

NHS
Heywood, Middleton and Rochdale

NHS
Bury

NHS
Oldham

The Pennine Acute Hospitals **NHS**
NHS Trust

NHS
Manchester

Chronic Obstructive Pulmonary Disease (COPD)



Patient information booklet



Acknowledgments

This document draws on information found in:

- A range of information leaflets produced by the British Lung Foundation. These are available on www.lunguk.org or by phoning the BLF helpline on 08458 50 50 20 (Mon to Fri 10am to 6pm).
- The National Institute for Health and Clinical Excellence (NICE) patient's guide to the NICE Clinical Guidelines for COPD. www.nice.org.uk
- Pennine Acute Trust's pulmonary rehabilitation programme patient leaflets.
- NHS Choices website: www.nhs.uk

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This booklet contains information that will help you and your family, friends and carers to understand more about COPD, how it may affect you and the things that you can do to help stay healthy.

It also includes information on what you can expect from your doctors and nurses and questions that you may like to ask them.

Your doctor or nurse will also offer you:

- A separate self management plan that is personalised to you. This will give the drugs that you are on, any actions you have agreed with your nurse or doctor and advice on what actions to take when you are unwell
- A copy of the measurements made during your reviews
- A copy of any clinic letters or hospital discharge summaries about your COPD.



This booklet has been produced by the North East Sector Clinical COPD group, a collaboration of Health Care Professionals working for:

- NHS Bury
- NHS Heywood, Middleton and Rochdale
- NHS Manchester
- NHS Oldham
- Pennine Acute Hospitals NHS Trust

This booklet is only available in English. The British Lung Foundation produces a number of leaflets on COPD in different languages. They also have a help line with an interpretation service. See below and page 55 for their contact details.



What is COPD?

This section contains information to help you and your family and friends to understand more about COPD and how it may affect you.

COPD stands for chronic obstructive pulmonary disease. COPD is the name for a collection of lung diseases including chronic bronchitis and emphysema. It also used to be known as chronic obstructive airways disease (COAD).

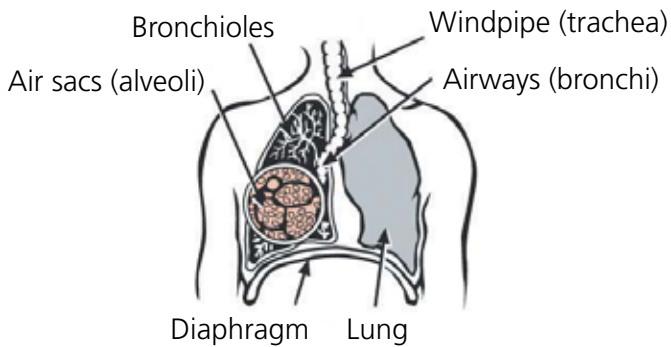
People with COPD have difficulty breathing because of long term damage to their lungs. The word 'chronic' means that the problem is long term.

COPD is one of the most common respiratory diseases in the UK. Around 900,000 people in the UK have been diagnosed with COPD, but it is thought that the actual figure is much higher.

It usually affects people who are over 40 years of age.

In COPD the airways in the lungs are damaged, causing them to become narrower and making it harder for air to get in and out of the lungs. The airways can also get inflamed, which causes cough and excess phlegm.

While there is currently no cure for COPD, the sooner the condition is diagnosed, and appropriate treatment can begin, the less chance there is that you will experience severe lung damage.



Some definitions:

Chronic bronchitis: Bronchitis means 'inflammation of the bronchi'. These are the tubes or airways which carry oxygen from the air into the lungs. This inflammation increases mucus production in the airways, producing phlegm which makes you cough.

Emphysema: this is where air sacs in the lungs lose their elasticity. This reduces the support for the airways, causing them to narrow. It also means the lungs are not as good at getting oxygen into the body, so you may have to breathe harder. This can result in shortness of breath.

What causes COPD?

In most people COPD is caused by smoking. Other causes of COPD are rare but include exposure to fumes or particles at work (such as coal dust or welding fumes) and alpha-1-antitrypsin deficiency (a genetic condition).

How is COPD diagnosed?

Your doctor may consider COPD as a possible diagnosis if you are over 35, you smoke or have smoked in the past, and you have breathing problems.

These problems include:

- Getting short of breath easily
- Having a cough that has lasted a long time
- Often coughing up sputum (the medical word for phlegm or catarrh)

or

- A lot of coughing, breathlessness or wheezing during cold weather.

Your doctor should also ask whether your breathlessness is brought on by anything, how your daily life is affected and other questions about your general health.

Sometimes people put these symptoms down to a 'smokers cough'. This might mean that they may not seek help at an early stage. The sooner people seek treatment the better.

COPD is different to asthma. Your doctor can usually tell the difference by asking you questions and examining you. If your breathlessness is better on some days than others, or you often wake up in the night feeling wheezy, you are more likely to have asthma than COPD. People with asthma also respond better to inhaled medicine than people with COPD. Some people do have both COPD and asthma.

Tests to confirm the diagnosis of COPD

The best way to confirm the diagnosis is through spirometry. This is a simple breathing test that measures the amount of air that you can breathe out. This is usually done at your GP's surgery - you just have to blow into a machine.

Your doctor should also arrange for you to have a blood test and a chest x-ray to rule out other causes of your symptoms.

It is difficult to make a definite diagnosis of COPD when someone has a chest infection or recent flare up of their symptoms. Your doctor will ask you to come for the spirometry test 6 to 8 weeks after any infection or flare up has resolved.

Occasionally more tests and/or a referral to a specialist is needed to confirm what is wrong and work out the best treatment for you. You may also ask to see a specialist if you would like a second opinion about your diagnosis or treatment.

Finding out what is wrong (diagnosis)

Questions you may like to ask your doctor or nurse:

- Can you tell me more about the tests I should have?
- Will I need to have tests in hospital?
- How long will I have to wait to have these tests?
- When will I get the results of these tests?
- Do I have asthma or COPD?
- What exactly is COPD?
- Should I see a specialist?

How do people feel?

The symptoms of COPD vary depending on how bad it is, and how people have adapted to their problems. In mild cases, symptoms like a cough, phlegm and shortness of breath may only be present during the winter or after a cold. In more severe cases, you may be short of breath every day. With more severe COPD, because of breathlessness, normal activities can become more difficult.

COPD can lead to feelings of anxiety because of breathlessness. People with COPD may reduce their activities to avoid becoming breathless. But by reducing activity levels you become less fit and get breathless even sooner when you try to do any activity. Keeping as fit as possible is important and will help to reduce how breathless you feel.

