

East Sussex

COPD Services

Winter 2024
Fourth Edition

Patient Information Pack

Patient name:

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Contents

- 3 | What is chronic obstructive pulmonary disease (COPD)?
- 4 | Managing breathlessness
- 5 | Pulmonary rehabilitation
- 6 | Treatments
- 8 | Managing worsening symptoms and flare-ups
- 9 | Smoking and respiratory conditions
- 10 | Living with COPD
- 11 | Weather advice
- 13 | Patient passport
- 14 | Self management plan
- 21 | Useful contacts

What is chronic obstructive pulmonary disease (COPD)?

COPD is a condition where your airways become inflamed and the air sacs in your lungs become damaged.

COPD stands for chronic obstructive pulmonary disease. This is the name used to describe a number of conditions including emphysema and chronic bronchitis.

It is 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.

Emphysema affects the air sacs in your lungs (alveoli), and chronic bronchitis affects your airways (bronchi).

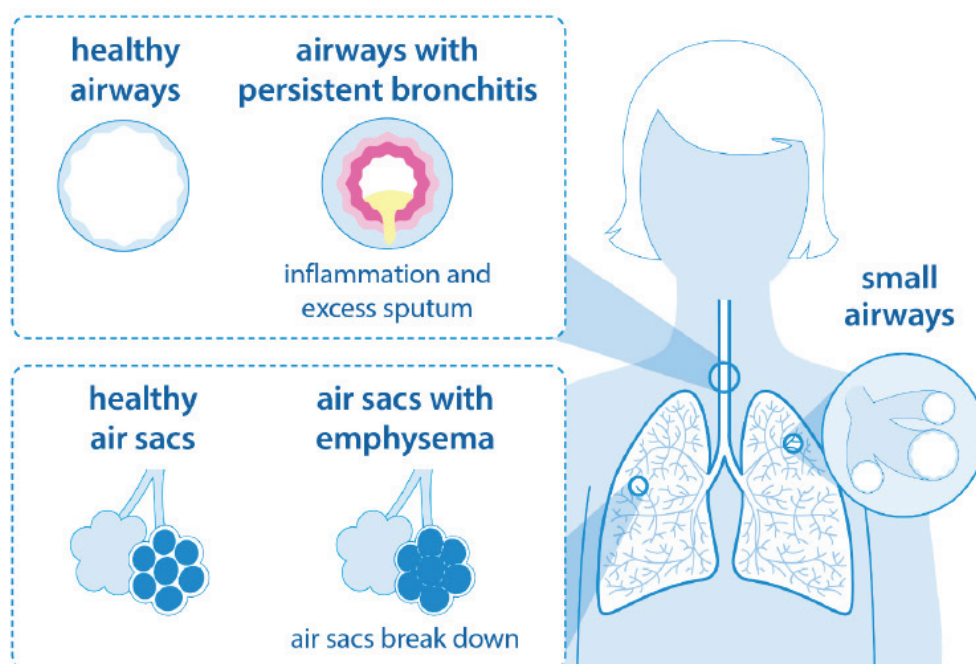
This diagram shows how emphysema and chronic bronchitis affect your lungs.

If you have COPD, you might have just one of these conditions, or you might have more than one.

If you have difficulty breathing this can affect many aspects of your day-to-day life.

Unfortunately, there is no cure for COPD, but there are lots of treatments to help you manage your condition, improve your symptoms and live an active life.

Asthma + Lung UK has a lot of information about COPD: including what it is, how to manage symptoms and what treatments are available. www.asthmaandlung.org.uk



Managing breathlessness



Find latest information at
www.blf.org.uk/support-for-you/breathlessness

Pulmonary rehabilitation

Attending a course of pulmonary rehabilitation is one of the best ways to reduce your breathlessness. Speak to your GP about a referral if you are feeling breathless and would like support to manage the symptoms of your condition.

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 practise them every day. They also help if you get breathlessness suddenly. Breathing control means breathing gently, using the least effort, with your shoulders supported and relaxed. Breathing techniques can be used as frequently as needed, or as advised by your clinician.

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:

- 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 as prescribed by the health care professional
- 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
- ask for help when you need it.
- once breathing has eased relax your shoulders and upper chest.
- stay still for a minute after you have got your breath back before returning to normal activities.

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

Positions to help you recover

Standing leaning backwards or sideways against a wall can help you to practise your breathing control or to recover your breath. Alternatively, try leaning forward from the hips and resting your forearms on a work surface, or on your knees, if sitting.

