CHEST SERIES C1

LIVING WITH COPD

Chest
Heart &
Stroke
Scotland

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Chest Heart & Stroke Scotland improves the quality of life for people in Scotland affected by chest, heart and stroke illness, through medical research, influencing public policy, advice and information and support in the community.

FUNDRAISING

Chest Heart & Stroke Scotland is a wholly independent Scottish charity. We receive no core funding from Government or any public body or private agency and rely entirely on the Scottish public to raise the £7 million a year we need to help people with chest, heart and stroke illness throughout Scotland.

RESEARCH

We are one of Scotland's largest charitable funders of medical research, with a programme worth over £600,000 a year. We fund research projects throughout Scotland into all aspects of the prevention, diagnosis, treatment and social impact of chest, heart and stroke illness.

PERSONAL SUPPORT GRANTS

We provide small grants to people in financial difficulty, because of chest, heart or stroke illness, for items ranging from disability equipment and household goods to respite care and holidays.

VOLUNTEER SERVICES

We give support to people whose communication skills are impaired after a stroke and those living with heart failure. The Volunteer Stroke Service (VSS) provides weekly group meetings and home visits for patients. The Heart Failure Support Service (HFSS) provides volunteer befrienders to reduce social isolation.

CHSS NURSES

Our nurses provide independent practical advice and support to those who have chest, heart and stroke illnesses, their families, carers and health professionals. There are dedicated nursing services in Fife, Forth Valley, Grampian, Highland, Lanarkshire, Lothian and Dumfries and Galloway. There is also a Scotland wide nurse led Advice Line (0845) 077 6000. Calls are charged at a local call rate (out of hours answerphone). We have a wide range of booklets, factsheets and videos on chest, heart and stroke illnesses.

COMMUNITY SUPPORT NETWORK

CHSS provides support to affiliated chest, heart and stroke clubs through the Community Support Network. The clubs are independent and are run by local volunteers. The groups provide a range of activities and offer people support, stimulation and companionship in a friendly and relaxed environment. Please ask for more information.

FOR FURTHER INFORMATION ABOUT ANY OF THE SERVICES ABOVE PLEASE CONTACT HEAD OFFICE BY PHONING 0131 225 6963 OR VISIT www.chss.org.uk

LIVING WITH COPD

WHAT IS COPD?

Introduction

Chronic obstructive pulmonary disease, shortened to COPD, is an umbrella term for a group of conditions which cause long-term damage to the airways.

COPD includes:

- chronic bronchitis
- emphysema
- lung damage which is caused by chronic asthma

If you have COPD you may have symptoms of all of the above conditions.

In Scotland over 100,000 people are diagnosed with COPD. Many more are living with symptoms but are not yet diagnosed. COPD is a chronic condition which means there is no cure; COPD usually worsens over time. However, there are treatments available which can ease your symptoms and there is a lot that you can do to help yourself and prevent further damage to your airways.

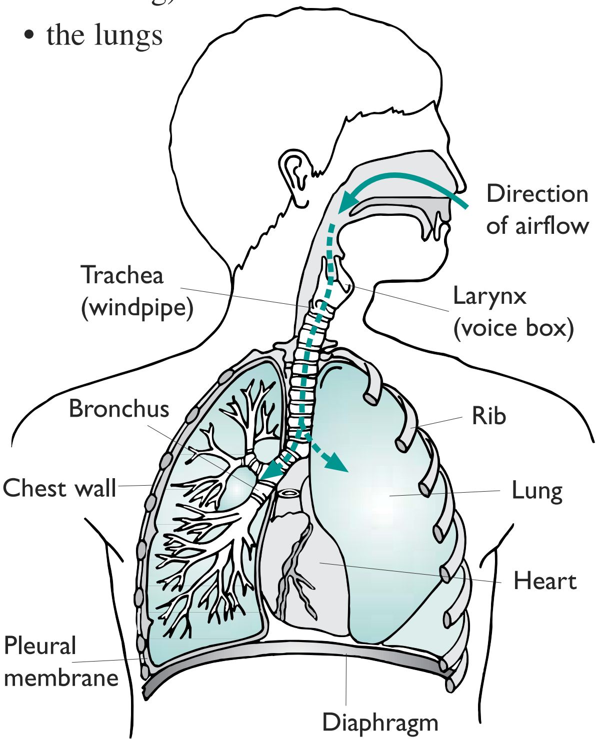
This booklet aims to help you understand what COPD is and describes coping mechanisms to help you get the most out of life. You may have to read it several times or dip in and out of the different sections as you need the information.

