

# How to live a full life with COPD

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Your guide to living an active life for longer with Chronic Obstructive Pulmonary Disease HEALTHY LIVERPOOL

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# Your Information

MY COPD IS	• • • •	MILD	MODERATE	SEVERE	VERY SEVERE
GP	• • • • •				
PRACTICE NURSE	•				
SURGERY TEL	•				

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# Useful Information for my COPD team

	DATE:	DATE:	DATE:
OXYGEN SATURATION LEVEL			
FEV1 (L)			
FEV1 (% OF PREDICTED)			
FEV1/FVC Ratio			

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# Managing your COPD is easier than you think

If you're living with Chronic Obstructive Pulmonary Disease you'll be glad to hear that there are some things that you can do to help manage your condition and reduce your symptoms. If you can make some simple changes to your lifestyle and follow the advice of your COPD healthcare team then you should be able to continue living an active life for longer.

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It may seem quite daunting at first but managing your condition isn't so hard when you know what to do. This pack brings you lots of easy to follow information that will help show you how things like cutting down or stopping smoking, being active, having your flu and pneumonia vaccinations, eating healthily and taking your medication can really help to improve your symptoms and keep you feeling healthy and well.

> Please take this pack with you to all of your appointments and fill in the relevant sections with your practice nurse, they may also give you additional information to keep in your pack.

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## Even small changes can make a big difference

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Remember that any change you make to help manage your condition, no matter how small, is a step in the right direction. We know everybody is different and some people may find it harder than others, but you don't have to make all these changes in one go and there is lots of help and support available to help you.

If you start making the right changes you should quickly start to notice an improvement in your condition and the more changes you make the better you'll feel. So try to stay motivated, keep going and you should be able to continue living your life.

### 6 WAYS TO HELP YOU FEEL BETTER WITH COPD



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Stop smoking or at least try to cut down

Be as active as possible

Ensure you have your vaccinations

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Take your medication

Try breathing exercises and take steps to avoid flare ups

Eat a healthy diet



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# Simple steps to help you deal with your COPD

Knowing what you can do to ease your symptoms and manage your condition can really help you to get the most out of life. There are lots of small simple changes that you can make to really improve your quality of life.

These changes can be as simple as learning some breathing exercises, being more active, taking your medication and starting to eat more healthily. Stopping smoking is also much better for your lungs and body, but we understand that this can be difficult to do and that's why there's lots of support available to help you through this. For more information go to page 18-21 of this pack.

The page opposite has some other great suggestions of relatively easy changes that you can make to start managing your COPD better.

### TIPS FOR GETTING STARTED

- Make a plan, your practice nurse can help you with this
- Set yourself goals focusing on things you enjoy that will motivate you
- Talk to your friends and family, being isolated can make you feel worse
- Try to stay positive, your practice nurse can support you if you are anxious or depressed
- Keep these questions in mind when discussing care options with your COPD healthcare team:

What are my options?

What are the benefits or risks of these?

How likely are these to happen?

What happens if I choose to do nothing?

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### GET EXPERT ADVICE ON MAKING YOUR HOME SAFER AND WARMER

Your local Healthy Homes team can support you. Find out how on page 41

### Be aware of the weather

It may sound simple but being aware of what's going on around you can reduce your symptoms. Certain weather conditions can make your symptoms worse, which is why it's vital to check the weather forecast, plan ahead and get help quickly if you notice a flare-up.

During winter you are more likely to get flu and pneumonia so it's important to make sure you get vaccinated. Try to steer clear of people with colds or flu and if you do get ill be sure to get treated quickly. You can protect yourself by wearing a coat, hat and scarf outdoors, eating warm meals and drinks, wearing non-slip footwear and using your inhaler before going out. If temperatures drop below 4°C try to limit your time outdoors.

During summer high heat, humidity and pollen can all cause breathing difficulties. Wearing loose cotton clothing, drinking lots of fluids and cooling off with an electric or paper fan can all help you feel better and deal with breathlessness. You should keep inhalers out of direct sunlight and remember that open windows let in pollen and pollution.

Your job could also make breathing difficult. If you work in a smoky or dusty environment this can damage your lungs. You might need to change your job or speak to your employer about changing where you work.

For more advice on any of these issues call the BLF helpline on 03000 030 555.

### A healthy home

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If your symptoms are affected by your home then your GP should be able to put you in touch with your local council and occupational therapist who'll be able to help and advise you on making changes to your home to suit your needs. This might include simple things ranging from keeping your home warm by closing your curtains at dusk to draught proofing and more. You can also contact the Healthy Homes team for help with this.

#### Rest after activity if tired

If you feel that your energy levels are low it's a good idea to make sure you sleep well and get enough rest each day. If you're having trouble sleeping, try to be more active each day and try not to have tea, coffee or alcohol before bed time. If none of this works, talk to your doctor or practice nurse.

### Plan ahead

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It's better to be prepared for changes in your condition, in the short term this could be thinking about what you need to do if your condition gets worse or if you experience a flare-up. Your practice nurse will give you an insert along with this pack to fill out with your own personal information on warning signs to look out for and how to manage them.

It's also good to start thinking about long term care plans. Advance care planning is a discussion you can have with your healthcare team and family members about what you would like for your future care. It's your decision to have this conversation, so don't feel under any pressure, however, it might help you to feel better about the future if you've shared your wishes. For more support and guidance on this talk to your GP or practice nurse.

## How to control breathlessness

Breathlessness can be a problem for people with COPD, but there are a number of ways to get your breath back and start feeling better. If you're suffering with breathlessness pulmonary rehabilitation, known locally as the Breathe programme, can help. There are also some things you can do for yourself to help ease your symptoms at home as well.

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# Breathing control techniques

Breathing techniques are a very effective way of reducing breathlessness on a day to day basis. They are also very helpful if you often suddenly become breathless. Give the following techniques a try and see how they can reduce your breathlessness when you do them every day.