People with COPD may have flare ups of their symptoms from time to time. Doctors and nurses call this an 'acute exacerbation'. These are sometimes caused by infection or changes in the weather. Living in cold, damp houses can also worsen symptoms.

For most people living with COPD isn't easy. It is a serious illness that can greatly affect your everyday life. But it shouldn't stop you enjoying life and by knowing what you have to do to manage it – you can live well with COPD.

It takes commitment from you to improve your health and to take medications correctly. Together with help from your healthcare professionals, you can learn to improve your breathing, fitness and prevent flare ups.



Treatments for COPD

This section explains what medications and other treatments are available to help slow down the progression of COPD and help to control your symptoms.

There is no cure for COPD and your COPD will get worse with time. However, treatments and stopping smoking can help to slow down its progression and help you to breathe more easily.

Stopping smoking

If you are still smoking, it will help a lot if you stop. If you carry on smoking, your lungs will get much worse, much more quickly.

Stopping smoking will slow down the rate of lung damage. You will also notice improvements in some of your symptoms very quickly after

stopping, such as coughing less and having less phlegm. Stopping smoking can also help to reduce the number of flare ups you have.

If you smoke, giving up is the single most important thing you can do - it will help to stop further lung damage.

Giving up smoking can be difficult but help is available.

Giving up smoking

Questions you may like to ask your doctor or nurse:

- I've tried stopping before but I couldn't. How can you help me succeed?
- Which 'stop smoking' programme would suit me best?

Stop smoking services

NHS Stop Smoking services offer free and confidential support and advice. People who use NHS stop smoking services are 4 times more likely to quit than those who don't.

The Stop Smoking Services in Greater Manchester have teams of trained advisors who can tailor the stop smoking support given to suit you. This includes:

- Choice of venues and appointment times
- Choice of type of help, including drop in sessions, telephone and text support
- Prescriptions for NRT(nicotine replacement therapy) or other drugs.

You can ring the services direct to find out more or ask your doctor or nurse to refer you.

Local stop smoking services

Manchester0161 205 5998
Bury0845 2239001
Oldham0844 8730032 or 0800 3288534
Rochdale0161 655 1581

National advice:

Web: www.smokefree.nhs.uk

NHS free smoking helpline: 0800 022 4 332, 7 days a week, 7am to 11pm.

Medication

The decision about which medicines your doctor or nurse prescribes depends on how severe your COPD is, how it is affecting your everyday life, and the side effects of the medicines.

The main aims of therapy are to improve symptoms such as breathlessness and to help prevent flare ups. Medication can also help to slow down the permanent damage to the lungs that happens in COPD. There are several types of medicines that can help, which work in different ways.

Inhalers

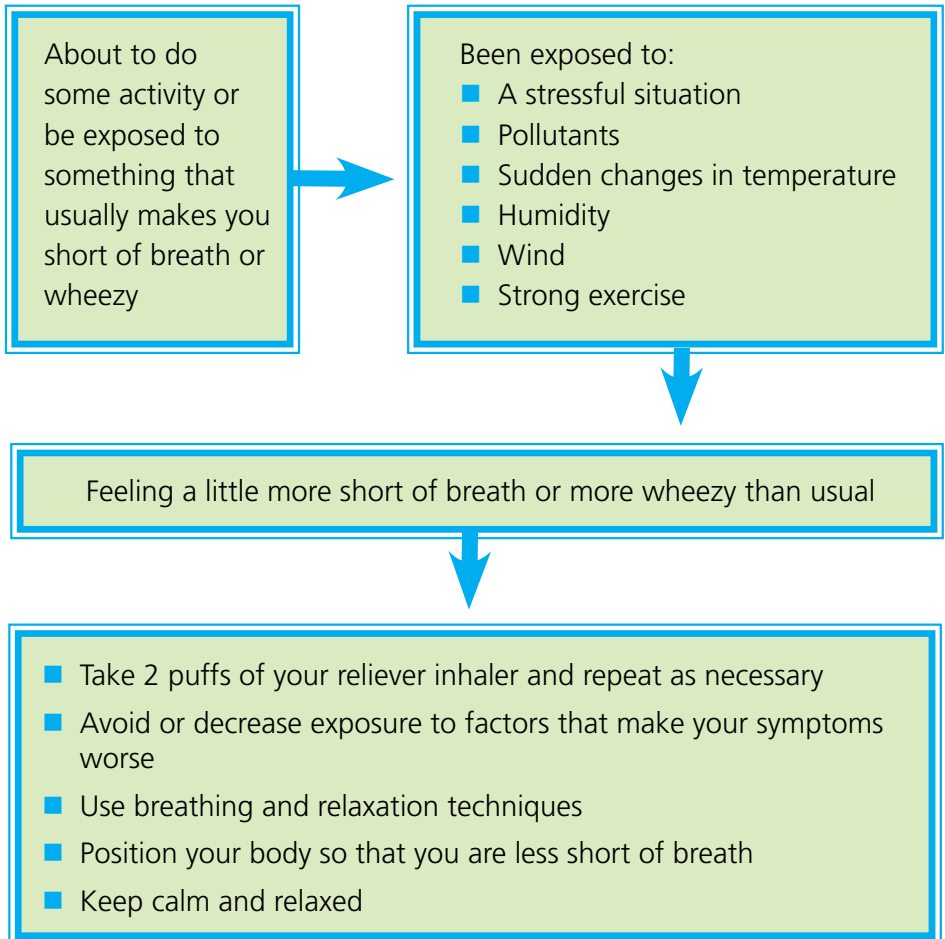
Bronchodilators

These relax the muscles in your airways and make it easier for you to breathe.

Short acting bronchodilator inhalers start to work within about 10 minutes and the effect should last about 4 hours. These inhalers are usually the first treatment tried. They are usually given on a 'use as needed basis' to relieve breathlessness. These inhalers are sometimes referred to as 'relievers'. You can take extra of these inhalers if you are feeling more short of breath

than usual or 20 minutes before doing something that you know is likely to make you feel short of breath (for example before going for a walk).

There are two main types of short acting bronchodilators (beta-2 agonists and anticholinergic or antimuscarinics) which work in different ways and you may be prescribed both.



Examples of beta-2 agonist inhalers include salbutamol and terbutaline. Common side effects include a headache, feeling shaky / tremor and/or feeling your heart beat faster than usual.

An example of an anticholinergic inhaler is ipratropium. Its common side effects include a headache, dry mouth and constipation.

If short acting bronchodilators are not controlling your breathlessness or you keep having exacerbations, you may be given a long acting bronchodilator.

These also help to relieve breathlessness. They take longer to take effect but last 12 - 24 hours. When prescribed they should be taken on a regular basis every day.