The respiratory system

The respiratory system is the group of organs, within your body, that are involved with breathing. It includes your:

- nose and mouth
- pharynx (throat)
- larynx (voice box)
- trachea (windpipe)
- the right main bronchus and left main bronchus (airways to each lung)
- diaphragm (sheet of muscle underneath the ribcage which helps with the process of breathing)
- intercostal muscles (groups of muscles found between the ribs that help with the process of breathing)
- the lungs

Figure 1. Diagram of the respiratory system



How your lungs work

Your lungs are found within your chest, situated on either side of your heart and protected by your ribcage.

Each lung is divided into lobes. Your right lung has 3 lobes; your left lung only has 2 (to make way for your heart). Your lungs are covered by a thin protective layer of tissue (called the pleura).

The function of your lungs is to help you breathe. Your body is made up of millions of tiny cells that need oxygen to function. By breathing in air (inhalation), your lungs can transfer oxygen to your blood stream, which can then be sent all round your body. Carbon dioxide, a gaseous waste product of body processes, is collected in the blood stream and expelled through your lungs by breathing out (exhalation).

Your air passages

Air is brought into your lungs through air passages from your nose and mouth. The process of warming, moistening and filtering inspired air is continued throughout the respiratory system.

- Air is warmed as it passes over the surface of your airways.
- The air is moistened by contact with mucus and filtered by cilia (tiny hair-like projections) which waft any particles of dust or debris (caught in the mucus) towards your throat to be either expectorated (coughed up) or swallowed.
- There are protective cells within your air passages that fight any infection or foreign particles that have not been trapped in the mucus.

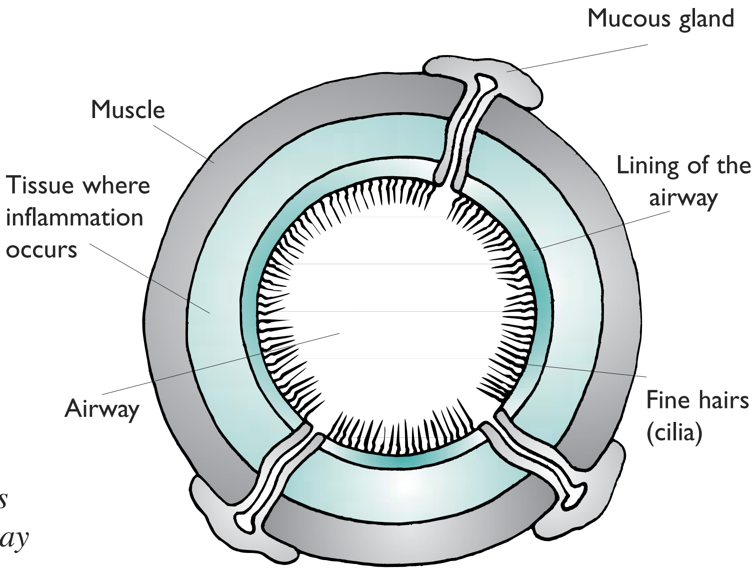


Figure 2. Cross section of airway showing lining, cilia, mucus glands and muscle layer

- There is a layer of muscle in the walls of your air passages that controls the width of the passageway and so controls the amount of air that can enter your lungs.

The path for air to enter your body starts at your nose and travels through your larynx and trachea to divide into two branches to supply your left and right lung. These are called your left bronchus and right bronchus. Your bronchi further subdivide and branch out into smaller and smaller air passages to form an intricate system of tiny air passages throughout your lungs, called bronchioles. These tiny passages end in millions of tiny air sacs called alveoli. These special structures contain tiny blood vessels or capillaries, which allow gases to pass in and out of your bloodstream. Your air sacs and passageways, blood and lymphatic vessels and nerves are held together by connective tissue, all of which makes up your lungs.