### 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. Do this until you get your breath back.

#### **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

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Breathe out when you're putting effort into something, for example going up steps, bending down or standing up. Basically, during the hardest part of any action, blow as you go. If you become breathless suddenly when resting, remember this simple rule "If in doubt, breathe out".

### **Paced breathing**

This is useful when walking or climbing the stairs. Breathe in with each step you take. Do this in a rhythm that suits how breathless you are. A good way to do this is to breathe in for one stair and out for one stair, or breathe in for one stair and out for two. Try different breaths out to find one that's right for you.

> IMPROVE YOUR LUNG HEALTH WITH THE BREATHE PROGRAMME (Also called Pulmonary Rehabilitation)

Attending a course is one of the best ways to help you to improve your lung health and help you feel better.

The course is flexible and you can learn from the team's expert know-how on how to manage COPD. They also offer professionally supported exercise sessions to help you to safely improve your strength and control your breathlessness.

#### For more information go to page 26

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## Positions to make breathing easier

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There are some positions that can help reduce breathlessness; the best ones require very little energy or effort. They are very easy to learn and can be a big relief if you're feeling short of breath. Different positions will suit different situations, so try all these positions and decide which ones are best for you.

### Stand leaning forward

Lean forwards resting your elbows on a surface. This could be a wall, windowsill, railing or the back of a chair.

### Rest your hands

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When you're standing or walking, try putting your hands on your hips or in your pockets, or stick your thumbs into your belt loops to support your arms without gripping. If you carry a shoulder bag, you can rest your arms on it.

## Rest your head and arms on a table

You can rest your head and arms on pillows on a table when you're really short of breath, or try lying on your side, propped up with lots of pillows.



### Sit leaning forward

Sit down and lean forward resting your elbows on your knees, make sure you keep your wrists and hands relaxed.

## Stand leaning back or sideways

Lean back or sideways against a wall; keep about a foot away and your feet slightly apart. Let your hands hang loose or rest them in your pockets or waistband.

### Use a walking aid

A walking aid can help you do all of these positions when you are out and about. Most people feel better pushing a supermarket trolley when shopping, as it works in much the same way.



For more information please go to the British Lung Foundations website: www.blf.org.uk/Page/chronic-obstructive-pulmonary-disease-COPD

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## Usual symptoms of COPD

Symptoms like getting out of breath quickly when being active, a cough with mucus or phlegm and reoccurring chest infections are all common, so you don't need to worry as much about these, unless they quickly become a lot worse. Your healthcare team will work with you to develop a personal action plan so you know what to do in these situations.

## Symptoms to get checked out



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### Chest pain

Pressure or tightness in the chest can be very uncomfortable and make it harder to stay active. Speak to your GP about how to reduce it. Remember if you experience severe chest pain seek urgent help by **calling 999**.



### Coughing up blood

If you're coughing up blood it's very important that you see your GP. This is not a normal symptom of COPD and can be a sign of other potentially more serious conditions.

### Ache or pain when breathing or coughing

If it hurts when you breathe or cough, or your cough is different to usual then you should contact your GP. This can be both unpleasant and a potential sign of other serious issues.



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### Rapid heart rate

If your heart is beating rapidly this is known as a palpitation. They can be quite worrying so it's a good idea to check with your healthcare team if you're concerned.

### Ankle and leg swelling

Developing swelling on your ankles and legs can be uncomfortable and difficult to live with. If you notice this contact your GP or COPD team quickly. There are a variety of medications available that can reduce it. Sometimes ankle swelling can indicate your condition is getting worse and you may be prescribed extra treatment as a result.



### Weight loss and lack of appetite

Breathlessness can make it difficult to eat and lead to you becoming underweight. This can make every day activities very tiring and you may need additional tests to make sure you aren't losing weight for another reason.



## Extreme tiredness and sleeping problems

If you're having trouble sleeping and find yourself feeling constantly sleepy or becoming easily confused this can make life difficult and lead to other health issues.

> Its good to know about some of the symptoms that may mean you need to change your treatment or have a problem other than COPD. If you experience any of these you should speak to your GP.

### 10 Managing your COPD

## Other conditions linked to COPD

There are a few conditions, like high blood pressure and heart disease, which are more likely to occur if you've been diagnosed with COPD. In this section we'll explain these conditions and how you can manage them.



### Colds, flu and pneumonia

You may be more prone to these conditions. Make sure you get the flu vaccination every year in the winter from your practice nurse. A pneumonia vaccination is also available but you'll only need have to have this once.



Sometimes COPD can cause air to get trapped in your chest. This puts pressure on the stomach and causes acid to be brought back up into your throat and mouth. This is called acid reflux and it's not usually a worry but will often leave an unpleasant, sour taste in your mouth and throat. It can also make your cough worse. If this is happens a lot, see your GP for advice and treatment.



### High blood pressure and heart problems

Although COPD doesn't directly cause these conditions, they are widely associated with it. This means that it's important to check for any problems regularly. As a result, you should attend your check up with your GP every year.



### Anxiety and depression

It's normal to feel a bit down or anxious now and then, especially if your condition stops you going out and doing things you enjoy. If you feel like this, talk to someone about it; whether it's friends and family or your GP and practice nurse. This can help motivate you and make you feel better. You can also ask the friendly staff at Talk Liverpool for more support too.



### IF YOU WOULD LIKE MORE SUPPORT FROM A MENTAL HEALTH PROFESSIONAL FOR ANXIETY AND DEPRESSION YOU CAN CONTACT THE TALK LIVERPOOL SERVICE

Go online www.talkliverpool.nhs.uk or call direct: 0151 228 2300

### LEAVING CONDITIONS LIKE THIS UNTREATED WILL ONLY MAKE THEM WORSE. IF YOU BELIEVE YOU ARE STARTING WITH ANY OF THESE CONDITIONS, CONTACT YOUR GP OR HEALTHCARE TEAM SO THEY CAN BE TREATED EARLY.