Examples of long acting beta-2 agonist inhalers include salmeterol and formoterol. Side effects are similar to those of short acting beta-2 agonists.

Tiotropium is a long acting anticholinergic inhaler. Its side effects are similar to those for short acting anticholinergic inhalers.

Steroid inhalers:

Are only used for people with more severe COPD or if you are having a lot of flare-ups. They help to reduce inflammation of the airways. When prescribed they need to be taken on a regular basis every day.

Steroid inhalers have fewer side effects than steroid tablets and can help to reduce the number of flare ups.

Side effects can include oral thrush and hoarseness. Rinsing your mouth out after using the inhaler can help to decrease thrush occurring.

Rarely with very high doses of inhaled steroids, some of the side effects seen with steroid tablets (see below) can occur.

Inhaled steroids are usually given together with a long acting bronchodilator as a combination inhaler. Examples of combination inhalers include:

Seretide = fluticasone (a steroid) + salmeterol (long acting bronchodilator)

or

Symbicort = budesonide (a steroid) + formoterol (long acting bronchodilator)

You will need to keep taking your inhalers, unless advised differently by your doctor or nurse. Inhalers won't get any less effective if you use them regularly, because they are designed to work this way.

Never run out of your inhalers. Always carry your reliever inhaler with you.

If taking more than one type of inhaler at the same time, use a bronchodilator (eg salbutamol) first to open up the airways and allow better penetration of the other drugs.

Different ways of taking your inhaled medicines

Several different types of inhalers are available e.g. aerosols or dry powder inhalers. Different ones suit different people. Some people find it helpful to use a 'spacer'. This is a plastic tube that attaches to an inhaler and makes it easier to coordinate breathing in the medicine.

Your doctor or nurse should help you to find the type of inhaler that suits you best and they should check how you are using it each time you have a check up.

A nebuliser is a machine that turns the medicine into a mist that you can breathe in. It is sometimes used when large doses of inhaled medicines are needed, such as when in hospital with a bad flare up.

Inhalers are just as effective as nebulisers for most doses and much more convenient. Very few people with COPD need a nebuliser on a regular basis. A nebuliser is unlikely to be considered unless you have had 4 or more admissions to hospital with bad flare-ups of your COPD.

Treating COPD

Questions you may like to ask your doctor or nurse:

- How will my inhalers help my COPD?
- What types of inhalers are there?
- What is a spacer?
- How often do I need to take them?
- Which one can I take extra of if I feel breathless?

Tablets

Steroids

Steroid tablets (prednisolone) are sometimes used to help to control flare ups (exacerbations). Usually they are only needed for a week or so.

Steroid tablets are very effective at decreasing inflammation of the airways that can contribute to flare-ups and can help to keep people out of hospital. However, they must be used sparingly as they can have serious long term side effects. These include causing osteoporosis, high blood pressure, weight gain, diabetes, thinning of the skin, impaired wound healing, difficulty sleeping and stomach ulcers.

Your doctor or nurse will explain more to you about when you may need steroid tablets and will record this in your self management plan.

If you are prescribed steroid tablets, it is best to take them after food when you get up in the morning.

Theophylline / Aminophylline (Phyllocontin)

If a mixture of bronchodilator and steroid inhalers are not controlling your breathlessness or you keep having exacerbations, you may be given theophylline tablets. These help to relieve breathlessness, wheezing and help to dry up secretions.

You will need to have regular blood tests to check the level of the drug is correct. Side effects include nausea, headaches and difficulty sleeping.

You should ensure that you are always supplied the same brand of theophylline as the different brands are not equivalent.

Mucolytics

If you cough up a lot of phlegm (sputum) these medicines can help to make the phlegm runnier and easier to cough up. Examples include Carbocisteine and Mecysteine.

Antibiotics

Are used to treat infections. This is explained in more detail later in the section on exacerbations.

Taking your medication

If you are prescribed medicine, the doctor or nurse believes that it will help you. So you should make sure you take it as instructed.

After starting or changing your treatment, your doctor or nurse should see you again to review how well it is working. You may need to try several medicines or combinations of medicines to find out what works best for you. Don't stop taking your medication without checking first with your doctor or nurse.

You should also be sure that you use your inhaler correctly - a lot of people don't. Ask the nurse to check your technique. And if you are using other equipment, like a spacer, or a nebuliser, you should make sure you clean and maintain it properly. Ask your nurse for instructions.

Oxygen

Some people with COPD develop low oxygen levels in their blood. Over a long time this can lead to a strain on the heart. Doctors call this cor pulmonale. Your doctor should consider cor pulmonale as a possible diagnosis if you have severe COPD and signs of a heart problem, such as swelling of the ankles.

If you have low blood oxygen levels, the use of long term oxygen at home could be of benefit to you by helping to prevent this heart strain. However, in order to get the benefits you need to use the oxygen for at least 15 hours a day every day.

If you have moderate or severe COPD, your doctor or nurse should check your oxygen saturation level. This is done using a small clip that goes over your finger. If your oxygen level is below 92%, then you should be referred to a specialist for more detailed tests to see if you would benefit from long term oxygen.

If you have signs of cor pulmonale, as well as checking whether you need long-term oxygen therapy, your doctor may give you a diuretic (water tablet) to help control ankle swelling.

Many people with COPD ask their doctor for oxygen, thinking it will help when they are feeling breathless. Oxygen does not treat breathlessness. However, there are many other things that you can do to help with the feeling of breathlessness. The breathing and relaxation exercises given on pages 42 to 48 often help. Also if you are troubled by breathlessness ask your doctor or nurse to review your treatment and whether there is a pulmonary rehabilitation programme locally that will suit you.

Only use oxygen if you have been prescribed it by a health care professional. The wrong dose can be harmful.

Oxygen

Questions you may like to ask your doctor or nurse:

- Do I need further tests to see if I would benefit from long term oxygen?
- What can help my breathlessness?

Vaccinations

Your doctor/nurse should offer you a vaccination (jab) against flu each autumn. Flu can be a very serious illness in people with COPD, so it is well worth having the injection each year.

You will also be offered a pneumococcal vaccination. This protects against a bacterial infection that can cause severe illness. The vaccination is only needed once (unless you have another disease or are on drugs that affect your immune system).

Pulmonary rehabilitation

Pulmonary rehabilitation is a 6 - 8 weeks course that includes a tailored exercise programme, information about COPD, medications and diet, and advice on living with COPD. The courses usually have two classes per week.

Each class includes some gentle exercise to help people to regain a level of fitness. People who are breathless are often anxious about becoming more breathless and so avoid exercise. This makes them less fit and so likely to become more breathless. The exercise part of the pulmonary rehabilitation course aims to break this downward spiral. The exercises will be designed specifically for you and supervised by a qualified physiotherapist.