Fan Therapy

Fan therapy is a very useful tool in managing breathlessness. Research has shown that the cool air flow from a battery powered handheld fan can be very effective in reducing breathlessness symptoms. Try holding the fan 15cm from your face when you're next feeling short of breath and using it alongside other breathlessness management techniques. Keep it in your pocket when out and about or by your bedside if you wake at night.

Pulmonary rehabilitation



Find latest information at

www.blf.org.uk/support-for-you/keep-active/pulmonary-rehabilitation

Pulmonary rehabilitation (PR) is a programme of exercise and education for people with long-term lung conditions which you can access locally.

It combines physical exercise sessions with discussion, education, and advice on lung health, and is designed to help you to manage the symptoms of your condition, including getting out of breath.

A course of PR lasts about six to eight weeks, with two sessions a week. Each session usually lasts two hours. You will be part of a group, commonly between eight and 18 people. Being with other people who have similar problems to you can be very helpful, as well as making sessions enjoyable and fun. Group members often share useful tips with one another. The programme will be tailored to your specific needs and goals.

PR can:

- help to improve your muscle strength, so you can use the oxygen you breathe more efficiently
- improve your general fitness and help you to cope better with feeling out of breath
- help you to feel stronger and fitter, and able to do more.

Please bear in mind, however, your lung function is not likely to change, so you might not see a difference when you take the simple 'blowing test'. This is also called a spirometry test.

During your course, your PR team will teach you how to increase your activity safely and effectively, and manage breathlessness and feelings of anxiety or panic.

Topics included in the education part of the session include:

- breathing management techniques and coping strategies to use when recovering your breath, or during physical activity
- why exercise is so important for people with lung conditions
- how to manage stress and anxiety
- management of sputum
- healthy eating
- how to use your inhalers and other medicines
- how to manage flare-ups
- financial and social support

You will get out of breath when you take part in a PR course, but this is part of the therapy. You will always be monitored and you will never be asked to do more than you can do safely.

PR is about helping you manage your condition better. It is not a cure, but you will feel better and more confident and in control. PR requires your commitment to work properly. You need to attend sessions regularly and follow the advice given by your team.

After you have completed your course, it is important to carry on exercising regularly, stay active and use the techniques you have learned.

Please talk to your GP or respiratory team if you would like to be referred to your local Pulmonary Rehabilitation service.

Treatments



Find latest information at www.blf.org.uk/support-for-you/copd/treatment/medications

If you have COPD, there are a number of treatments that can improve your symptoms, reduce exacerbations (flare-ups) and improve your energy levels.

Getting the right treatment can make it easier for you to carry out daily activities like dressing, washing and walking.

Smoking – if you smoke, the single most important treatment for COPD is giving up.

Diet – it is important to eat well to prevent infections and keep your lungs healthy.

Medication

Types of Inhalers

There are different types of inhalers that do different things and require different inhalation techniques to get the medicine out of them and into your lungs.

It is important that you are shown how to use your inhaler properly and your technique is checked by a health care professional regularly.

Bronchodilator inhalers

If you experience mild symptoms now and then, your doctor might give you a short-acting bronchodilator inhaler. This relaxes the muscles in your airways to keep them as open as possible and relieve 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.

You may be given an inhaler that contains two long-acting bronchodilators in one inhaler.

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

Steroid inhalers

If you continue to have regular flare-ups despite your current inhaled bronchodilators, you may have a steroid inhaler added to your medication.

This type of inhaler is usually given as part of a combination inhaler – when two medications are given in one inhaler. This medication may help you to have fewer flare-ups.

Green Inhalers





The majority of inhalers used in the UK currently are Metered Dose Inhalers (MDIs). They contain a propellant gas that helps move medicine into your lungs when you press down the canister. Unfortunately this propellant gas is a greenhouse gas which has a large carbon footprint and contributes to global warming.

The other types of inhalers, Dry Powder Inhalers (DPIs) and Soft Mist Inhalers (SMIs), do not contain this propellant gas so are better for the environment. DPIs use a patient's breath and SMIs use an aerosol mist to move medicine into your lungs.

The most important thing is that you can use your inhaler properly and that it is managing your condition. If you are able to use a DPI or a SMI inhaler, then it is better for the environment if you do so. If you need to use a MDI, it is recommended that you use a spacer as this helps get more medicine to your lungs.

Talk to your health care professional about what is the right inhaler for you.