## Dealing with flare-ups

Occasionally you may suffer from what we call an exacerbation. This is often referred to as a 'flare-up' and it just means when your symptoms suddenly worsen for one reason or another. You can tell you're having a flare-up if you experience any two of the following symptoms; worsening breathlessness and increased or discoloured mucus or phlegm.

### Cold and damp weather can cause flare-ups

Weather changes can often trigger flare-ups especially when it's cold. So always wear a coat, scarf and hat when you're outdoors in cold weather. You may also want to pull your scarf up loosely over your mouth to help you breathe easier.

### Other causes of flare-ups

Some other causes of flare-ups are things like stress or infections. If you do have an infection it can be easily treated but it's important to treat your illness early to avoid your symptoms getting worse. Your GP will be able to advise you on the best treatment.

### Personal action plan

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It's important to plan ahead so you know what to do to relieve flare-ups before they happen. This should be covered in your personal action plan, which is something that your practice nurse will help you with. It's used to help you work out which symptoms are typical for you and what to do to relieve them.



### YOUR PERSONAL ACTION PLAN WILL HELP YOU MANAGE FLARE-UPS

Your plan will be given to you, to fill out with your healthcare team and keep as an insert for this pack

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### If you are in need of additional help

Always keep the contact details of your GP or practice nurse handy, that way you can arrange an emergency appointment or get a prescription if you have a flare-up that's getting worse, even when using the antibiotics and steroids in your rescue pack. You should have written the details for your GP and practice nurse in your personal action plan.

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If you feel really breathless or unwell you should take your inhaler and rest in a comfortable position. If you feel like this isn't working and you need to go to hospital then ring an ambulance and tell the staff on the phone that you have COPD, that way they can prepare the right medication for you in the ambulance.

### What to do if you're frequently having flare-ups

If you're getting more than 2 flare-ups a year you should get in contact with your GP or practice nurse who will be able to discuss with you whether you need to keep a rescue pack at home containing antibiotics and steroids. Using these medicines as soon as you start to have the symptoms of a flare-up will help reduce the problem quickly.

Sometimes you'll need more than a rescue pack to manage your flare-up. If this is the case, your GP can refer you to the Community Respiratory Team for extra support at home whilst you are unwell. Learn more about your COPD healthcare team on the next page.

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# Meet your COPD healthcare team

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Your local COPD healthcare team will offer help and support whenever you need it.



Your GP will help other professionals to support you to manage your condition by ensuring that all the necessary members of your healthcare team are informed and up to date on your progress.

You should contact your GP practice if you have any issues or flare-ups. If you are unwell with a flare-up make sure you tell the receptionist that you have a chest problem and need treatment, you should expect to be assessed within 4 hours.

You can also use the GP Out-of-hours service at night and weekends by calling your usual practice number.

Some patients may need additional specialist care and your GP may refer you to see a hospital COPD specialist.



Your practice nurse will be your main point of contact for the management of your condition. They're here to help support you to manage your COPD and they'll also provide you with vaccines, including flu and pneumonia jabs. They'll also monitor your progress to make sure that you're always getting the right help.

### Where will you see them?

At your local GP practice.

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### How often should you see them?

You'll have a review with your practice nurse soon after your diagnosis. Following this you'll see them as often as you need to, at least once a year. They will be the person who mainly helps you manage your care.

### CONTACT YOUR GP PRACTICE TO ARRANGE AN APPOINTMENT



Pharmacists are here to help you manage your medications effectively. They'll explain how all your medications work together with your body, your lifestyle and your diet.

### Where will you see them?

Either at your local pharmacy, GP practice or specialist hospital clinic.

### How often should you see them?

Whenever you pick up your prescription you will see your community pharmacist. They'll be happy to help you if you're having any problems with your medication. If you'd like a full medication review ask for your medication management team's contact details at your GP practice.



Pulmonary rehabilitation, known locally as the Breathe programme, is a flexible course of up to 10 weeks that uses a combination of exercise and education to help improve your lung condition. You can benefit from an exercise programme because even small amounts of exercise help to remove the fear of breathlessness and improve your quality of life.

### Where will you see them?

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At local centres, ask your GP or practice nurse for more information.

### How often should you see them?

Typically you will attend at least one session a week which will usually last between an hour and a half to two hours. You will be part of a group, commonly between 8 and 16 people.



Community matrons are highly experienced senior nurses who'll work closely with you to provide, plan and organise your care. They mainly work with patients with serious long term or a complex range of conditions. If you've been hospitalised for your COPD twice or more in the last year, you may be allocated a community matron.

### Where will you see them?

They will visit you at home.

### How often should you see them?

If you've been allocated a community matron they regularly visit you and will be your first port of call when you're ill.



This team includes specialist respiratory nurses and physiotherapists and is an alternative to hospital for some patients during a COPD flare-up. Your GP or community matron will assess you when you're having a flare-up and can refer you to CRT if they think you might need to be admitted to hospital.

### Where will you see them?

At home within 2 hours of the doctor/nurse referring you to CRT. Some patients still need to go into hospital, but are often able to come home earlier after they are discharged with support from the community respiratory team.

### How often should you see them?

Not everyone with COPD will need to see the CRT team, this will be decided by your GP, community matron or your hospital team.

### ENSURE YOU GET THE RIGHT CARE BY USING THE CHECKLIST ON THE NEXT PAGE

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# Make sure you're getting the right care

From diagnosis your COPD healthcare team will offer their care and support to get you on the road to feeling better. There are lots of different treatments, check-ups and reviews you'll be invited to attend. It's really important you attend them all so you can start to manage your symptoms.

