

# Living well with chronic obstructive pulmonary disease (My COPD information)

Department of Respiratory Medicine

Information for Patients

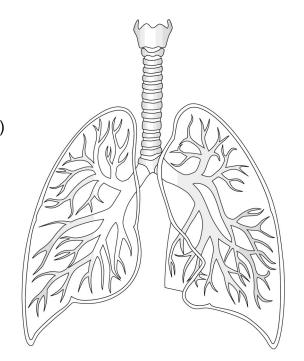
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#### Introduction

This information is designed to help you to understand and manage your condition. If you need help and advice about your breathing, please contact Single Point of Access (SPA) on **Tel: 0300 300 7777** and ask for a community respiratory nurse (Long Term Conditions Team).

If you were given this leaflet by a COPD specialist nurse, they will contact you 2 to 3 days after you leave hospital. Tel: 0116 250 2781 - Monday to Friday, 8.30am to 4.30pm.



Would you like to improve your breathing?

Would you like to be able to do every day things without struggling so much?

Ask your doctor or COPD nurse to refer you to the Pulmonary Rehabilitation

Service so you can activate your lungs!

# Health information and support is available at www.nhs.uk or call 111 for non-emergency medical advice

Visit www.leicestershospitals.nhs.uk for maps and information about visiting Leicester's Hospitals

To give feedback about this information sheet, contact InformationForPatients@uhl-tr.nhs.uk





#### What is COPD?

Chronic **o**bstructive **p**ulmonary **d**isease (COPD) is a condition that affects breathing. With COPD it becomes harder for the lungs to move air in and out, so they are less able to breathe in oxygen and breathe out carbon dioxide. The lungs lose elasticity and the muscles weaken making the airways narrower. Inflammation in the airway causes swelling, which also makes the airways narrower. COPD is also sometimes known as persistent bronchitis and emphysema.

**Bronchitis** is when the airways are inflamed and narrow. People often cough up phlegm or mucus (sputum).

**Emphysema** is when the air sacs at the end of the airways break down and the lungs become baggy and full of holes which trap air.

### What causes COPD?

COPD is most likely to happen if you are over 35 years old and have smoked cigarettes, or smoked any other drugs. Harmful substances in these causes damage to the lung tissue. If you have been exposed to dust, fumes, chemicals, or air pollution, this can also damage your lungs.

Your risk of having COPD is greater if your parents have lung problems. There is a rare genetic condition called alpha-1-antitrypsin deficiency that makes people more likely to have COPD at a young age.

# What are the symptoms of COPD?

Symptoms may happen every day but will be worse when you have an infection or breathe in smoke. Daily symptoms may include:

- getting short of breath when doing usual things (e.g. walking, housework or gardening).
- producing phlegm (sputum).
- wheezing in cold weather.
- having a cold that lasts a long time.
- having frequent chest infections.

# How is COPD diagnosed?

Your doctor will ask you about your symptoms and exposure to smoking or other chemicals. They may arrange for you to have a chest X-ray and blood tests. You will need a simple test called **spirometry** to check how well your lungs are working. This involves blowing into a machine that measures how quickly you can empty your lungs in 1 second (this is known as FEV<sub>1</sub> which stands for forced expiratory volume) and the total amount of air that you can blow out (this is known as FVC which stands for forced vital capacity).

You may be referred for more detailed tests.



# How can I cope with COPD?

There is no cure for COPD but there are things you can do that may help you to breathe easier and feel better. Learning about your condition will help you to identify changes in your disease and know when to ask for help.

# Lifestyle changes

## Stop smoking:

Stopping smoking is the most important action you can take to manage your COPD and slow lung damage. The chemicals and particles in cigarette smoke will continue to damage your lungs if you do not stop smoking.

You are 3 times more likely to stop smoking if you have support as well as stop smoking medicines, such as patches or gum. For more information visit: <a href="www.quit.org.uk">www.quit.org.uk</a> or <a href="www.smokefree.nhs.uk">www.smokefree.nhs.uk</a>.

For free help to stop smoking call:

- Live Well 0116 454 4000 (if you live in Leicester City)
- QuitReady 0345 6466666 (if you live in Leicestershire and Rutland County)

It is never too late to give up smoking as your lungs will feel the benefit. This time you could succeed even if you have tried and failed in the past.