If you are using 'triple therapy' to manage your COPD (steroid and 2 bronchodilator medicines) it's easier for you and better for the environment to take these in a single combined 3 in 1 inhaler.

Types of inhalers	Dry Powder Inhaler (DPI)	Metered Dose Inhaler (MDI)	Soft Mist Inhaler (SMI)
			
Inhaler technique required	Requires QUICK and DEEP inhalation (within 2-3 secs)	Requires SLOW and STEADY inhalation (over 3-5 secs)	Requires SLOW and STEADY inhalation (over 3-5 secs)
Can you use a spacer with it?	No	Yes	No
			
Does it contain a propellant that is a greenhouse gas?	No	Yes	No

Treatments



Find latest information at
www.blf.org.uk/support-for-you/copd/treatment/medications

Using an inhaler

Your healthcare professional, doctor or pharmacist should teach you to use your inhaler properly to make sure the medication is effective.

You can also watch videos on your phone or computer to show you or remind you how to use your inhaler properly. Videos can be found on www.rightbreathe.com

Other medications

Your doctor might give you a medication called a mucolytic to reduce the thickness of your phlegm.

It is very important to use your medications regularly and correctly.

Inhaler disposal

To help improve the environment and reduce waste, try and use up all the doses in your inhaler (as many are thrown away half full). Please return unwanted or used inhalers to your local pharmacy for safe disposal.

Possible side-effects

Side-effects from inhaler medicines are not common, since the dose is usually very small.

Steroid inhalers can occasionally cause hoarseness or thrush in the mouth. You can reduce the risk of this by making sure you are using your inhaler correctly, rinsing your mouth with water (or cleaning your teeth) after use to remove any medicine particles or using a spacer device to reduce the impaction of particles in the mouth.

Pharmacy services

As well as your GP or nurse, your local pharmacist is another highly trained healthcare professional who can answer questions about your medication.

You'll find a pharmacist in your local health centre or high street pharmacy. They're also based in supermarket pharmacies, GP surgeries and hospitals.

If you have any concerns about your COPD, it's easy to walk into any local pharmacy and ask to see the pharmacist.

- You don't need an appointment.
- Some pharmacies are open outside GP surgery hours.
- Many pharmacies have a private consultation room.
- You can ask about repeat prescription support, stop smoking and losing weight advice.

You can ask your pharmacist about the medicines you've been prescribed. This is useful if you have concerns about things like side effects, using your inhaler, or your inhaler not working properly. You can also ask about any over-the-counter medicines you're taking.

Pharmacies can also provide flu vaccinations and some Covid vaccinations

New Medicine Service (NMS)

The New Medicine Service in community pharmacies provide support when you have been prescribed a new medicine for Asthma and COPD.

This is a great opportunity for you to:

- help you to find out more about the new medicine you have been prescribed
- help to sort out any problems you are having with your new medicine
- give you a chance to ask questions about your medicine and discuss any concerns
- help to improve the effectiveness of your new medicine, for example, there may be an easier or better way to take it
- help you to make your own decisions about managing your condition
- help you to improve your health, which could lead to fewer GP and hospital visits.

Managing worsening symptoms and flare-ups



Find latest information at
www.blf.org.uk/support-for-you/copd/flare-ups

An exacerbation happens when you experience any two of the following symptoms: worsening breathlessness, increased coughing, increased phlegm or discoloured phlegm.

This is also known as a flare-up, when your symptoms get suddenly worse. You might feel unwell, or have a fever.

A flare-up might be triggered by viral infections (such as cold and flu), a bacterial infection, or other causes such as air pollution, weather changes or stress. Antibiotics do not always help a flare-up because it may not be caused by a bacterial infection.

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 medicines (steroid tablets and sometimes antibiotics) 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 you have started this medication you keep at home and also if things don't improve within two days.

If you have frequent or prolonged flare-ups with increased or discoloured phlegm, you may be given preventative antibiotics. 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 prescriptions if you have a flare-up that is getting worse, even when taking the medicines you keep at home.

Coronavirus Disease

If you live with COPD, you are at a higher risk of severe complications if you get COVID-19. It's important you follow social distancing advice particularly carefully and continue to self-manage your condition well. It's recommended you get a COVID jab if you have a long-term lung condition.

Continue your usual care, including taking medications as prescribed. Wash your hands often, and clean things like face masks, spacers, nebulisers and peak flow meters regularly.

For breathing exercises or non-invasive ventilation, keep the room well-ventilated and ask other members of your household to wait for a few minutes before entering. This is to avoid them breathing in any droplets in the air. If you are more breathless than usual and worried about COVID, use the 111 online coronavirus service (111.nhs.uk/covid-19).