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We've created a handy checklist so that you have a log of exactly what you should be offered from your healthcare team. You can tick each one off when you've attended so you're always up to date. If you think that you need one of these services and it hasn't yet been offered to you, please talk to your practice nurse.

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### You should have had your diagnosis checked and confirmed.

A breathing test called spirometry should be performed by a qualified professional to check and confirm your diagnosis.

- 2 You should know where to go for advice and support. A member of your healthcare team should have explained exactly what COPD is and where you can go to get more information and support.
- **3** You should have had a chat about your treatment options. A member of your healthcare team should have discussed which inhalers and tablets are used for COPD and asked which ones you feel are best for you.
- 4 You should have a personal written action plan. This plan will help you set some goals you can work towards. They could be cutting down on smoking or healthy eating and you should have a written copy of this.
  - You should have been offered help to stop smoking. If you're a smoker the most important treatment for COPD is to stop. Your healthcare team should have offered you information, help and support to stop or at least cut down.

### You should know about staying healthy.

It's important to lead a healthy and active lifestyle. Your healthcare team should have helped you work out what level of physical activity is best for you and told you about Pulmonary Rehabilitation, known locally as the Breathe programme. See page 26 for more information about this.

## You should know what your medications and inhalers are for and how to take them.

A member of your healthcare team should have told you which medications you need to take and what they are for during a check-up. You should also have been shown how to use your inhaler and given a chance to practice this.

You should know what to do if you have a flare-up. A member of your healthcare team should have explained what happens when

you have a flare-up and how to use your inhalers and if you need a 'rescue pack' of steroids and antibiotics to control it.

#### You should see your practice nurse for a yearly review of:

- Your lung function measured through a breathing test called spirometry
- Your medicines and inhalers
- Your breathlessness
- Your activity

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- Your oxygen levels
- Your personal action plan

### 10 You should know your options.

If your COPD is very severe you should have had the chance to go over your options with your doctor for the future as your condition changes. If your symptoms are not under control or if you're having 4 or more exacerbations per year you should be referred for a review by a chest consultant at your local hospital. Talk to your GP about this.

### IF YOU'RE CONCERNED THAT YOU'VE NOT HAD ANY OF THESE CHECKS SPEAK TO YOUR COPD HEALTHCARE TEAM

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# Stop smoking, start feeling better

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If you're a smoker the best treatment for COPD is to stop, it's a great way to slow down the damage to your lungs and improve your sense of taste and smell. We understand how hard it is to quit but with all the help and support available it is achievable.

You may have some worries about quitting if you've tried on your own in the past and not succeeded. We know that it's difficult but with NHS stop smoking groups and your healthcare team right behind you, you don't have to do it alone. They'll be able to advise you on ways to kick the habit and how medications can help. You'll be surprised how much of a difference the support makes to your progress.

In this section we discuss why it's so hard to quit and why it's important that you try. Getting a friend or family member to quit with you can also really help as it allows you to support each other and work together to stop smoking successfully.

## STOPPING SMOKING WILL HELP



Stop further lung damage



Ease your <sup>1</sup> symptoms



Clear your lungs

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Improve your sense of taste and smell

18 Stop Smoking Advice

### Why is it hard to give up smoking?

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Cigarettes contain a really addictive substance called nicotine that gets into your brain when you smoke. When you haven't smoked for a while, the level of nicotine in your brain drops. This then tells your body that you need more, creating a craving to smoke. Sometimes you might just do it out of habit and the right help and advice can help you to change this behaviour.

Taking control of your habits and cravings is key to quitting, however difficult it may seem.

## Why does smoking damage your lungs?

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As well as nicotine there are lots of other harmful and poisonous chemicals in cigarettes that harm your body. These chemicals affect your airways and lungs and when you have COPD this makes your condition worse. Stopping smoking means your airways can function better and get to work clearing away mucus, bacteria and chemicals out of your lungs. This will help to ease your symptoms.

## Remember even cutting down is a victory that will do your lungs the world of good.

FAMILY SUPPORT PROFESSIONAL SUPPORT



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MEDICATION SUPPORT

## The benefits of quitting

When you have a lung condition you might feel like your lungs are already damaged and there isn't any point in giving up smoking, but that isn't true. It's never too late and there are lots of reasons to give up smoking:

- It will help to improve your breathing especially when you're active, meaning you should find you wheeze and get breathless less often
- If you have a cough that produces mucus or phlegm, this will improve when you quit
- Your inhaled medications will work more effectively and it could help to reduce the amount of chest infections you get
- It will help slow down the progression of your condition and keep your lungs healthy for as long as possible
- You could live longer, feel better and have more money to spend on the things you enjoy.



# We'll help you every step of the way

We know that giving up smoking is never easy, but when you do feel like you're ready there's plenty of advice and support out there to help you quit:

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#### **Medications can help**

There are lots of medications available that can help to reduce your cravings and make it easier to quit. Nicotine replacement therapy (NRT, such as patches or gum), works to reduce your cravings by releasing nicotine steadily into your bloodstream at much lower levels than cigarettes, without the tar, carbon monoxide and other poisonous chemicals. You can get this from your GP, pharmacist or stop smoking service.

If you don't pay for your prescriptions, free vouchers are available for NRT. If you pay for prescriptions you can also claim vouchers to ensure you receive the right medication for the price of a normal prescription. Champix is also available on prescription from your GP. Together with the support of a stop smoking advisor, these products can significantly increase your chances of quitting successfully.

### Avoid second hand smoke

You may also want to limit the amount of second hand smoke you're exposed to. This can often be as bad as smoking yourself and will make it harder to quit.

### **Smokefree Liverpool**

Smokefree Liverpool is a free, confidential Stop Smoking Service which allows you to quit smoking, your way. The service offers different types of support from friendly, experienced advisors so that you can build a tailored package to help you become smoke free. You can choose the type of support you would like to receive and this can be through drop in sessions, individual appointments or over the phone.