# Be physically active:

Being active will help your lungs and reduce breathlessness caused by being unfit.

- Build up to a daily walk. You can start by walking for 1 minute at a pace slightly faster than usual, but not so fast that you cannot talk. When 1 minute becomes easier start to walk for 1½ or 2 minutes. Gradually build up to a daily 10 minute walk each day. You may become breathless but you will recover and it will help your lungs to become stronger.
- Take simple steps like standing up and sitting down from your chair.
- Use the stairs whenever you can.

A pulmonary (lungs) rehabilitation (PR) course can help you to learn more and to practice moving while supported by health care professionals. It is an essential part of recovery from a flare-up (also known as an exacerbation) of COPD to help you to regain the strength you have lost whilst unwell. Ask your doctor or nurse to refer you to a local course.

Many people with COPD avoid getting breathless as they think it is harmful. However weaker muscles need more oxygen to work so strengthening breathing muscles will help you. Your age and the severity of your COPD will not stop you from doing PR or from seeing an improvement after you complete the course.



#### Eat well:

Eating a well-balanced diet will help you to feel better and assist your general health and recovery from illness.

- Try to drink at least 8 cups of caffeine-free fluids daily.
- Eat foods that contain protein (lean meat, pulses or fish).
- Include calcium for bone strength (milk and dairy foods).
- Include foods containing potassium (fresh fruit and vegetables) unless you have been advised against this by your doctor.
- Ensure you eat the right amount of calories. If you are unsure about this your doctor or nurse can advise you.
- Controlling your weight is important in helping you to breathe. If you are overweight your lungs have to work harder. If you are underweight you can lose muscles that help you to breathe.
- Eat small portions of food several times a day, as one large meal may make you feel bloated and make breathing more difficult.

# Reducing your risk of flare-ups

It is recommended that you get a vaccination to seasonal diseases that may make your COPD symptoms worse:

- Flu (influenza) vaccination every year.
- A one-off pneumonia vaccination (unless your doctor asks you to have this more often).
- COVID vaccinations as recommended.

Avoid people with coughs and colds.

Ensure you wash your hands regularly and especially before eating or taking medicines. Disinfect door handles, television remote control and telephones to reduce the spread of bacteria and viruses.

Clean your inhaler mouthpieces and spacers every 2 to 4 weeks and after you have been treated for a chest infection.

#### Take extra care in winter:

Keep your home at a steady comfortable temperature. Wear clothing layers to help you to feel warm.

Try not to sit still for more than an hour at a time.

It is better to eat little and often, even if you do not feel hungry, to keep your energy levels up.

Keep some basic stores in your cupboard in case you cannot get to the shops.



### Take your medicines and inhalers:

You may be prescribed medication to help control symptoms of COPD including breathlessness, inflammation and sputum.

**Inhalers** deliver medicines directly to the lungs if they are used correctly. This means that side-effects are unlikely. If the medicines are not used correctly they will not work and you are more likely to have symptoms of COPD.

You can ask your nurse, doctor or pharmacist to show you how to use your inhaler and check you have the right technique so that you get the best from your inhaled medicines. Ask them how your medicines work, and talk to them before making any changes or if you think you might be having any side-effects.

Most people with COPD have 2 types of inhalers:

• A Preventer that works throughout the day to control symptoms and reduce flare-ups (exacerbations). It is important that these medicines are taken as prescribed and on time so that they keep working, even when you feel well.

It is important that you do not run out of your medicines. Do not increase your medicines without talking to a health professional as you may experience unwanted side-effects.

The preventer medicines come in 2 types and it is important that you learn to breathe correctly depending on the device you have:

- Dry powder inhalers require a **quick and deep** technique.
- Aerosol sprays require a slow and steady technique.
- A Reliever that works within a few minutes. It helps to open the airways, lasts for 4 to 6
  hours and can be taken when needed.

Using the reliever medicine:

- Only inhale 1 dose at a time.
- You can inhale 2 single doses if you feel breathless despite resting.
- You can inhale 10 single doses, four times in one day if **very** breathless.
- If you are having to use the reliever more you should talk to your doctor, pharmacist or nurse for advice.
- It may help to use your reliever medicine before doing anything that makes you breathless e.g. showering or climbing stairs.