How do you breath?

There are special cells in your brain, lungs and blood vessels that monitor the levels of oxygen and carbon dioxide in your blood. They send messages to the respiratory centre in your brain stem. In turn the respiratory centre sends signals to your respiratory muscles so that your body's needs are constantly being met. For example, you breath faster when you exercise or hurry.

Your respiratory muscles consist of your diaphragm and the intercostal muscles.

- The diaphragm sits underneath your lungs separating them from the rest of your abdomen. When you breathe in, the muscle contracts, i.e. shortens and flattens. This action pulls air into your lungs from the atmosphere and your lungs expand.

  As you breathe out, it relaxes and air moves from your lungs back out to the atmosphere and your lungs deflate. In relaxed breathing, this is a passive process and requires no effort.

- Your intercostal muscles are found between each of your ribs, allowing your chest to expand outwards and contract inwards.

These muscles work together to create more space within your chest for your lungs to fill with air and empty again. This is possible because your lungs are actually attached to the inside of your chest wall by a covering called the pleura. It has two layers, separated by a thin layer of fluid, to allow smooth movement between your lung and the chest wall as you breathe in and out.

Breathing is carried out without you having to consciously think about it. However you can override the signals by conscious control, for example to cough, sneeze, sing or hold your breath.

In COPD your airways are narrowed, due to a variety of causes, so the air you breathe in cannot flow freely in or out of your lungs.

- **Chronic**: means it has been present for a long time.
- **Obstructive**: a narrowing of your airways, causing blockage. This can be due to swelling of your airways, spasm of your airways and too much mucus in your airways. It is most noticeable when you breathe out. You may wheeze as the air is squeezed out through narrowed tubes.
- **Pulmonary**: another way to describe your respiratory system.
- **Disease**: refers to illness.

Symptoms of COPD

As COPD encompasses chronic bronchitis, emphysema and chronic asthma you may have symptoms of all 3 conditions.

The 4 main symptoms of COPD are:

- coughing
- regular production of sputum (phlegm)
- breathlessness
- wheezing

You may also have other symptoms such as repeated chest infections, weight loss and tiredness (fatigue).

Causes of COPD

In COPD your airways are damaged, usually through constant irritation. For example:

- working in an occupation that creates dust
- poor living environment and / or air quality, e.g. smog
- chronic asthma
- genetic factors, for example a deficiency in Alpha-1-antitrypsin can cause COPD (Alpha-1-antitrypsin is a protein that protects your lungs.)

But by far the most common reason for airways being irritated and damaged is smoking.

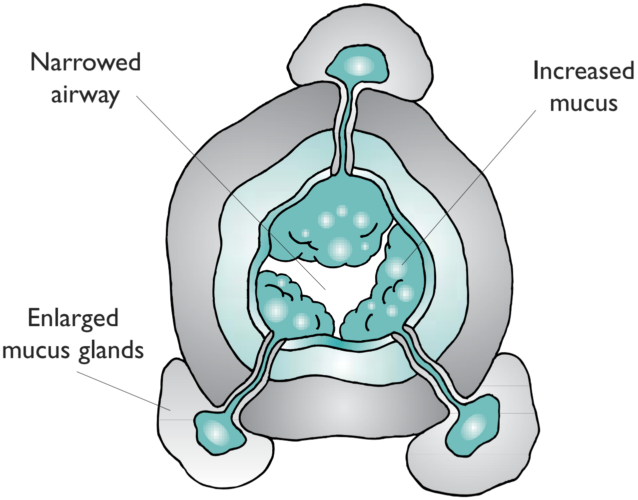


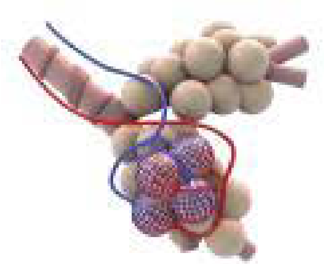
Figure 3. Damaged airway

When your airways are irritated they become swollen and inflamed. The muscles in your airway walls tighten to try to stop the irritation getting further into your lungs. The mucus glands produce more mucus to trap any debris and act as a protective mechanism to cushion the lining of your airways. The cilia have to work harder to move the debris and extra mucus up towards your throat to be expectorated (coughed up). The cilia also become damaged and are less able to carry out this function.