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They also offer dedicated support for women and their families at any time during their pregnancy and help and support is also available for giving up e-cigarettes. You can call them direct on 0800 061 4212 or visit www.smokefreeliverpool.co.uk to find out more. You can also Text QUIT to 66777.

### smokefree Liverpool

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# Being active helps you feel better

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One of the best things you can do for your lung health is being more physically active. It keeps your lungs healthy and helps you feel more energised. Being active doesn't have to be hard work either; it could be something as simple as taking the dog for a walk or doing some housework.

For people with COPD staying as active as possible is really important. You might be worried about this making you more breathless, but you'll be surprised how good it can be for your condition. Being active improves your fitness, muscle strength, helps you to build a good breathing technique and can make you feel better.

If you feel anxious about becoming more active, speak to your healthcare team about taking part in a local Pulmonary Rehabilitation programme, known locally as 'Breathe'. This is an expert course, monitored by professionals who can advise you on how to keep active safely, and there is the option to take part in exercise groups that are tailored to you and your condition.



### TIPS FOR BEING MORE ACTIVE



Get off the bus a stop earlier



Use the stairs instead of the lift

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Walk more on short journeys



Do some gardening, housework or DIV

Remember, anything is better than nothing and even small activities that make you feel slightly out of breath are good. Just make sure you follow the guidance on the next page and rest afterwards.

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### Being active can make a big difference

Even a small amount of physical activity can have a huge impact on your condition. You might be surprised at just how positively it will affect your life. As well as improving fitness, strengthening your muscles and helping you build a good breathing technique, there are lots of other benefits:

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- It will help you get less chest infections and you will be able to fight them more easily
- Daily activities will become much easier and you'll become steadier on your feet
- It will strengthen the bones and muscles you use to breathe
- You'll find yourself with a lot more energy and start to look and feel better
- The strength of your heart muscles and circulation will improve
- It will help to keep your stress levels low
- It can lower high blood pressure
- It reduces the risk of conditions like arthritis, diabetes, heart disease and stroke
- It will help to reduce anxiety and depression.





### DON'T WORRY ABOUT GETTING BREATHLESS

Find out how to manage your breathlessness on page 08

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## Before you begin

Regular physical activity is a great way to improve your general health as it will help reduce how breathless you feel and make doing every day tasks like getting dressed or walking to the bus stop much easier. Being active can do you a world of good but there are a few things you need to think about before you start to decide on the right level for you.

### Talk to your healthcare team

Have a chat with someone from your healthcare team and see if they can advise you on which types of activity may be best for you. This can be anything from doing some gardening or going for a walk.

#### Ask about pulmonary rehabilitation

See if you can join a pulmonary rehabilitation course, known locally as the Breathe programme. This is a specially designed, flexible programme of up to 10 weeks designed to help you find a safe level of exercise that you're comfortable with; whether that's some simple breathing exercises or walking on a treadmill.

Choose a programme that's right for you. There are all sorts of ways to join in, including home based and education-only options that offer lots of useful tips, information and expert advice that can help improve your lung condition. This kind of personalised exercise and professional support can reduce your fear of breathlessness, help you manage your condition better and improve your quality of life. Find out more on page 26.

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#### **Pace yourself**

Work at a pace that makes sure you can work out for longer and don't get tired out too easily. Try doing a variety of exercises that work different muscles or split your exercises up and do some of them in the morning and some in the evening. Walking up and down stairs is a simple exercise that you can do at any time of day.

### If your oxygen levels drop

Some people may experience a drop in oxygen when they are physically active; this will only happen to a small number of people with COPD and is easily treated with portable oxygen. If you feel like this is happening to you, have a chat with your healthcare team so they can assess you and offer the right support to help.

### Remember being out of breath is OK

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It's good to try and do something every day that makes you feel slightly out of breath. We understand that getting out of breath when you're active can feel worrying, but rest assured it's a natural response and you will recover. The talk test below is a simple way to help you understand which level is best for you.

### THE 'TALK TEST'

This test is a really easy way to find out if your activity routine is too hard or too easy. Whilst you're doing it say this phrase aloud:

> "Being active is going to do me good!"

You should be able to say the whole sentence with two or three stops for breath. If you say the whole sentence without stopping, your routine is too easy and if you can't say more than one word at a time your routine is too hard.

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# Pulmonary Rehabilitation

Pulmonary rehabilitation, known locally as the Breathe programme, is a flexible service offering anything from a one to one support session, up to a full 10 week course depending on what's right for you.

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Whether you'd prefer to join in with a group at a class or you'd rather learn and exercise at home, it's up to you. You can try education-only, exercise-only or a bit of both, it's all about helping you get tips, information and advice to help you improve your lung condition. The right mix of personalised and professional support can help you reduce your fear of breathlessness, manage your condition better and improve your quality of life.

Whatever level of COPD you have, mild or severe, you could benefit from an exercise programme. We understand that lots of people with COPD are concerned about exercising and worry about it making them breathless, but the truth is that not exercising is more likely to make you more breathless in the long run.

The small, safe amounts of exercise that are part of this course are nothing to worry about. They will help you improve your quality of life and be more independent. The course is typically made up of one session a week, each lasting between 1-2 hours and usually involves a group of between 8-16 people.

# THE COURSE AIMS TO HELP YOU



Understand your condition



Get to know your medication



Learn treatment techniques

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Use your local facilities



Reduce hospital admissions



Achieve a better quality of life

26 Pulmonary Rehabilitation

### Is it right for you?

If you have COPD then you should seriously consider coming along. You don't have to commit to the full course but taking the time to come to a session and see what it's all about is often enough to show you how beneficial the course is.