If you are:

- struggling to breathe or
- feel like you're panting or
- having difficulty speaking or
- feeling like you're choking

use your usual techniques to control your breathing. If these don't work as quickly as they usually would, call 999 for help. The NHS is here to look after you, and it's important to get the help you need for your lung condition.

Find up-to-date information and advice at:

www.asthmaandlung.org.uk/conditions/coronavirus
www.gov.uk/coronavirus

Smoking and Respiratory Conditions



For information on steps you can take to quit, visit www.blf.org.uk/support-for-you/smoking

According to the World Health Organisation, smoking is the main cause of COPD. This includes smoke from cigarettes, cigars, and pipes as well as secondhand tobacco smoke exposure. People are exposed to secondhand smoke when they breathe near someone who's smoking. COPD is rare in people who have never smoked but can develop if you have had asthma for many years or had weak lungs as a child.

Cigarette smoke contains harmful toxins that affect lung function and trigger the onset of COPD. This process happens over 20 to 30 years which is why most patients start to get the COPD symptoms of cough, phlegm and breathlessness when they are 40 to 50 years old.

The best way to prevent the disease from getting worse is to quit smoking immediately and to avoid second hand smoke.

- Stopping smoking can prevent further lung damage and allow your inhalers to work better. It's never too late to stop, no matter how long you have smoked for.
- People who continue to smoke risk accelerating the disease and its symptoms. Smoking also increases your risk of heart attacks and lung cancer.

There is no safe way to use tobacco. Roll-ups are just as dangerous as manufactured cigarettes and can be more so without filters.

There's no cure for COPD and lung damage can't be reversed. However, some medical treatments and lifestyle adjustments can help you feel better, improve your overall health, and prevent your symptoms from getting worse.

Some lifestyle changes that may ease symptoms include:

- quitting smoking if you smoke
- avoiding secondhand smoke and places with air pollution
- having a diet that largely consists of vegetables, lean proteins, and whole grains
- exercising at least three times per week.

When they're used in combination, medical and lifestyle remedies can slow down the progression of COPD and decrease the severity of symptoms.

E-cigarettes and your lungs

E-cigarettes are less harmful than tobacco, but they're not risk-free. More research is needed on how long-term vaping can affect your lungs and overall health.

We know that vaping can cause inflammation in the airways, which might cause harm over time. We don't recommend that anyone uses e-cigarettes unless they are trying to stop smoking.

If you have a long-term lung condition, it's a good idea to stop vaping eventually. But it's important to not give up vaping before you're ready, as this could cause you to start smoking again. Many of the same techniques used to quit tobacco smoking can be used to quit vaping.

“Giving up smoking can be really tough. It's important to remember that getting support from Stop Smoking Services is still the most effective way to quit.”

Alison Cox, Director of Cancer Prevention at Cancer Research UK.

Living with COPD



Find latest information at

www.blf.org.uk/support-for-you/looking-after-your-mental-health

Living with COPD can affect many aspects of your life. You'll have physical symptoms, like getting out of breath and feeling tired. However, COPD can also affect your mood and how you manage your condition.

You are not alone

Many people with COPD can feel anxious. Some people also have low mood or symptoms of depression. It's common to experience anxiety and depression together.

Symptoms of anxiety often occur with breathlessness, which can be frightening. Being anxious can make all of us feel out of breath, and if you are living with COPD your main symptom may be getting short of breath. Being anxious can make this feeling worse, and may make you panic.

Symptoms such as coughing and breathlessness may cause you to stay at home more and avoid physical activity. You might not sleep as well, and lose interest in your usual activities. You may feel that your breathing problems have stopped you doing what you enjoy. This can leave you feeling angry, disheartened or hopeless. These emotions can be symptoms of depression.

Support for your wellbeing

People often experience symptoms of anxiety and depression at the same time. That, in turn, can make your COPD worse. Remember that many other people have experienced anxiety and depression and have recovered from them. They are both very normal reactions to living with COPD. Treatment and support is available.

When you experience anxiety or depression, it can be hard to find the energy to look after yourself. However, keeping active, eating well and getting good sleep will help to improve your mood and boost your energy levels. Try to plan in activities that you enjoy, such as reading, cooking a meal or taking a long bath. You might like to try keeping a mood diary to help you notice if any activities, people or places affect your mood.