A nebuliser is a device that blows air through liquid medicine to produce a mist. Inhaled medicines via an inhaler device (as above) is the preferred method. Using a nebulizer to relieve breathlessness is only recommended in an emergency or if you are unable to use inhaled medicines due to a disability. If you do have a nebuliser remember to clean it regularly as per the manufacturer guidance.



### The 7 steps to using a metered dose inhaler and small volume spacer:

(e.g. AeroChamber, Space Chamber Plus, A2A)

- 1. Remove mouthpiece cover from the inhaler.
- 2. Shake the inhaler and put the mouthpiece into the hole in the end of the spacer device.
- 3. Breathe out gently as far as is comfortable.



for each type of 🖫 inhaler device scan this QR code

- Tilt your chin up slightly and put the **spacer** mouthpiece in your mouth and close your lips 4. around it.
- 5. Press the canister of the inhaler down to release 1 puff of medicine into the spacer. Breathe in slowly and steadily. If you are using an AeroChamber and you hear a whistling sound, you are breathing in too quickly.
- 6. Remove the spacer from your mouth and hold your breath for up to 10 seconds or as long as possible, then breathe out slowly. If you find it difficult to take deep breaths, breathing in and out of the mouthpiece 4 to 5 times is just as good (tidal breathing technique).
- Wait a few seconds before repeating steps 2 to 6 for a second dose, if needed. Replace 7. mouthpiece cover on inhaler after use so that dust or debris do not get inside.

You can watch videos that show you how to use inhalers on the Asthma + Lung UK website (www.asthma.org.uk/advice/inhaler-videos/).

Inhaler disposal and/or recycling: - all used or unwanted inhalers should be returned to a pharmacy to be disposed of safely, unless you have an inhaler recycling scheme available to you. They can be disposed of by the pharmacist with other drug waste which is thermally treated to destroy the greenhouse gases. This environmentally safe disposal route is available at all pharmacies.

# Using medicines to manage a flare-up

Use your My COPD Plan to guide you in knowing when to start your medicines for a flare-up (exacerbation) of your COPD, or when to call for help.

**Steroids** - steroid tablets help to reduce the inflammation in your lungs. They usually do not cause side -effects if taken for a short time and a low dose. Common side-effects include increased appetite, mood change and sleep disturbance. It may be helpful to talk to your nurse, doctor or pharmacist before starting a new course or if you needed more than 2 courses in the last 6 months.

**Antibiotics** - you can feel quite ill when you have an infection like a cough, but antibiotics often do not help you feel better any faster. They do not work on viral infections, and may harm your good gut bacteria. Antibiotics may help when you have a bacterial infection in your lungs which makes your phlegm change colour. Antibiotic-resistant infections are increasing, so antibiotics should only be used when they are really needed. It may be helpful to talk to your nurse, doctor or pharmacist before starting a new course.



# Taking care of your mental health

### What is depression?

Depression is a common mental health problem which affects 1 in 10 people. Depression is often caused by life's stressors such as bereavement, financial issues, relationship difficulties and physical health problems. Some people are more vulnerable than others in developing depression due to family history, early experiences, personality traits as well as body chemistry. Depression affects our emotions, physical health, thoughts and behaviour, which can leave you feeling hopeless and alone.

Most people can live with depression and continue with their lives on a daily basis, however sometimes it can become severe whereby people experience thoughts that their life is not worth living. Whatever the cause of depression, there is always help and support available and this is different for each person.

## What is anxiety?

Anxiety is something we can all experience from time to time. It is our bodies' natural response to a situation or experience which we find threatening causing us fear. Anxiety can be helpful when dealing with emergencies or when we need to perform well. However there are times when anxiety is not helpful.

When anxiety becomes unhelpful it effects the way we think, the way we feel, the way our body works and the way we behave. Anxiety can be treated in many different ways. Self-help such as relaxation and breathing techniques are very effective.

# How does depression and anxiety effect those with a respiratory condition?

For people with a respiratory condition, depression and anxiety can develop due to the physical symptoms that impact daily life. Many of these physical symptoms can lead to feelings of frustration, fear, isolation and helplessness.

# What can I do to help myself? / Where can I go to for help and support with mental health?

The most important self-help is to speak to a health care professional about how your condition is impacting your life. A health care professional can offer advice on self-help techniques or they may feel the need for you to be referred onto other specialist services such as a mental health team. A specialist service can help you to learn, accept and change the thoughts, feelings and behaviour you experience through your condition.