Pulmonary rehabilitation is appropriate for most people who feel that their breathlessness is interfering with their lives.

We are working hard to increase the number of courses. Ask your doctor or nurse about what is available.

Pulmonary rehabilitation

Questions you may like to ask your doctor or nurse:

- Would I benefit from pulmonary rehabilitation?
- Are there any local pulmonary rehabilitation classes?

Anxiety and depression

Living with a lung disease can affect many aspects of your life. There are the physical symptoms, like getting out of breath and feeling tired. But lung diseases can also have an effect on your feelings, and on how you cope with life. Many people with a lung condition feel anxious. Depression is also a common problem but it can be treated.

It can sometimes be difficult to tell apart the symptoms of COPD and those of anxiety and/or depression. For example, people with lung disease often find their breathing gets more difficult when they are upset, angry or anxious.

Your doctor/nurse should ask you about how you are coping at your regular check-ups but do contact them if you are feeling anxious or down.

There are many things that can help, including:

- Learning techniques such as breathing control and relaxation techniques to reduce anxiety
- Trying to exercise more and stay active. Exercise can trigger the release of a chemical in the brain called serotonin, which boosts your mood
- Learning how to relax
- Eating a well balanced diet
- Joining a support group such as Breathe Easy (see page 56) and discussing your feelings and concerns. You are not alone
- Trying to identify negative thoughts and change them to positive thoughts
- Using a problem-solving approach to deal with stresses and worries.
- Taking antidepressant medicines.

Anxiety and depression

Questions you may like to ask your doctor or nurse:

- Are there any techniques that I can use to help control my anxiety?
- Are there any patient / carers support groups that I could go to?
- I'm feeling very down, is there anything that you can do to help?

Lung surgery

A small number of people with severe COPD may be offered surgery on their lungs to remove a large air pocket (called a 'bullae'), or part of the lung. Very occasionally, people with severe COPD who are severely disabled by their disease despite trying all other treatments may be referred to see whether they are suitable for a lung transplant. Lung transplantation is a high-risk operation and is only suitable for a small number of people.

Having an operation

If an operation is being considered for a problem unrelated to your COPD, the anaesthetist and surgeon should consider a number of factors, including the severity of your COPD, your general health and how much the operation is needed.

Air travel

You should ask your doctor or nurse for advice before flying, especially if you're having long-term oxygen treatment. Also, see the British Lung Foundation website or call their help line for practical advice.



Flare ups (exacerbations)

This section explains about flare-ups (exacerbations), how you can recognise when you are having one and the importance of getting urgent treatment.

Most people with COPD will have good and bad days. It is normal to find that how you feel will fluctuate from day to day and learning how to adapt to this and when to take extra of your reliever inhalers is important (see page 14).

However, you may have times when your symptoms become a lot worse. These 'flare-ups' are known as exacerbations. Most people can be treated at home when they have an exacerbation, but sometimes they can be so bad that you need to go into hospital.

Exacerbations can lead to worsening of the permanent lung damage that occurs in COPD. So it's important to try to prevent exacerbations, to know the early warning signs of an exacerbation and to get prompt treatment when they occur.

What causes exacerbations?

Exacerbations may be caused by a variety of things, including:

- an infection
- changes in the weather
- fumes or smoky environment.

Sometimes it is not clear what has caused the exacerbation.

What can I do to help to prevent exacerbations?

You can help to reduce the number of flare ups you have by:

- Stopping smoking if you still smoke
- Taking your medications regularly
- Having a flu vaccination each year.

You can also help to limit the damage done by exacerbations by learning to recognise the warning signs of a flare up and taking action to get treatment early.

How to recognise an exacerbation

It is important to know how you are normally, so that you can spot when things change.

When you are well, take note of your usual symptoms. Know:

- How much you can do each day
- How your breathing is at rest and during activity
- What makes your breathing worse
- How much phlegm (sputum) you have and what colour it is
- What your appetite is like
- How well you sleep.

Be aware of the symptoms of a flare up and ask your nurse or doctor about how you can tell the difference between your usual fluctuation in symptoms and a flare-up.

The main symptoms of a flare up are:

- New or worsening cough
- Much more breathless or wheezy than usual
- Change in amount of phlegm (sputum)
- Change in colour and/or thicker phlegm (sputum)
- A raised temperature/fever/feel shivery or hot and cold.

You may only have a couple of these symptoms.

You may also:

- Feel tired/lack energy
- Lose your appetite
- Have difficulty sleeping
- Have ankle swelling.

How are exacerbations treated?

Flare ups are treated by:

- Increasing your bronchodilator (reliever) inhalers
- Antibiotics if you have an infection

and/or

- Prednisolone tablets (steroids) for 7 - 14 days if you are more short of breath.

Your doctor may prescribe you some antibiotics and prednisolone to keep at home to start as soon as you get symptoms of a flare up. Alternatively your doctor or nurse may arrange for you to be able to phone the surgery for a prescription as needed.

Ask whether you are going to have a home supply of antibiotics/steroids or how you are going to get these quickly when needed.

Most people can be treated at home if they have an exacerbation, but some will need to go into hospital. The decision about whether to go into hospital depends on factors such as: how bad the exacerbation is; what your COPD is normally like; your general health; and how well you would be able to cope at home.

Additional treatments that may be given in hospital include:

- Oxygen
- Nebulisers
- Physiotherapy to help with coughing up sputum
- Help with breathing via a non-invasive ventilation machine
- Rarely, people may need treating in intensive care.

Non-invasive ventilation (NIV)

NIV is an emergency treatment that you may receive if you are taken to hospital because of an exacerbation. NIV is a method of helping someone get enough oxygen into their blood. It is not the same as oxygen therapy. It involves wearing a mask that covers the nose and is connected to a small machine that pushes oxygen through the mask and into the lungs.

Flare-ups (Exacerbations)

Questions you may like to ask your doctor or nurse:

- How will I know if I am having a flare up?
- When and who do I call for help?
- Can I have some antibiotics and steroid tablets to keep at home?
- When do I need to go to hospital?



Regular check-ups (reviews)

This section looks at the importance of having regular check-ups (reviews) with your doctor or nurse and what you can expect to happen at your review.

How often should you have a check up?

You should see your doctor or nurse regularly for check-ups. They may call this your annual review.

How often you need to be routinely seen depends on the severity of your COPD. Your doctor or nurse should assess how severe your COPD is when they initially diagnose that you have COPD and then reassess the severity each time you are reviewed.