Talking to someone you trust about your anxiety and low mood could help, or you can access help from the resources and services included in the 'Useful contacts' section of this patient information pack.

Your local talking therapies service is called Health in Mind (see 'Useful contacts') and covers East Sussex. There are courses you can attend with other people who have COPD and who want to find out about ways to manage the impact their COPD has on their anxiety and mood.

Alternatively, there is individual support to help manage the experience of anxiety and low mood.

There are also respiratory support groups for patients and their carers. More details of these can be found in the 'useful contacts' section.

Weather advice



Find latest information at
www.blf.org.uk/support-for-you/hot-weather

Warm weather advice

As summer approaches and the temperature rises, you may find that high temperatures cause your symptoms to flare up.

If you know you're affected by hot weather, there are things you can do to help keep yourself well.

Check the weather, pollen and pollution forecasts

Warm weather, high pollen and pollution levels can increase your chances of a flare-up, so be aware when a heatwave is forecast and plan ahead. You can sign up for air quality notifications with airAlert (see 'Useful contacts').

Avoid the heat

If a heatwave is forecast, don't go outside during the hottest time of day, normally between 11am and 3pm. If you have to go out, plan your day around the early morning or evening when the air is cooler. Where possible, walk in the shade and avoid main roads.

Keep out of the sun

If you do need to go out during the day, avoid being in the sun for long stretches. Wear loose, cool clothing and a hat.

Pack a bag of essentials

If you're going out, take a bag of essentials. Include any medication that you might need, plenty of water and a fan.

Exercise sensibly

Do your exercise indoors in a cool, well-ventilated room or gym. Try to do activities like housework and gardening in the early morning or evening when it's cooler.

Drink cold water

Have a drink of cold water regularly even if you don't feel thirsty – it's important to stay hydrated. Drinks with caffeine, alcohol or that are high in sugar will make you more dehydrated.

Keep your house cool

Closing blinds or curtains can help to keep your house cool. If it's cooler in your house than outside, close the windows to keep the cool air in. Try using a handheld fan.

Eat as normal

Try to eat as normal – even if you aren't hungry - to replace the salt lost through sweating. Cold foods like salad and fruit are particularly good because they contain a lot of water.

Weather advice



Find latest information at
www.blf.org.uk/support-for-you/cold-weather

Cold weather advice

Avoid catching colds or flu

Catching a cold or another infection can lead to your symptoms getting worse or your condition flaring up. If you can, avoid contact with people who have cold symptoms.

If you catch a cold, watch out for symptoms that get worse. Make sure you know what to do if you become breathless or start to cough up phlegm.

Get a flu jab

People with long-term conditions are eligible for a free flu jab. Ask your GP or pharmacy in the autumn. Having a flu jab reduces the risk that you will need to be admitted to hospital.

Get an anti-pneumonia and COVID vaccination too

It's recommended you get an anti-pneumonia and COVID jab if you have a long-term lung condition such as COPD, bronchiectasis or pulmonary fibrosis.

Stay warm

Heat your home to at least 18°C (64°F). Overnight in winter, keep your bedroom at this temperature too and wear warm nightclothes.

If possible, air your home for 10 minutes each day to reduce condensation and damp conditions.

Wear multiple layers of clothing when it's cold. This traps warm air better than one bulky layer.

Have lots of hot drinks and at least one hot meal a day, if you can.

Keep active

Try to stay as active as you can to generate body heat. Get up, move around and try to do some exercise. Chair exercises are a good way to keep active.

When you're out and about

Check the weather before you go out and sign up for airAlert and coldAlert notifications (see 'Useful Contacts'). If it's too cold or breezy for you or you are not feeling well or are having trouble breathing, stay indoors and keep warm.

Try to breathe through your nose instead of your mouth as this will help warm the air you breathe in. Protect your lungs and airways by wearing a hood or scarf that covers your mouth.

Plan ahead and stock up

If you have medicines at home, check the use by dates to make sure they will see you through the winter. If you take your emergency medication, tell your health care professional that you have started it and use it as prescribed.

Patient passport



www.passport.blf.org.uk

Asthma + Lung UK provide an online patient passport for you to find out if you're getting the care you need for your COPD. Complete the questionnaire and discuss your answers with your doctor or nurse.