If you'd like to feel healthier but are concerned about exercise then this course is perfect for you. The team will assess your health and identify the right level and type of exercise that you should be OK with, and they'll be by your side while you do this.

Taking part will help you learn how to exercise safely in a friendly, relaxed and sociable environment. It will help you to gain confidence and meet other people who are in the same situation as you.

Research has shown that this type of course regularly helps people to be able to do more, such as walk further, improve your quality of life and it can reduce future hospital admissions. So if you follow this course you should feel less tired and breathless when doing day-to-day activities like walking up stairs, shopping and dressing.

Breathe has already helped so many people overcome their fears and improve their quality of life. To find out more and hear from people like you, who've benefited from the course visit www.thebreatheprogramme.co.uk

#### How to start a course

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The first step is to ask your GP, practice nurse, respiratory team or chest clinic staff to refer you to your local programme. Some courses are held in a hospital, but often they take place in local community halls, leisure centres or health centres, which often makes them easy to get to.

Before your first class you will have an assessment with the pulmonary rehabilitation team, who'll explain more about what's involved and help you set some achievable goals. Your GP, practice nurse or the rehabilitation team can give you some general information over the telephone or as part of your care if you're unsure about anything.





### LOCAL PULMONARY REHABILITATION COURSES SHOULD BE AVAILABLE STRAIGHT AWAY BUT SOMETIMES THERE WILL BE A WAITING LIST.

If you're interested make sure you put your name down quickly.

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## What happens during a Breathe course?

During your course, the Pulmonary Rehabilitation team will teach you how to become more active in a safe and effective way. Your team will be made up of trained healthcare professionals like physiotherapists, specialist nurses and occupational therapists. They are there to help you manage breathlessness and feelings of anxiety or panic.

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Typically your course will begin with an assessment of your health and abilities. Ideally, this assessment will take place a week or two before you start your course and gives the team a better picture of your needs.

The team will ask you questions that will give them an understanding of your life and your body. The answers you provide will help them to understand what type of support you need so they can make your programme personal to you.

There are lots of options available to suit all kinds of people, so helping the team understand what you can and can't do, how activity effects you and how well you're coping, will help them suggest a programme that you're happy with. This can really help make sure that you get the best possible results.

### 2 Exercise and advice

Around half of each session is based on physical exercise, which will be carefully planned according to your needs to provide the best level of activity for you. You won't be forced to do anything that you can't manage.

The rest of the time will be used to give you information and tips about living life with COPD and different ways that you can improve your quality of life. This will include friendly, supportive advice about:

- Breathing techniques that you can use to get your breath back during physical activity or if you feel anxious
- Why being active is so beneficial for people with COPD
- Great ways to manage stress and anxiety
- How healthy eating can improve your condition
- Tips for using your inhalers and other medicines
- Different ways of dealing with flare-ups and what to do when you're not well.

28 Pulmonary Rehabilitation

### 3 Meet other people with COPD

Talking to other people who have similar problems can be very helpful, enjoyable and fun. These people understand how you feel and it can be a great relief to know that you're not alone and share useful tips with each other.

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### 4 Exercise can be safe and enjoyable for you

Although you'll get out of breath during this course, you'll always be monitored by professionals who'll never put your health in danger. Being out of breath is part of the therapy and over time this will really help you to manage your condition better.

The course is not a cure but if you regularly attend sessions and follow the advice you're given then you should start to feel better more confident and in control.

## 5 After the course

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The fun doesn't stop after you've finished your course, it's important to carry on exercising regularly, staying active and using the techniques you have been taught. Try to make it part of your daily routine.

Ask your pulmonary rehabilitation team about interesting ways you can continue to be active after the course.

# Using medication to stay healthy

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Along with eating healthily and keeping active, medication can help you control and manage your symptoms. It can't replace being active and eating healthily but the right combination of all three will help you feel healthier. Your symptoms will never disappear completely but medication can really help you to get more out of life.

Most people with COPD are prescribed medication to help them control their symptoms. You should always take your medication as instructed by your healthcare professional. If you're ever unsure of how you should be using your medication don't be afraid to ask a member of your healthcare team, they'll be happy to help you. We understand that not every medication suits everyone, so please contact your GP surgery if you are unable to take any medication. There could be other options that you will find more beneficial.

Remember side effects are possible with all medications, if you experience any unusual side effects you should contact your healthcare team to discuss your medication.

### TYPES OF MEDICATION



Inhalers and nebulisers



Tablets



Non-invasive ventilation



Oxygen therapy

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30 Medications

### Using an inhaler

The most prescribed treatments for COPD are inhalers. Ask your practice nurse or community pharmacist to show you how to use them properly. With a little practice you'll be able to use them without any problems.

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The choice of device should be tailored to ensure you can use it properly. There are several different types of inhalers and the addition of a 'spacer' may help you. A spacer is a long plastic tube that attaches to a certain type of inhaler and makes it easier for you to breathe in the right dose of medicine. Once inhaled, most of the drug works directly on your lungs.

### Different types of inhaler

#### Reliever

You should keep this type of inhaler with you at all times and use it when you feel breathless. It works quickly to help relieve symptoms. Reliever inhalers cause the airways to relax and help you become less breathless. They can also can be used in advance of a task that you know will cause you to be breathless such as walking up a hill.

#### Preventer

8396 COPD Info Pack AW Amend.indd 31

This type of inhaler works for either 12 hours or 24 hours. These must be used regularly even if you don't have any symptoms. They help the lungs work more easily throughout the day, making you less breathless and not as prone to flare-ups. Some patients may need to have more than one of these inhalers to keep their symptoms under control.

Some inhalers are combinations of different preventer medications which may include inhaled steroids. Remember to rinse your mouth out after using this type of inhaler to avoid thrush in the mouth.