Practicing self-help such as relaxation and breathing techniques are very effective.

Managing anxiety and recognising the way a physical symptom makes us think, feel and behave, and knowing how our body works, helps us to break the cycle of anxiety.



# Coping with breathlessness

Everyone gets breathless at times. People with COPD may get breathless more easily and it can take longer to get your breath back. This can be frightening and cause anxiety that may make the breathlessness worse. There are actions that you can take that may help you. It is important to practice the different techniques when you are feeling well so that you can remember what to do when you do become breathless. Everyone is different so choose what works well for you.

#### Pace your activity:

- Breathlessness is not harmful and you will get your breath back in time.
- Break up strenuous activities (e.g. making the bed, showering) into small chunks that you
  can do and rest between each part.

#### **Positioning:**

- Make sure your muscles are not tense as this will limit your lung movement.
- Sit with your arms relaxed or use a table to support your arms and lean forward.
- Relax your shoulders and check they are not raised.

#### **Distraction:**

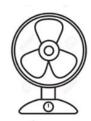
- Try to think about something or someone else in the room and do not focus on your body.
- Watch TV or listen carefully to the radio.
- Talk to yourself and reassure yourself that you have experienced and recovered from breathlessness in the past.

#### Relaxation or meditation:

It is important to practice relaxation or meditation when you are feeling well so that you feel confident using it when you become breathless. There are many ways you can find help with this through phone apps and DVDs.

### Fan therapy:

Use a hand-held or desk top fan to circulate the air. Hold the fan about 15cm (6 inches) from your face and move it cheek to cheek; you should feel the benefit in a few minutes. You can also try standing by an open door or window to catch a breeze for the same effect.



### Pursed lip breathing:

- Put your hand on your stomach and breathe slowly through your nose.
- Breathe out through pursed lips (lips together with a small gap in the middle). You should try
  to breathe out for longer than you breathe in.
- Try to make your stomach move out as you breathe in, and move in as you breathe out.



#### Rectangle breathing:

- Focus on a rectangle-shaped object (such as a picture, photo frame or TV).
- Set your eyes on one corner.
- As you move your focus along the short side of the rectangle you should breathe in (inhale).
- When your eyes reach the next corner, you should breathe out **(exhale)** along the long side until your eyes reach the next corner.
- Continue around the frame slowly until you feel relaxed and less breathless.

#### Medication:

You may be prescribed medication that may help you to relax and calm your breathing. It is important that you take these medicines as prescribed to avoid unwanted side-effects.

#### **Breathlessness clinic:**

Sometimes you can develop changes in your breathing pattern that can make you feel breathless. Health care professionals as a breathlessness clinic can help to retrain your breathing and practice actions that will help. Your nurse, physiotherapist or doctor can refer you.

### Treating fluid retention/ leg swelling:

If your body is holding onto fluid this may cause your leg to swell and in turn make your breathing worse. If you feel more breathless when you go to bed this may be due to fluid retention. Ask your nurse or doctor for advice about how to cope with this.

#### Oxygen use:

Feeling breathless does not mean that you have low oxygen levels in your body.

When you have a bad flare-up that requires going to hospital, you may need oxygen to help because your lungs are swollen and may be blocked with extra sputum. As your medication takes effect your lungs will be able to breathe more easily and the oxygen can be stopped.

People with more advanced COPD may find their oxygen levels fall when they are active. Oxygen may be prescribed after an assessment. The assessment must be done when the lungs are not inflamed so 6 to 8 weeks after a flare-up is advised.

For safety reasons, oxygen should not be put into a house where there are smokers or open flames due to the risk of explosion.



#### Chest clearance

People with COPD may have more phlegm (sputum) each day, even when they do not have a flare-up (exacerbation). Coughing alone may not clear your lungs and it may become tiring.

The 'active cycle of breathing technique (ACBT)' may help you to reduce the effort you need to clear your airways:

- Before starting make sure you have been drinking fluids so that your sputum is less sticky.
- Choose a time when you have most sputum and you are not too tired.
- Avoid doing the technique after you have just eaten a meal.
- Spend at least 10 to 15 minutes doing this each day.
- You may need to practice this 3 or 4 times each day if you have a chest infection.