Patients with mild, moderate or severe COPD should have a routine check-up at least once a year.

Patients with very severe COPD should be routinely seen at least twice a year.

Your doctor should send you an invitation to come for the routine check-up but don't wait - if you are due for a check-up, or if you are concerned about anything, make an appointment.

You should go for your routine check-up even if you're feeling well.

You also need to be seen whenever you have a flare up and two weeks after any hospital admission because of your COPD.

What happens at a check-up?

During your check-up, you should be asked about:

- How well your symptoms are controlled
- How breathless you get and how much exercise you are able to do
- How often you are having flare ups
- Any other symptoms or problems you may be having
- How your COPD is affecting your everyday life, including emotional issues such as feelings of anxiety or depression
- What medicines you are taking and whether you have had any side effects or other problems with the medicines.
- Whether you smoke and if you want to stop.

At the check up, your doctor or nurse should:

- Answer any questions that you have about your illness, its impact on your life and what you can do to help to cope with it

- Use a spirometer (blowing machine) to check how well your lungs are working
- Use a pulse oximeter to measure oxygen levels in your blood if you have moderate or severe COPD or any signs of heart strain
- Weigh you and work out your Body Mass Index (BMI)
- Work out your MRC dyspnoea (breathlessness) score by asking you questions
- Check how you are using your inhalers
- Review whether you need any changes to your medication or further investigations
- Consider if you would benefit from pulmonary rehabilitation (where courses are available).

MRC Breathlessness Score

- 1** Not troubled by breathlessness except on strenuous exercise.
- 2** Short of breath when hurrying or walking up a slight hill.
- 3** Walks slower than people of the same age on level ground because of breathlessness, or has to stop for breath when walking at own pace.
- 4** Stops for breath after walking about 100 metres or after a few minutes on level ground.
- 5** Too breathless to leave the house or breathless when dressing or undressing.

Your doctor or nurse should also:

- Assess your nutritional status if you have very severe COPD
- Consider whether referral to any other health care professional (eg physiotherapist, occupational therapist, community matron, dietitian) or other agencies (eg social services, welfare advice services, AWARM) would be helpful
- Consider whether your family and anyone who helps to look after you need any help or support
- Provide you with information about local support groups for patients with COPD or their carers. (eg Breath Easy - see page 56)
- Check whether you have any other conditions apart from COPD.

Regular checkups

Questions you may like to ask your doctor or nurse:

- Why do I need regular checkups?
- How often should I have a check up?

Preparing for your check-up

To help you get the most out of your check up before you go:

- Make a list of anything that is concerning you or questions that you would like to ask
- Take your current medications with you to the check up
- Fill in the questionnaire below. This will help you and your healthcare professional measure the impact COPD is having on your wellbeing and daily life.

The COPD Assessment Test (CAT)

For each item below, place a mark (X) in the box that best describes you currently. Be sure to only select one response for each question.

Example: I am very happy (1) (2) (3) (4) (5) I am very sad

I never cough	(1) (2) (3) (4) (5)	I cough all the time	
I have no phlegm (mucus) in my chest at all	(1) (2) (3) (4) (5)	My chest is completely full of phelgm (mucus)	
My chest does not feel tight at all	(1) (2) (3) (4) (5)	My chest feels very tight	
When I walk up a hill or one flight of stairs I am not breathless	(1) (2) (3) (4) (5)	When I walk up a hill or one flight of stairs I am very breathless	
I am not limited doing activities at home	(1) (2) (3) (4) (5)	I am very limited doing activities at home	
I am confident leaving my home despite my lung condition	(1) (2) (3) (4) (5)	I am not at all confident leaving my home because of my lung condition	
I sleep soundly	(1) (2) (3) (4) (5)	I don't sleep soundly because of my lung condition	
I have lots of energy	(1) (2) (3) (4) (5)	I have no energy at all	
		Total	



Other health and social care services

Depending on how severe your COPD is, how much it is affecting your life and whether you have other illnesses, your doctor or nurse may refer you to other health or social care services. Ask your doctor or nurse for details of local services and whether they may be appropriate for you.

Service	What they can help with
Consultant with specialist expertise in chest problems	Your doctor or nurse may ask a consultant (specialist) to see you if: <ul style="list-style-type: none"><li data-bbox="319 1292 957 1348">■ There is uncertainty as to whether you have COPD or another condition<li data-bbox="319 1364 716 1396">■ Your COPD is difficult to control<li data-bbox="319 1404 823 1436">■ You ask for a second opinion at any time.

Home oxygen assessment service	This service does detailed checks of your blood oxygen levels and assesses whether you would benefit from long term oxygen.
Stop smoking service	The stop smoking advisors can provide you with a tailored programme of support to help you quit smoking.
Community specialist respiratory team	Most areas have a team of specialist nurses and/or physiotherapists who can provide 'one off' advice or ongoing help for people with COPD and their carers.
Hospital at home schemes	Some areas have 'hospital at home' services, where nurses provide an emergency service, to help keep people having a flare-up stay out of hospital, or enable them to be discharged earlier from hospital. This service may be provided by the community specialist respiratory team.
Community matrons	These nurses have advanced training to help people with a variety of long term illnesses to manage their conditions at home. They tend mainly to help people who either have two or more long term illnesses or who have had a lot of recent admissions to hospital.
Occupational therapists	Help people to adapt to living with a long term illness by providing advice, aids and adaptations to help with activities of daily living.
Physiotherapists	Help people with chest problems learn ways to help control their breathing and to bring up phlegm. They also help people with walking and mobility problems.
Dietitians	Provide dietary advice to people with a range of illnesses. They can help people who are under or overweight or at risk from malnutrition.
Social services	Coordinate support for people who need help in order to be able to continue living at home.
Palliative care teams	Support people with advanced COPD to stay as comfortable as possible and support their families and carers.



How to get the best from your health and social care professionals

Have you ever come out of your doctor's surgery feeling that you haven't got the answers you went in for? This section aims to help you get the most from your appointments.

- It may help to prepare a list of the subjects you want to discuss. But remember, it is not always possible to mention two or three separate concerns - routine GP appointments are normally ten minutes long - so think about making a double appointment.

- Before your visit, think through all the information you believe your doctor needs to know - when did the symptoms start, how have they changed, how is your life affected and, most importantly, tell him or her how you actually feel.
- Decide what you aim to get out of the visit. Is it medication, advice and/or another therapy?
- Take a relative or friend with you if this will make you feel more comfortable.
- Listen to what the doctor says. If you don't understand, or if you feel that he or she has not answered your questions, ask.
- Make a note of your doctor's comments, or ask your doctor for further information. Many doctors can now provide information leaflets - such as British Lung Foundation leaflets - or web based leaflets that are accurate and understandable.
- Check your list at the end of the appointment to make sure that you have covered all the points you want to.
- Remember don't be afraid to say how you really feel - after all, you are the only person who knows.