The commonest reason for airways being irritated and damaged is smoking

Damage caused by smoking

When you smoke the irritation to your airways usually continues over a long period of time. After a while your airways remain swollen and inflamed and don't return to their normal state. The muscle in the lining of your airways loses its tone (due to constant irritation and coughing) and no longer performs as it should, which means that your airways become floppy. All of this makes it more difficult to move air in and out of your lungs. You may notice yourself becoming more breathless or starting to wheeze when breathing out, particularly on exertion.



Alveoli

The mucus glands continue to pour out excess mucus, so the cilia get gummed up from all the excess mucus and stop working. So, instead of your lungs being able to clear themselves, the mucus falls deeper into your lungs and becomes more and more difficult to clear. Therefore, you will notice an increase in cough and mucus production. The excess mucus pooling in your lungs is a good environment for bacteria to grow (like a stagnant pond) and you may have frequent chest infections.

As well as your airways, the alveoli (or air sacs) are also affected by smoking. Smoking causes enzymes in the structure of the alveoli to start damaging themselves. If enough alveoli are damaged then insufficient oxygen will be able to get into your bloodstream and you will notice breathlessness – initially on exertion, but gradually this can get worse especially if you do not stop the irritation by stopping smoking.

Degrees of severity of COPD

It may be helpful to use a scale to try and assess the severity of your symptoms.

The Medical Research Council dyspnoea scale (dyspnoea is medical term for shortness of breath / difficulty breathing) looks at how you feel your symptoms affect you and puts this information into grades. Please note: spirometry is needed to actually assess this. See ‘Tests and investigations’ section for details.

Grade	Degree of breathlessness related to activities
1	Not troubled by breathlessness except on strenuous exercise.
2	Short of breath when hurrying or walking up slight hill.
3	Walks slower than contemporaries on the level 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 the level.
5	Too breathless to leave the house, or breathless when dressing or undressing.

The (modified) Borg scale of perceived breathlessness

This is a tool that can be used to help you assess how breathless you are feeling at any one time. This can be helpful in teaching yourself how to adjust your activity depending on how you are feeling.

A physiotherapist can go over this and explain how to use it. It involves imagining a line with 0 at one end and 10 at the other and judging where on that line you are with your breathlessness.

Rating	Description
0	No breathlessness at all
0.5	Very, very slight (just noticeable)
1	Very slight
2	Slight breathlessness
3	**Moderate**
4	Somewhat severe
5	Severe breathlessness
6	
7	Very severe breathlessness
8	
9	Very, very severe (almost maximum)
10	Maximum

How is COPD diagnosed?

COPD tends to creep up on you. You may tolerate some symptoms for many years before they reach a level that make you go to your GP. You might not develop any symptoms until later life and put them down to ‘getting older’. A diagnosis can often seem sudden. For example, when a chest infection won’t go away and your doctor suggests further tests.

Your doctor will ask you about your symptoms and your smoking history.

This, and a physical examination, will alert your GP or practice nurse to the possibility that you have COPD. Your doctor will examine you by looking and listening to your chest and other parts of your body (such as your fingers and ankles) to exclude any other conditions that may be causing your symptoms. You may need some of the following tests and investigations.

Sputum specimen

The mucus in your airways is also referred to as sputum. If you have a chest infection you may be asked for a sputum specimen to find out exactly which antibiotic is required to fight the infection.

Chest x-ray

You may have a chest x-ray. This is usually done to exclude any other conditions or if your symptoms have worsened.