Questions to ask your doctor

- Was my diagnosis of COPD confirmed with a lung function test (spirometry)?
- Can you explain more about my COPD, and how to find information, advice and emotional support?
- Can I agree a self-management plan and get a written copy?
- I would like to find out more about the free annual flu vaccination and the one-off pneumonia jab and covid-19 vaccine.
- I'd like to be offered support and treatment about giving up smoking.
- Can we discuss the importance of keeping active and eating well?
- I'd like to discuss pulmonary rehabilitation.
- Can you advise me about ongoing exercise and nutrition?
- Can we discuss what all my medicines and inhalers are for and when I should take them?
- Can we review how I use my inhaler?
- How do I know if I'm having a flare-up?
- What medicines should I take and who should I contact if I'm having a flare-up?
- When do I have my yearly review to discuss health, care and treatment?

Contact Asthma + Lung UK

Phone the helpline: 0300 222 5800
Monday to Friday from 9am to 5pm.

Email: helpline@asthmaandlung.org.uk

Post: Supporter Care Team,
Asthma +Lung UK,
18 Mansell Street,
London,
E1 8AA.

A self-management plan for patients with Chronic Obstructive Pulmonary Disease (COPD)

This is your personal self-management plan. Bring it with you every time you see a healthcare professional about your COPD.

The aim of this plan is to help you have better control of your COPD. It will enable you to monitor your symptoms and to know what to do if you have an exacerbation. An exacerbation is a rapid and sustained worsening of your symptoms that may warrant a change to your regular treatment.

This plan includes sections for recording medication, monitoring symptoms and treating exacerbations.

Name:	Date of birth:
NHS number:	GP practice:
Diagnosis:	

Outside normal GP practice hours, please call NHS 111 or 999 for emergencies and urgent care.

Usual COPD symptoms when well

Breathlessness score

Please record the MRC breathlessness score (see below) that describes your symptoms when you are well.

Date:	Score:
-------	--------

The MRC breathlessness scale

Grade	Degree of breathlessness related to activities
1	Not troubled by breathlessness except when taking strenuous exercise.
2	Short of breath when hurrying on the level or walking up a slight hill.
3	Walks slower than most people on the level, stops after a mile or so or stops after 15 minutes walking at own pace..
4	Stops for breath after walking about 100 yards or after a few minutes on level ground.
5	Too breathless to leave the house, or breathless when undressing.

Sputum production

The normal colour of your sputum is:

How much sputum do you produce each day?

Cough

Do you normally have a cough?

Swollen ankles

Do you normally have ankle swelling?

Usual respiratory medication

Inhaler or tablet name	Preparation	Dose and frequency

Oxygen saturation level

Normal oxygen saturation is 92 per cent or above

Your usual level is %

How do I keep well?

- daily exercise
- eat a good balanced diet
- drink plenty of fluids
- do not smoke, and avoid smoky environments
- plan ahead and have things to look forward to
- always have enough medications – never run out
- take all medication regularly as prescribed whether I think they help me at the time or not
- make sure I have my annual flu vaccination.

Your COPD may be getting worse if you:

- are more breathless than usual
- have an increase in the amount or change in the colour of your sputum
- have a new or increased cough
- have new or increased ankle swelling
- are more frequently using reliever medication
- are less able to do your normal activities or they are taking longer because of shortness of breath.

Action to take if your COPD symptoms are getting worse:

- increase reliever medication
- balance activity with plenty of rest
- eat little and often
- drink plenty of fluids.

Continue to monitor your symptoms closely.

- If your symptoms improve within two days, continue your usual medication.
- If they are no better or getting worse, continue with the increased dose or reliever medication and see What to do if you have an exacerbation on the next page.

What to do if you have an exacerbation

You are having an exacerbation if you have two or more of the following three signs:

- you are much more breathless than usual
- you have an increase in the amount of sputum
- you have a change in the colour of your sputum.

What to do if you have an exacerbation of your COPD:

- contact your GP or practice nurse
- contact the community nurse and/or respiratory nurse
- start taking your standby supply of steroids and/or antibiotics
- other _____

Standby exacerbation medication (Your health professional will assess as to whether this is required)

Steroids (prednisolone)

If you are much more breathless than normal, and your daily living activities are affected, continue with increased reliever medication and start taking prednisolone.

Dose of prednisolone: 30mg, once a day for _____ days.

Antibiotics

If the colour of your sputum changes from your normal colour, start your antibiotics.

Preparation:

Dose:

If you experience an exacerbation of your COPD, and start prednisolone and/or antibiotics, always let your GP or practice nurse know as soon as possible.

Emergency symptoms of COPD

- extremely short of breath with no relief from inhalers
- chest pain
- high fever
- feeling of agitation, drowsiness, panic or confusion.