Things that you can do to help you stay well

The previous sections have discussed the importance of:

- Trying to stop smoking
- Having regular check ups with your doctor or nurse
- Taking your medicines regularly and never running out of your medicines
- Having a flu jab each year
- Pulmonary rehabilitation
- Getting prompt treatment for exacerbations (flare-ups).

There are also lots of other really practical things that you can do to help to stay well and cope with your COPD. This section gives some useful tips for you.

Take some exercise every day

Exercise is particularly important if you have COPD because it is one of the most important ways of reducing breathlessness. Many people with COPD stop taking exercise because it makes them breathless. But not exercising makes things worse.

Regular exercise can:

- Reduce breathlessness
- Give energy
- Improve mood
- Help you walk further for longer
- Strengthen muscles and bones
- Help to maintain a good weight
- Prevent constipation.

Take some exercise every day. Set some time aside each day for a walk. Start with 20 minutes and gradually increase. You can't do yourself harm by over-exertion, because breathlessness will stop you. Try to walk, even if it's just around the house or up and down the garden. All types of exercise are valuable eg gardening or household chores can also count as exercise.

If you find that taking exercise makes you more short of breath, try taking two puffs of your reliever inhaler 20 minutes before starting the exercise.

Some leisure centres hold special exercise groups for people with breathing difficulties. There may also be walking groups for people with health problems in your area. Your GP surgery should be able to tell you what is available locally.

Eat well, drink well

Having COPD means that you use up a lot of energy in breathing, which is why many people with COPD lose weight.

It's really important for you to eat a healthy diet. You should aim to eat a variety of foods including meats, fish and eggs; dairy products; potatoes, bread, rice and pasta; and fruits and vegetables every day.

It's also important to drink a lot of water (unless your doctor has told you not to). It keeps the lining of the airways moist and your sputum will be thinner.

If you are underweight or losing weight you may need to increase your calorie (energy) intake by having larger amounts of fats, sugar or protein containing foods in addition to eating a good variety.

Eating little and often will stop you getting breathless during long meals and feeling bloated.

Try to keep a supply of foods in the cupboard for quick and easy meals. When you have the energy, cook more meals than you need and freeze them for another day. And if you can, share the cooking and eating with someone else.

If you are overweight, you may be advised to lose weight. You will find that this helps with your breathing and decreases the amount of effort it takes to do everyday tasks.

Your doctor/nurse may provide you with information on eating to stay well or may refer you to a dietitian if you need special dietary advice.

Sleep well

It's vital to get enough rest every day. Take time to relax before going to bed. Make sure your bed is comfortable and that your medicine is where you can reach it if you need to. Some people prefer to prop themselves into a more upright position to sleep, or to sleep on their side. You may find sleeping with your body at a 30 degree angle helps with your breathing during the night.

Be careful what you breathe

Because your lungs are more sensitive:

- Don't go to smoky places, and ask people not to smoke around you
- If you know of places where there are regular traffic jams, or where there are lots of exhaust fumes (e.g. underground car parks), try to stay away.

- Only use strong-smelling products (like cleaning products) when there's lots of ventilation.
- Don't use air freshener plug-ins or sprays, scented candles, hair spray or perfume
- If you work in a dusty or smoky environment, then you might need to change departments - talk with your employer and explain the problem.

If you know you are going somewhere where you can't avoid the above, take two puffs of your reliever inhaler 20 minutes before going there.

Breathing, coughing and relaxation techniques

There are various exercises to help with breathlessness, coughing and to help you to relax. If you practice these and use them every day, they will help you when you are active and getting breathless. They will also help you manage if you get short of breath suddenly. See pages 42 to 51.

Try to avoid infections

Stay away from people who have colds, flu or a sore throat.

Keep an eye on the weather forecast

In winter, the cold air, fog or mist can make breathing more difficult. In summer an increase in temperatures, humidity or air pollution may also cause breathing to become more difficult.

If changes in temperature increase your breathlessness, take two puffs of your reliever inhaler 20 minutes before you go out. Always carry it with you.

Take a moment or two to sit at the front door and get used to the temperature outside.

If you're going outside on a cold or windy day, wrap up well and cover your nose and mouth with a scarf.

In hot weather, open windows at night for ventilation. Try electric fans, taking cool showers and cool baths.

Try to keep your home at recommended temperatures

Cold and dampness can worsen your COPD symptoms. Try to keep your living room at 21°C and your bedroom at 18°C.

There are a wide range of things that can be done to your house to help make it warmer and save you money on your heating bills. These are known as affordable warmth measures and include things such as insulation and draft proofing. There are a number of different grants available to help with the cost of these. Advice is also available to check whether you are entitled to any benefits.

For advice phone the **Energy Savings Trust** on 0800 512012

Or

Ask your doctor/nurse or social worker to refer you to **AWARM**

AWARM provides confidential advice for all on income maximisation, debt and benefits advice, energy use and efficiency advice, and, for those who are eligible, free or reduced cost access to housing improvements such as loft and cavity wall insulation and heating schemes.

The British Lung Foundation helpline (08458 50 50 20) or the Department for Work and Pensions Benefit Enquiry Line (0800 88 22 00) can give you general advice about benefits you may be entitled to.

Relax

Stress and anxiety may make your symptoms worse. So make sure you talk with your friends, family or health professionals - let people know how you are feeling and share your concerns. And try to avoid situations you know will worry you. Try the relaxation techniques on pages 46 - 48.

Sex

Sexuality is a very important part of one's life but having an illness like COPD can upset any relationship. Remember, a healthy sex life is not just limited to intercourse. The feelings created by ambience such as music, dinner and touching are also important.

Here are some practical tips:

- Explore your likes and dislikes. Share your findings with your partner.
- Be creative. Do not limit yourself to intercourse
- Take your time
- Touching and creating the right ambience are important too
- Stay in shape with regular exercise. Physical effort during intercourse is equal to climbing a flight of stairs at a normal pace
- As with everyday life, avoid factors that may make your symptoms worse such as perfumes, hair sprays and scented lotions
- As with any physical exercise, you can take your short acting bronchodilator (reliever) inhaler 20 minutes before having sex
- If you do not want to be bothered by sputum, practice your controlled cough before beginning sexual activity (see page 60)
- Use breathing and relaxation techniques to reduce your shortness of breath (see pages 42 - 48)
- Use positions that require less energy and do not put pressure on your chest. Use pillows to support your back. If necessary, let your partner take a more active role.