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## Tablets, treatments and therapies

Sometimes you may need the addition of other treatments to work alongside your inhalers. These can be added to help deal with worsening symptoms. Your healthcare team may add in oral medications to help with breathlessness or other medication to and make it easier to cough up sputum (mucus/ phlegm). If you're unsure why you are on any medication, just ask.

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### Antibiotics and steroid tablets

If you're prone to frequent flare-ups you may have a 'stand by' course of antibiotics or steroid tablets prescribed called a rescue pack. You should start this as soon as you feel a flare-up begins and inform your GP surgery that you have started it. Where possible, you should make an appointment to see your practice nurse or GP two weeks afterwards so they can review you and replace your pack.

### **Nebulised medication**

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You'll only need to use nebulised medication at the time of a flare-up or if a specialist in hospital advises you to. Nebulised therapy contains the same medication as your inhalers, but in much larger doses.

### Ambulatory oxygen

This involves a portable oxygen tank, which is useful as a treatment, only if your oxygen levels drop when your active. You should never smoke while using any kind of oxygen therapy as the oxygen in the machines is highly flammable and combined with a lit cigarette could trigger a fire or explosion.

### 32 Medications

### Long-term oxygen therapy

When you see your nurse in the practice for your annual check up, they will routinely check your oxygen levels with a small device on your finger called a 'pulse oximeter'. If these levels are low, you may be given long-term oxygen therapy. Not everyone with COPD requires oxygen therapy in this way so you will need to be referred for a specialist oxygen assessment. Ask your GP if you have any questions.

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For this therapy to work properly you need to use it at least 15 hours every day. This may sound difficult but with long tubes from the machine that let you move around your home and a portable version for when you go out, it's possible to fit it around your life.

### Non-invasive ventilation (NIV)

You may need this treatment in hospital during a flare-up. It involves a portable machine that helps you breathe using a mask covering your nose or face. If you have used this treatment in hospital, you may be referred to a specialist centre to see if it could help improve your lung function whilst at home.

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# Taking care of your feelings

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We understand that being diagnosed with a condition like COPD can often take its toll on you and can be particularly hard to live with. The symptoms can get you down from time to time but if you can stay positive you can overcome these feelings.

It's normal to sometimes feel low and also a bit anxious, particularly when your breathing symptoms flare-up. There are a number of techniques you can learn to feel more in control of your mood, which will help you deal with looking after your lungs and can make you feel better. Ask your practice nurse if you need any help with this.

Although it might feel like it sometimes, you're never alone. You have a healthcare team who are always here to help and if you can talk to friends and family about how you're feeling that can really help too.



### HOW TO COPE WITH COPD



Try to stay positive



Set yourself achievable goals



Talk to friends and family

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Visit local support groups

## Get out and meet people

When you have COPD you can feel isolated at times but you don't need to. There are lots of local groups where you can meet like-minded people who you can talk to and you can also join up with patients online.

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### **Breathe Easy support groups**

Meeting and talking to other people with COPD can help you come to terms with your condition, as it allows you to share your experiences with people who really understand what you're going through.

These local support groups help you do this in an accessible, friendly and supportive way. They're also a great opportunity for you to ask questions and get more information and support designed to help you live with COPD.

To find the nearest support group in your area call the BLF helpline on 03000 030 555 or go online www.blf.org.uk/inyourarea

### Pen pals and online forums

If you would prefer to talk to people via letter or online, the British Lung Foundation offer a pen pals service and an online forum where you can write to others with COPD.

Visit their website to find out more www.blf.org.uk/page/chronicobstructive-pulmonary-disease-COPD

### Other groups and activities

You don't have to limit yourself to just meeting people with COPD however, there's a whole world of different groups for you to enjoy some of which can benefit your condition too! For example, a local singing group is a great place to meet friendly people, have fun and it will do wonders for your breathing technique.

Visit LiveWell to find out what local groups and services are available www.livewellliverpool.info

You can also call the staff at Healthwatch on 0300 77 77 007 if you would like to speak to someone in person.





REMEMBER YOU CAN ALWAYS SPEAK TO YOUR PRACTICE NURSE OR GP ABOUT YOUR CONDITION.

If you would like more support from a mental health professional you can contact Talk Liverpool on 0151 228 2300 or go online to www.talkliverpool.nhs.uk

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# Eat healthy and stay healthy

Eating healthily and leading an active life is a great way to keep you feeling well and help you to breathe more easily. A balanced diet puts the right nutrients in your body which helps fight against chest infections and keep your lungs healthy.

There are a few easy things you can change in your diet that will help you gain the right nutrients and have a lot more energy, for example eating more fruit and vegetables.

It's also a good idea to drink about six to eight cups of water a day to help keep the mucus moving in your body. This way it won't stick to your airways and you're less likely to get infections. Remember tea, coffee and juice all count but alcoholic drinks do not.

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### 4 STEPS TOWARDS A HEALTHY DIET



Eat 5 portions of fruit and veg daily



Choose wholegrain carbohydrates

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Eat lean meats, poultry & fish



Avoid sugar & sugary foods

36 Healthy Eating

### **Healthy weight**

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Making sure you are at a healthy weight is really important for people with COPD. Being overweight can make it harder for you to be active and make your breathing more difficult; being underweight is no good either as this makes your body weak, which can make it harder to do things for yourself and easier to get chest infections.

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Therefore it is important to keep an eye on your weight. If you are losing weight without trying, it is very important to talk to your doctor. You should also consult your healthcare professional if you are putting on too much weight. In both cases, you can be referred to a dietitian or local scheme for advice and support.

If you're not sure what weight you should be you can always have a chat with your GP or practice nurse who'll help you work it out.

# Maintain a Healthy Weight

This section is full of tips that will help you maintain a healthy weight. Remember, if you're losing weight without trying or putting weight on ask your GP for help and support. They can also refer you to a dietitian for further advice.

