpline: 0300 222 5800

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