If you are still concerned talk to your doctor or nurse.



Breathing Exercises

Shortness of breath for people who have COPD is part of daily life. Nothing will make it disappear completely but there are many things you can do to reduce your breathlessness. This section gives some tips on how changes in your position and the way that you breathe can help.

Positioning

Changing your position can reduce the feeling of shortness of breath. Try all these positions and decide which ones are best for you. Different ones will suit different situations.

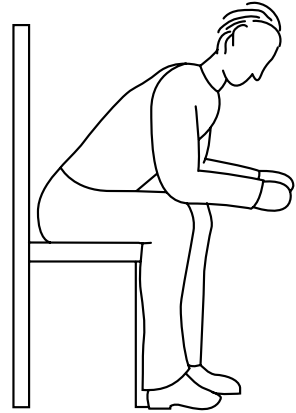
Sitting:

Support your feet

- Lean your chest forward slightly
- Rest your elbows on your knees
- Rest your chin on your hands

Or:

- Support your feet
- Lean your chest forward slightly
- Rest your arms on a table
- Rest your head on a pillow



Standing:

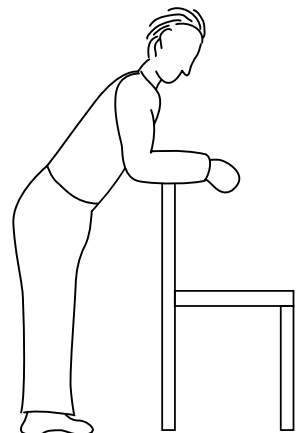
- Lean your chest slightly forwards
- Rest your forearms on something the right height (eg a piece of furniture, kitchen worktop, garden wall)

Or:

- When you're standing or walking, try putting your hands on your hips, 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.

Or:

- Using a walking aid (walking stick, or a frame with wheels at the back and front) can help you find one of these comfortable postures when you are out and about. Most people feel better pushing a supermarket trolley - it works the same way.



Lying down:

- Try lying on your side, propped up with lots of pillows.

Breathing techniques

Certain breathing exercises can help to reduce shortness of breath. Here are some exercises that you can use when you get short of breath. Practice them all at different times to find the ones that work best for you.

First, get into a comfortable position with your shoulders relaxed. One of the positions on the last page may be good.

As you get better at breathing exercises you may be able to do them while you are walking, climbing the stairs or exercising.

Basic Breathing control

- 1 Breathe in gently through your nose. Try to take a middle size breath – avoid deep breaths.
- 2 Breathe out slowly through your nose or mouth. Make your out-breath twice as long as you're in-breath. Do not empty your lungs completely. Do not force the out-breath.
- 3 Repeat until you feel your breathing rate slow down and your breathlessness decrease.

Pursed lips breathing

Just like Basic Breathing Control but when you breathe out, purse your lips as you would to whistle or kiss someone.

This slows your breathing down and helps to make your breathing more efficient.

Breathing with the belly (Diaphragmatic Breathing)

While doing Basic Breathing Control ...

- 1 Place one hand on your abdomen (belly).
- 2 Feel your belly rise as you breathe in.
- 3 Feel your belly move inwards as you breathe out.
- 4 Repeat until you feel your breathing rate slow down and your breathlessness decrease.

'Blow as you go!'

Breathe out when you're making a big effort, for example:

- stretching your arms above your head
- reaching for something on a shelf
- bending down
- going up a step or stair
- standing up.

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:

- breathe in when on the stair, and breathe out as you go up a stair (blow as you go!), or
- breathe in for one stair and out for one stair, or
- breathe in for one stair and out for two.

Remember: Avoid taking more than 3 or 4 deep breaths at a time. If you feel dizzy, stop the breathing exercise and sit down. Read the instructions and check that you are doing them correctly.



Relaxation Techniques

Having a long term illness or life in general, can be very stressful. Being short of breath may make you feel anxious, which in turn can make your breathlessness worse. Breaking the cycle of breathlessness and anxiety, can help you cope with your breathlessness much better. Here are some relaxation exercises that can help. Try a few out to see which one works best for you.

Relaxation through breathing control

- 1 Find a quiet place, where you will not be disturbed.
- 2 Get into a comfortable position with your arms and shoulders relaxed.
- 3 Breathe in slowly through your nose. Take a middle sized breath.
- 4 Exhale slowly, making your out-breath twice as long as your in-breath. Do not force the out breath. Purse your lips if you like.

- 5 Repeat until you feel your breathing rate slow down and your body relax. Allow 10 - 15 minutes to become really relaxed.
- You will be more relaxed if you close your eyes and think about a quiet place or the word “calm”.
 - Soothing music in the background may help.
 - Do not worry if you find it hard to become really relaxed at first. After several 10 - 15 minute sessions it will become easier.

Progressive Muscular Relaxation

- 1 Find a quiet place, where you will not be disturbed.
- 2 Get into a comfortable position with your arms and shoulders relaxed.
- 3 Tighten the muscles in your left foot. Hold for five seconds then let the foot completely relax.
- 4 Tighten the muscles in your left calf. Hold for five seconds then let the calf completely relax.
- 5 Tighten the muscles in your left thigh. Hold for five seconds then let the thigh completely relax.
- 6 Repeat steps 3 to 5 for the other leg.
- 7 Tighten your buttocks. Hold for five seconds, then let the muscles completely relax.
- 8 Make a fist with your right hand. Hold for five seconds, then let your hand completely relax.
- 9 Tense the muscles in your right arm. Hold for five seconds, then let your arm completely relax.
- 10 Repeat steps 8 and 9 for the other arm.
- 11 Push your shoulders back, pushing shoulder blades together and hold for five seconds. Then completely relax the shoulders.
- 12 Tighten your jaw, hold for five seconds then let it relax completely.

- 13 Scrunch up your eyes, nose and forehead, hold for five seconds, then completely relax your face.
- 14 Sit quietly for five or ten minutes, practicing your breathing control. Try to still your thoughts and focus only on your breathing.

Visualisation

- 1 Picture an image that makes you feel happy, confident and relaxed. You may want to picture a special person, place, thing or accomplishment.
- 2 Concentrate on the image.
- 3 Begin to relax. Focus on your breathing while you are visualising your image.
- 4 End the exercise by remembering your image.



Cough techniques

Some people with COPD produce lots of phlegm (sputum) all the time, others only when they have a chest infection. It is important to remove sputum from your lungs so that you can breathe more easily and prevent chest infections. Coughing is one way to removing excess sputum.

However, coughing “fits” or “spasms” can leave you feeling breathless and exhausted. Coughing can also make your chest feel tight. There are other techniques that you can learn to help you clear sputum with less effort.