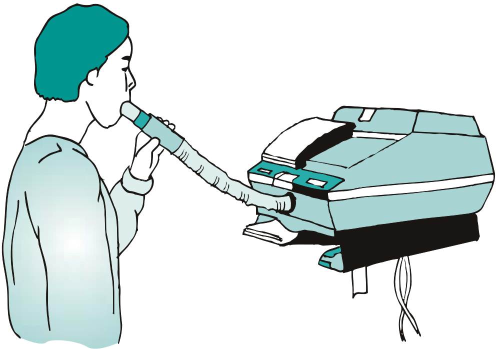
Heart tests

Your doctor may suggest that you have some heart tests to check how your heart is working, e.g. to see if your heart is working excessively hard to get the blood through the lungs. An electrocardiogram (ECG) looks at the electrical activity of your heart and an echocardiogram ('echo') looks at the structures of your heart.

Lung function tests

Your doctor will assess the extent of damage to the lungs by doing lung function tests:

- **Peak flow test**
  Measures how hard you can blow air out of your lungs. You have to blow into a 'peak flow meter' which has a marker on the side which moves as you breathe out, giving a 'peak flow reading'. Usually the best of 3 readings is used. The peak flow reading measures the amount of air you blow out (in litres per minute). If your airways are narrowed you will not be able to blow very quickly and your peak flow reading will be low. This can be done at your doctor's surgery or you can be given a peak flow meter to do this test at home.



Spirometry

- **Spirometry**
  Spirometry will assess how well you actually breathe. The results give a clearer picture of your condition and how best to treat it. Spirometry is the most important test in diagnosing COPD. It can be done at many doctors surgeries or at the respiratory clinic at your local hospital. It involves breathing into the mouthpiece of a spirometer to measure the volume of air that you can inhale and exhale over a period of time.

- **Pulmonary function test (PFTs)**
  This is a more complex breathing test that measures the volume of a full breath in and also the volume of air that you exhale. This has to be done at your local hospital.

Blood tests
Routine blood tests include:

- Full blood count (FBC): measures the levels of red blood cells, white blood cells and platelets. It also measures the haemoglobin (oxygen-carrying component of red blood cells).
- Urea and Electrolytes (U & Es): urea levels help to monitor how your kidneys are working. Electrolytes (e.g. sodium, potassium) and minerals (e.g. calcium) help to stabilise your heart rhythm.
- Glucose: measures the level of sugar in your blood.
- Liver and thyroid function.

Hospital doctors also sometimes want to check your arterial blood level. (Routine blood tests are taken from a vein.) Arterial blood samples are usually taken from an artery in the inside of your wrist and can be uncomfortable.

Another method of checking your blood oxygen levels is to take a capillary blood sample from your earlobe. This is less painful than an arterial blood sample.

Arterial and capillary blood samples give an accurate level of the oxygen and carbon dioxide in your blood. This can help to see if you need oxygen therapy.

CT scan

A CT scan gives a more detailed picture of your lung tissue. This is helpful in diagnosing certain chest diseases such as emphysema or bronchiectasis and also in ruling out other disorders.

Flexible bronchoscopy

A flexible bronchoscopy allows your doctor to look at the inside of your lungs and take biopsies and specimens. It is performed in hospital, usually as a day case. Local anaesthetic spray is used to numb your nose and throat and some mild sedation can be given if required. A small flexible tube is passed up your nose and down into your lungs. It is a relatively quick and painless investigation.

(There is also an investigation called a rigid bronchoscopy, which is done under general anaesthetic).

Inhalers

The most common way of delivering drugs to treat COPD is in inhaler form. Inhalers allow drugs to be delivered directly to your lungs. There are different types including dry powdered and aerosol metered dose inhalers (MDIs).

The 3 main groups of inhalers used for COPD are:

- relievers
- long-acting relievers
- preventers

The drugs used in inhalers are also usually available in solution form to be used with a nebuliser.

Some of the dry powder and metered dose inhalers available

Relievers

Your doctor may suggest you use an inhaler that helps to open up your airways if your lung function tests show that they are narrowed. These drugs are called bronchodilators. They work by helping the muscles around your airways to relax and dilate, allowing the air to get into your lungs.