Contact your GP surgery immediately. Outside normal GP practice hours, please call NHS 111 or 999 for emergencies and urgent care.

Have you used your standby exacerbation medication?

Remember to:

- contact your GP or community nurse (delete as appropriate) if you do not start to feel better after three days of treatment
- contact your GP or community nurse (delete as appropriate) if you take **more than one** course of standby steroids and antibiotics in **one month**.

Exacerbation diary

Date	Treatment used	Hospital admission

My hospital consultant is:

Any other relevant information or advice:

Notes:

.....

Top tips from my clinician:

.....

My key contacts for help (e.g. nurse or carer):

.....

My reminders to keep well:

.....

Actions I need to take if my symptoms get worse:

.....

Useful contacts

Stop smoking and lifestyle support

One You East Sussex has a range of services available to help you go smoke free, be more active and eat well. You will receive the expert help of a specialist and all the support you need to stop smoking and remain smoke free. One You's fully trained advisors will work in partnership with you to discuss behaviour change techniques and develop a tailored support plan.

One You East Sussex

Phone: 01323 404600
Email: hello@oneyoueastsussex.org.uk
Web: www.oneyoueastsussex.org.uk

Support groups

Support groups such as the Asthma + Lung UK support group network provide support and information for people living with a lung condition, and for those who look after them.

Breathe Easy groups are run by members, with help and support from Asthma + Lung UK when it's needed. Groups may run a range of additional activities, such as singing or exercise.

Web: www.asthmaandlung.org.uk/groups-support

Breathe Easy Eastbourne

Where: Deerfold Centre, 233 Seaside, Eastbourne BN22 7NR
 Committee room available for small donation

When: Drop-in Centre 10am-3pm Mon, Wed & Fri
 Support Group 3rd Tuesday of the month
 Rehabilitation maintenance programme every Wednesday 1pm-3pm

Contact: For details call our support line on 07949811599

Email: breatheasyeastbourne@gmail.com
Web: www.breatheasyeastbourne.org
Facebook: Breathe Easy Eastbourne

Breathe Easy Lewes

Where: Ringmer Village Hall, Lewes Road, Ringmer, BN8 5QH

When: Support group last Friday of the month 2.00pm-4pm
 Rehabilitation maintenance programme every Thursday 11am-1pm

Contact: For details call our support line on 07969 490379

Email: breatheasyeastbourne@gmail.com
Web: www.breatheasyeastbourne.org

Singing groups

Groups meet to sing to support their breathing and health. Some groups are COPD specific, some are breathing specific, some are for all aspects of health.

Motivational Mondays

Where: Groups are held online
When: Every Monday 10.30-11.15am (except Bank Holidays)
Contact: 0300 222 5800, option 4
Email: supportgroups@asthmaandlung.org.uk
Web: www.asthmaandlung.org.uk/groups-support/motivational-mondays

Harmonica for lung health

Where: Groups are held online, but places are limited.
Contact: 0300 222 5800, option 4 to register interest
Email: supportgroups@asthmaandlung.org.uk
Web: www.asthmaandlung.org.uk/groups-support/harmonica-lung-health

Singing for Better Breathing – Rye

Where: Sessions are held online
Contact: 01797 226330
Email: enquiries@themusicwell.org.uk
Web: www.themusicwell.org.uk

Sing for Better Health – Groups in Brighton & Hove

Contact: 01273 556755
Email: udita@singforbetterhealth.co.uk
Web: www.singforbetterhealth.co.uk

Exercise and Activity

Bexhill Breathers

Where: The Pelham, Holliers Hill,
Bexhill-on-Sea TN40 2DD
Every Thursday 2.30-around 4pm

Where: Hastings Centre, The Ridge,
Hastings TN34 2SA
Every Friday 2.30-around 4pm

Contact: Tim Birch 07508408813

Email: bexhillbreathers@gmail.com

Pulmonary Rehabilitation

Exercise and education programme for people with long term lung conditions, held at venues across East Sussex. Referral by health professionals – Ask your GP for information.

Web: www.esht.nhs.uk/leaflet/pulmonary-rehabilitation

Ongoing Pulmonary Rehabilitation (Eastbourne, Polegate & Lewes)

Ongoing pulmonary rehabilitation with Eastbourne Breathe Easy Group, in partnership with the University of Brighton. Groups are led by a qualified professional and physiotherapy students.