Huffing

Huffing causes less breathlessness than regular coughing. It is more easily controlled and helps avoid fits of coughing.

- 1 Position yourself comfortably with arms supported
- 2 Take a slow deep breath in
- 3 Hold the breath for a couple of seconds
- 4 Gently breathe out about half the air
- 5 Then, strongly breathe out with an open mouth (as if you were making a mist on a window)
- 6 Repeat twice only

If you still have sputum to clear, do breathing control for at least 10 cycles before huffing again.

Controlled cough technique

- 1 Position yourself comfortably with arms supported
- 2 Take a deep breath in
- 3 Hold the breath for a couple of seconds
- 4 Keep your mouth slightly open and cough twice

If you still have sputum to clear, do breathing control for at least 10 cycles before trying controlled cough again.

Some more suggestions to help to remove sputum:

- Position yourself comfortably. Don't try to rush it... Relax
- If there is little or no sputum, do not persist in attempting to cough
- Some people find it useful to perform coughing techniques in the morning as sputum can accumulate overnight. Others find it more effective later in the day
- Try taking your short acting bronchodilator inhaler (reliever) or nebuliser about 20 minutes before you start
- If you are worried about coughing while you are out take some time to clear your sputum before you leave the house
- Drink a warm drink before coughing. This can help to loosen up your sputum
- Avoid coughing fits. This wastes energy and causes shortness of breath
- Learn to control your urge to cough. Do not let your cough control you
- Drink plenty of decaffeinated fluids throughout the day

If you have a lot of sputum, or are still finding it difficult to clear, ask to see a physiotherapist.



Partners and carers

How will my condition affect my spouse/ partner/carer?

It is inevitable that at some stage your spouse/partner/carer will feel anxious or frustrated about your health problems. It can help to keep your partner/family/carers fully informed about your illness. For example, they may like to read this information booklet and to see your care plan. It can also be very helpful for both you and your partner, if your partner is also involved in decisions about your treatment.

It is important to talk about worries together. Sometimes partners and carers don't like to bother you with their concerns but talking things through together can make a real difference.

Your partner/family may react by doing everything for you, but this isn't always the best approach. It is important that you remain as active as possible and continue to enjoy things together.

Help people to help you - they won't know unless you explain it to them. But they will want to help if they understand your problems.

What help is available for partners and carers?

The Breathe Easy network and the British Lung Foundation are a great resource for information and support. Partners and carers are very welcome to join Breathe Easy. See page 54 to 57.



Useful local and national contact details

This section lists a number of local and national organisations and sources of information that may be of help to you and your family/carers.

Stop smoking services

National advice:

Web: www.smokefree.nhs.uk

NHS free smoking helpline: 0800 022 4 332, 7 days a week, 7am to 11pm.

Local stop smoking services

Manchester	0161 205 5998	Bury	0845 2239001
Oldham	0844 8730032 or 0800 3288534	Rochdale	0161 655 1581

British Lung Foundation

National charity that helps people with lung diseases.

Website: www.lunguk.org

Helpline: 08458 50 50 20 (Mon to Fri 10am - 6pm)

Services offered by the British Lung Foundation include:

- Wide range of leaflets on COPD and living with lung diseases
- Comprehensive web site with lots of useful advice
- Helpline
- Patient/carers support groups

The helpline offers free, confidential and impartial advice, information and support on a number of subjects including travel & transport, oxygen, equipment, welfare benefits, as well as many issues relating to COPD and other lung conditions.

The helpline is staffed by:

- **respiratory nurses**, who can provide help and information on lung conditions, their diagnosis and treatment, and how best to live with them
- **welfare benefits advisers**, who can help with money matters, enabling you to make sure you are getting the financial help you are entitled to
- **parent counsellors**, providing emotional and practical support to parents whose children are affected by lung disease

An interpreting service is available to help answer telephone enquiries from someone whose first language is not English. The caller will be asked which language they speak, and then via the Helpline, they will be connected to an interpreter so that they can continue with their enquiry.

Breath Easy support groups

Local British Lung Foundation support groups for people with lung conditions and those who care for them.

Groups	When	Where	Contact
Bury	First Friday of the month, 2 - 4pm	Parish Hall, St James Church, Walshaw Road, Bury, BL8 1TD	Bea Gilmore 0161 724 7821
Oldham	First Tuesday of the month, March - November 1.30 - 3.30pm	Honeywell Centre, Hadfield Street, Ashton Road, Oldham, OL8 3BP	Chair: Selwyn Hodge 0771 288 6230 Secretary: Mrs Kath Roye 0161 665 1919
Newton Heath	One Wednesday per month, 1 - 3pm	Heathfield Resource Unit, Heathfield Street, Newton Heath, M40 1LF	Dot Rathbone 0161 273 4709
Heywood, Middleton and Rochdale	First Wednesday of the month, March - December, 1.30 - 3.30pm	The Castleton Community Centre, Manchester Road, Rochdale, OL11 3AF	Barbara Leeming 01706 341668

NHS Direct

For health advice 24 hours a day, 365 days a year.

Website: www.nhsdirect.nhs.uk

Phone: 0845 4647

NHS Choices

Website that includes advice on a range of health conditions, advice for carers. It can help you to make lifestyle choices about things like smoking, drinking and exercise. Also helps you find local health services.

Website: www.nhs.nhs.uk

Department for Work and Pensions Benefit Enquiry Line

A telephone advice and information service you can call if you are sick or disabled or if you are caring for someone and acting on their behalf.

Phone: 0800 88 22 00. Mon - Fri 8.30am - 6.30pm, Sat 9am - 1pm.

Textphone: 0800 24 33 55. You can also use the text relay service.

Age UK (formerly Help the Aged and Age Concern)

Wide range of advice including help with living at home, health issues and health services, benefits.

Website: www.ageuk.org.uk

Phone: Age UK Advice 0800 169 6565

Support for carers:

Carers UK

Provides free and confidential information and advice on carers' benefits, carers' employment rights, carers' assessments and the services available for carers, and how to complain effectively and challenge decisions

Website: www.carersuk.org

E-mail: advice@carersuk.org

Advice line: 0808 808 7777 (Wednesday and Thursday 10am - 12pm and 2pm - 4pm)

Crossroads Association

Provides support services for carers including trained carer support workers who comes into the home to take over the caring responsibilities, enabling the carer to take a break.

Website: www.crossroads.org.uk

Phone: 0845 450 0350



NHS
Heywood, Middleton and Rochdale

NHS
Bury

NHS
Oldham

The Pennine Acute Hospitals **NHS**
NHS Trust

NHS
Manchester

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