You may have been prescribed medication that helps to break up sputum in your lungs (mucolytic medicine) making it easier for you to cough this up. If you have found it makes no difference you should discuss this with your nurse, doctor or pharmacist.

### Active cycle of breathing technique:

- 1. **Breathing control or quiet breathing -** sit in a comfortable upright position in a chair or supported by pillows in bed. Wait for your breathing to slow down and be breathing more quietly again.
- 2. **Deep breathing** it is good to check the colour of your phlegm (sputum) each day, as this can be an early warning of an infection starting.
  - Breathe in slowly through your nose and then sigh out gently though your mouth. Repeat this 2 to 3 times and then relax and breathe quietly again.
- 3. **Huffing** when you have done steps 1 and 2 a few times you can then try to huff. Breathe in gently, a medium sized breath through your nose, then breathe out like a fast sigh but without force (imagine you are trying to steam up a mirror with your breath). Repeat this about 2 to 3 times.
- 4. If you feel you have moved sputum and it is high enough to clear, then do one strong cough and see if you can cough it up.
- 5. If you are still struggling to clear sputum from your lungs, speak to your nurse or doctor.



# My COPD symptom diary

Getting to recognise early symptoms of a flare-up of your COPD can help you to decide when to ask for medical attention. Keeping a record of flare-ups can help your doctor to assess how your medicines work. Your community respiratory nurse can offer advice and support.

Date	Symptom	Treatment	Comments

# **Useful numbers**

Activate Your Lungs	Pulmonary rehabilitation	0116 258 3181
Community Respiratory Nurses	Long term conditions	0300 300 7777
Single Point Access (SPA)	Community services	0300 300 7777
COPD Specialist Nurses	Glenfield Hospital	0116 250 2781
Silver line	Free self-referral advice and befriending	0800 470 8090
Hospital to Home	Free shopping help after hospital	0116 266 7712
British Lung Foundation	Respiratory help and advice	0300 0030 555 www.blf.org.uk
Dial-a-ride	Transport help	0116 221 1457
Citizens Advice	Financial concerns	City - 0808 2787970 County - 0808 2787954
Blue Badge Application		0116 305 0001 www.gov.uk/apply-blue-badge
Leicester City Adult Social Care		0116 454 1004
Leicestershire County Social Care		0116 305 0004
Carers Assessment		0116 251 0999
Age Concern	Help to complete attendance allowance forms	0116 299 2233
Macmillan Nurses	General enquiries about benefits and care	0808 808000
LOROS	Hospice services	0116 231 3771
Hospital Palliative Care Team	Support with symptoms	0116 250 3540
Vita Health Group	Help with anxiety or depression - self-referral	0330 0945595 www.vitahealthgroup.co.uk

# My COPD plan

A usual day for me:	I will:	
I feel well. I can be breathless when I am active but recover when I rest.	Use my inhalers and other medicines as prescribed.  Take a walk or try to do some exercise.	
A bad day for me:	I will:	
I feel like I am getting a cold.	Use my regular prescribed preventer inhalers and medicines.	
I feel more breathless/ wheezy.	Try to clear phlegm (sputum) from my chest by coughing it up.	
I may cough more.	Use my reliever inhaler (e.g. salbutamol) through a spacer. Inhale 2 to 4 doses, four times a day when breathless. I can take up to 10 single doses if very breathless.	
I am feeling worse:	I could:	
I may have ankle swelling.	Ask my respiratory nurse for advice.  Keep my feet up when sitting. I must tell my doctor.	
I may have a wheeze.  I feel more breathless.  My chest feels tight.	You may need a course of steroids and should seek medical advice.	
My sputum has changed to dark yellow or green.	You may need a course of antibiotics and should seek medical advice.  Complete the course of medication that I have been prescribed.	
I feel even worse:	I must:	
My breathing is much worse.	I must call my GP or ring 111. I must call 999 if I need urgent help.	

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہِ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔ علی ھذہ المعلومات بلغةٍ أُخرى، الرجاء الاتصال علی رقم الهاتف الذي يظهر في الأسفل જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો

ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ 'ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ। Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

If you would like this information in another language or format such as EasyRead or Braille, please telephone 0116 250 2959 or email equality@uhl-tr.nhs.uk



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