Email: breatheeasyeastbourne@gmail.com

Psychological therapies and counselling and wellbeing services

Health in Mind

Free NHS service for anyone in East Sussex experiencing emotional or psychological difficulties.

Tel: 0300 00 30 130

Email: spnt.healthinmind@nhs.net

Web: www.healthinmind.org.uk

Sussex Mental Healthline

Registered clinicians are at the other end of the freephone number to provide help, support and advice to anyone who needs it, at any time of the day or night.

Tel: 111 and 'select mental health option'

Text: the word SUSSEX to 85258

Tel: 0300 5000 101 to use text relay

East Sussex Mental Health Directory of Community Support

Online directory of community mental health support services, including carer support, drug and alcohol services and lifestyle changes.

Web: www.eastsussex.gov.uk/socialcare/healthadvice/mental-health/directory

East Sussex Community Network

A network of free community-based mental health recovery services, including Wellbeing Centres and a Peer Support Service, to enable you to get well, stay well and prevent crisis.

Wellbeing Centres in Hastings/St Leonards, Bexhill, Eastbourne, Lewes, Newhaven, Hailsham, Uckfield and Crowborough.

Tel: 01323 405 334

Email: ESCN@southdown.org

Web: www.southdown.org/mental-health-recovery

Community Connectors

When everyday life is affecting your mental health and wellbeing, Community Connectors work in partnership with GPs to help you access local services and activities that can help.

Tel: 01323 340 151

Email: social.prescribing@nhs.net

Web: www.southdown.org/mental-health-recovery

Recovery Partners Peer Support

Recovery Partners is a mental health recovery project, offering 1-2-1 and group peer support.

Tel: 07976 628737
(contact Anna Stratford Director)

Email: info@recovery-partners.co.uk

Web: www.recovery-partners.co.uk

Mind (Brighton & Hove)

National charity with a focus on information, rights and involvement.

Tel: 01273 66 69 50

Email: info@mindcharity.co.uk

Web: www.mindcharity.co.uk

Supporting someone with breathlessness

Help and advice for family and friends of people with breathlessness.

Web: www.supporting-breathlessness.org.uk

Big White Wall

National website with online guided support and counselling

Web: www.bigwhitewall.com

Local and national organisations

Asthma + Lung UK

Advice and support for people affected by asthma and lung disease.

Helpline: 0300 222 5800

Email: helpline@asthmaandlung.org.uk

Web: www.asthmaandlung.org.uk

Action for Pulmonary Fibrosis

Supporting patients and families to raise awareness of pulmonary fibrosis through research, education and campaigning.

Web: www.actionpf.org

Rightbreathe

Inhaler device prescribing information and training materials.

Web: www.rightbreathe.com

coldAlert

Providing free cold weather alerts for residents of Sussex.

Tel: 01273 484 337

Email: information@coldalert.info

airAlert

Free messages informing you if poor air quality is predicted in your area.

Email: information@airalert.info

Web: www.airalert.info/Sussex

Tel: 01273 484 337

Keep Warm and Well in East Sussex

Website providing tips to help you keep well, details about Warm Home Checks, financial assistance, information and support.

Web: www.warmeastsussex.org.uk

East Sussex Welfare Benefits Helpline

Tel: 0333 344 0681
(Monday to Friday, 9am to 5pm)

Email: benefitseastsussex@harcuk.com

Gov.uk

Useful information about money, tax and benefits, caring for someone and travel and transport.

Web: www.gov.uk

NHS website

COPD can be found in the Health A-Z section. The pages contain information about diagnosis, treatment and support and include a video interview with a patient who had COPD.

Web: www.nhs.uk

Care for the Carers

Independent charity supporting unpaid carers in East Sussex.

Tel: 01323 738390

Email: info@cftc.org.uk

Text: 07860 077300

Web: www.cftc.org.uk

Age UK

Advice and support for older people, their families, carers and professionals. Age UK East Sussex also offer community services and social activities.

Advice line: 0800 678 1602 (8am to 7pm)

Tel: 01273 476704

Email: information@ageukeastsussex.org.uk

Web: www.ageuk.org.uk

East Sussex Community Information Service (ESCIS)

Free directory of local and community information, groups and activities, managed by the Library and Information Services.

Web: www.escis.org.uk

East Sussex 1Space

Directory of care support and wellbeing services

Web: www.1space.eastsussex.gov.uk



If you would like further copies of this Patient Information Pack, or require the information in an alternative format, please contact PolicyStrategyAdmin@eastsussex.gov.uk. This Information Pack is also available in PDF form on request.