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# IF YOU'RE UNDERWEIGHT

### Plan your meals

If you have a small appetite try eating little and often. Small meals 3 to 4 times a day with small snacks in between will give you enough energy without leaving you over faced.



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Add 2 or 3 small snacks throughout the day like full fat milk, smoothies, hot chocolate, fruit juice and cheese.

### **Eat regularly**

Try not to skip meals, eating regularly when your appetite is small will help make sure you get enough energy and protein in your diet.

### Don't fill up on water

FULL FAT

Avoid drinking before a meal as this can leave you feeling bloated and full. If you can, try to drink after eating and in-between meals.

### Load up on calories

Try to avoid diet or low fat products, for example choose full fat milk over skimmed. Add butter to vegetables, custard or cream to deserts and use mayonnaise or butter on sandwiches.



You can buy high nutritional supplement drinks from most chemists and supermarkets that will help supplement your diet. Complan and Build Up are available as soups or sweet flavours.

## How alcohol affects COPD

Drinking alcohol is bad for your condition as it can make your symptoms worse by slowing your breathing and making mucus or phlegm more sticky.

38 Healthy Eating



## **IF YOU'RE OVERWEIGHT**

### Make healthier choices

There are plenty of great tasting alternatives to the high fat foods we love. Try skimmed or semi-skimmed instead of full fat milk, diet or 'no added sugar' drinks and puddings and sweeteners instead of sugar. Try to avoid high fat dressings like mayonnaise or salad cream, try vinaigrette or low fat dressing instead.



Try to avoid frying food: grill, boil, steam or bake instead.

### Cut down on snacking

If you find yourself snacking between meals it may not be because you're hungry, you could be thirsty or even just bored and eating out of habit.



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Try to distract yourself or drink some water when you feel the urge to snack.

### Control your portion sizes

Keep an eye on your portion sizes; fill up on vegetables or salad, these should cover at least half your plate.



Using a smaller plate is an easy way to cut down your portion size.

## Calories in alcohol



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as eating a stir-fry

### LARGE WINE UNITS 3 CALS 170 That's the same as

drinking a hot chocolate
ALCOPOP

UNITS 1.4 CALS 200 That's the same as eating a piece of cake

Another reason to cut back on alcohol is that it's very high in calories. This can lead to you becoming overweight which is bad for your condition. Please be aware however, if you're underweight you should not use alcohol to try and gain weight.



# Even more help and support

In this section there's lots more helpful information for you and anyone who cares for you.

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Remember the British Lung Foundation have lots of additional information, advice and support that can help you to manage your condition. You can find the contact details for their website and helpline on this page.

–UNDERSTANDING

# SUPPORT FOR CARERS

If there's someone who cares for you and helps you manage your condition, such as a partner, parent, friend or relative, they might also benefit from some extra help. All adults and young carers (aged up to 18), are entitled to have a carer's assessment and, if eligible, access support services.

### To find out more call Careline on 0151 233 3800

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Liverpool Carers Centre provides advice and support to carers. The centre runs activities and training, which you can take part in and meet other carers in similar situations.

To find out more call 0151 705 2307 where you can also register on the carers' database.

The British Lung Foundation website has lots of information on looking after someone with a lung condition.

Visit www.blf.org.uk/supportfor-you/carers

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### **Health Technology**

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Health Technology is a way of using simple technology to monitor your own health, with the support of professionals. It can help you stay well, become more independent and give you peace of mind.

Health Technology enables you, family members or your carer to take your vital signs, such as blood pressure, pulse and oxygen levels at home using a small, easy-to-use piece of equipment that works through a supplied tablet, your TV or an app on your own device. This information is then sent to health professionals so they can monitor you and give you the right support when you need it.

If you would like to find out more and to be referred to the service for an assessment, ask your GP or a member of your community COPD healthcare team. **For more information see pages 14-15.** 

### **Healthy Homes**

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The condition of your home can have a negative effect on your COPD if it's not right. It is recommended that the main room of your house remains at 21°C for 9 hours a day.

The Healthy Homes Team provide free help and advice for local people who are struggling to pay their energy bills and to heat their homes. You can arrange a home visit with the team who will assess your situation and see if you can be offered any repairs or other energy efficient measures and can give you advice and guidance on understanding your bills and using less energy.

They can also discuss any other issues you might have around personal health and wellbeing and direct you to the services that can offer help and support.

#### Call Freephone: 0800 012 1754

Or email **healthyhomesprogramme@ liverpool.gov.uk** to find out more information.

IF YOU HAVE COPD AND WISH TO FIND OUT MORE ABOUT THE OPTIONS YOU HAVE RELATING TO THE CARE YOU RECEIVE, INCLUDING WHAT BENEFITS AND FINANCIAL SUPPORT YOU MAY BE ENTITLED TO, YOU CAN CALL THE STAFF AT HEALTHWATCH ON 0300 77 77 007 FOR MORE INFORMATION.

They will be able to inform you about what services are available and how best to access them

### TALK TO SOMEONE ABOUT YOUR CONDITION

If you want to talk about your condition and any difficulties you may be having you can call and receive confidential advice from specialist nurses with lots of knowledge about COPD.

#### British Lung Foundation helpline 03000 030 555

(Open Mon to Fri, 9am to 5pm) Calls will never cost more than a local call, even from a mobile.

Or visit their website for lots more support on how to manage your <u>condition</u>: **www.blf.org.uk** 

### **OR LOOK ONLINE**

### **NHS** Choices

The NHS Choices website has lots of handy information about COPD.

www.nhs.uk/conditions/ chronic-obstructive pulmonary-disease

### **Patient UK**

A great resource to help you understand and manage your condition.

www.patient.info/health/ chronic-obstructivepulmonary-disease-leaflet

Notes

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This information is brought to you by Public Health Liverpool on behalf of Liverpool Clinical Commissioning Group

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