It is important to keep your reliever with you at all times as you never know what might trigger an attack of breathlessness / wheeziness.

Example	Comments	Side effects
Salbutamol	**Quick acting bronchodilators:** usually prescribed on an 'as required' basis. Can also be used regularly.	Can cause a tremor especially noticeable on your hands. Some people may experience palpitations.
Terbutaline		
Ipratropium bromide (Atrovent®)	**Anticholinergic bronchodilators:** work in a different way and takes longer to have an effect. It is taken regularly	Tends to have few side effects but can cause a dry mouth and very occasionally constipation and difficulty passing urine.
Salbutamol + Ipatroprium: known as Combivent®	**Reliever combinations:** allow you to take two different bronchodilators at the same time. Usually prescribed on a regular basis.	Combination of above: tremor, palpitations, dry mouth, constipation.
Fenoterol + Ipatroprium: known as Duovent®		

Long-acting relievers
These are long-acting bronchodilators which are used to keep your airways open and help control the symptoms of breathlessness.

- These inhalers must be taken regularly.

Example	Comments	Side effects
Salmeterol Formoterol	**Long-acting bronchodilators**: taken twice a day, usually in the morning and at night. They take about 30 minutes to work but their effects last for 12 hours.	Similar to bronchodilators: fine muscle tremor in the hands, palpitations and cramps in hands and feet.
Tiotropium (Spiriva®)	**Long-acting anticholinergics**: only need to be taken once every 24 hours. Cannot be taken with another anticholinergic inhaler (e.g. Atrovent® or Combivent®).	Can cause a dry mouth and very occasionally constipation and difficulty passing urine.

Preventers
Preventer inhalers contain steroids. They are used to reduce the inflammation of your airways. It can take up to a week for preventer inhalers to take effect and up to 6 weeks to get maximum benefit.

- Preventer inhalers must be taken regularly. They will not help during a breathlessness attack.

Steroids can have quite serious side effects but, because inhalers deliver the drug directly to the part of the body that needs it, the side effects of steroid inhalers are usually minor and easy to control.

Example	Comments	Side effects
Beclomethasone Budesonide	Steroid inhalers taken twice a day, usually in the morning and at night.	Voice hoarseness, sore mouth and / or oral thrush. Making sure that you rinse your mouth out after using these inhalers can minimise this.
Fluticasone + Salmeterol: known as Seretide® Budesonide + Formoterol: known as Symbicort®	**Preventer combinations:** combination of a preventer and a long-acting reliever.	As above plus fine muscle tremor in the hands, palpitations and cramps in hands and feet.

Using your inhaler

Inhalers are very effective but only if used correctly:

- Make sure you know how to use your inhaler and that you are comfortable using it even when you are very breathless. Different inhalers work in different ways. Most GP surgeries have practice nurses who will be happy to help you with your inhaler technique.

- It is important that you use your preventer and long-acting reliever inhalers regularly. If you stop taking them, or frequently forget, you will not get the full benefit from your treatment. If you are prescribed more than one inhaler and you have to take them together always use your reliever first.
- Always have a spare inhaler in case you lose it or it runs out.

Spacers

If you have difficulty either with your inhaler technique or the physical handling of an inhaler you may find a spacer helpful. They are designed for use with aerosol inhalers.

A spacer is a plastic dome with a mouthpiece at one end and a fitting for your inhaler at the other. Your inhaler is triggered into the space delivering the dose required. You then have more time and more than one chance of breathing it all in. The drug is delivered more effectively to your lungs, reducing some side effects, especially those caused by steroids.


Spacers

There are large and small volume spacers available. Large volume spacers are very helpful but tend to be cumbersome and not easy to carry around. Small volume spacers are available for carrying in your pocket and using if required with your inhaler when out and about.

Using your spacer and inhaler correctly can be more effective than using a nebuliser.

Using your spacer

If you have 2 puffs to take of your inhaler, you go through the following routine twice.

It is important that your inhaler fits onto your spacer properly. Ask your practice nurse if you are unsure.

Make sure the valve in the spacer is working: some click open and shut when you breathe through them, and others make a whistling noise.

Types of small volume spacers

1. Always shake your inhaler well before fixing it onto to the spacer.
2. Breathe out to empty your lungs.
3. Seal your lips around the spacer mouthpiece.
4. Holding the spacer level, activate the inhaler.
5. Breathe in slowly and deeply.
6. Hold your breath for a count of 10 or as long as you can. (This allows the medicine to reach the smaller airways of your lungs).
7. If you are unable to take slow deep breaths or hold your breath, then breathe in and out as normal several times.

Taking care of your spacer

Take your spacer apart once a week, wash it in warm soapy water, rinse and drip dry. Never dry it with a towel or paper towel or tissue as fibres can interfere with its action. Your spacer should be replaced every 6 – 12 months.

Nebulisers

A nebuliser is an electrical machine that is used to help deliver the correct dose of drugs into your lungs. It works by blowing air through a solution of the drug, creating a very fine mist that can easily be inhaled. The drugs used in inhalers are also usually available in solution form to be used with a nebuliser.

Nebulisers have to be prescribed by a doctor

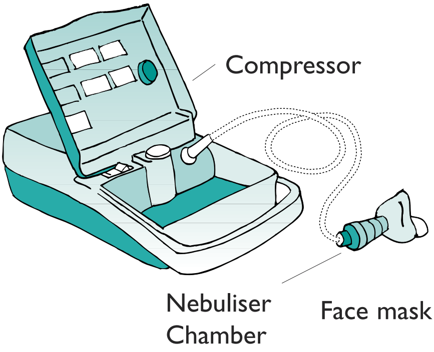
A nebuliser is actually made up of two parts: the compressor, which blows the air, and the nebuliser, which is the chamber that holds the solution of drug(s). A nebuliser comes with either a mask or a mouthpiece like a pipe. Either is suitable but the mouthpiece prevents any of the solution lying on your skin or getting into your eyes. Steroids such as fluticasone or budesonide and the bronchodilators ipratropium bromide or Combivent® should always be nebulised with a mouthpiece.

It takes around 10 minutes for your drugs to nebulise. Don’t stay on your machine longer than 15 minutes.

How to get a nebuliser

A nebuliser has to be prescribed by your doctor. If your doctor feels that you would benefit from one he / she will arrange for you to have a nebuliser and will assess and monitor how you use it.

Nebuliser parts need to be serviced regularly (this may need to be as often as every 3 months.) Most hospitals will only service their own units. Also the drugs have to be prescribed, so you **must** speak to your own doctor before thinking of buying a nebuliser.



Nebuliser

See ‘Useful addresses and websites’ section at end of booklet for the details of NARA, an organisation that hires nebulisers.

Taking care of your nebuliser
The compressor should be wiped down with a damp cloth at least weekly. The nebuliser should be washed in warm soapy water, rinsed and left to **drip dry** after each use.

If condensation appears in the tubing, remove the drug chamber and run the machine for a minute to ‘blow the tubing dry’.

Remember correct use of an inhaler with a spacer can deliver a better drug level into your lungs than using a nebuliser.

Oxygen therapy

Not all people with COPD will need or benefit from oxygen

Studies have shown that for some people with chest problems, breathing air with a higher concentration of oxygen can help reduce some of the symptoms caused by a lack of oxygen. It is very important to understand that oxygen will not necessarily relieve breathlessness. You must be individually assessed to find out if you will benefit from oxygen therapy and how much you require. This assessment is done at a clinic. If you continue to smoke there might be issues about providing oxygen. The oxygen flow rate and how long you should use your oxygen will be confirmed. This is a prescription and your oxygen should be used as directed only.

Long-term oxygen is normally given at home using an oxygen concentrator. Oxygen therapy is provided by Health Facilities Scotland who will make all the arrangements for you. They will also answer any queries about your oxygen, the refund of costs for electricity and the supply of equipment. Your concentrator will be provided a supplier called Dolby's Medical. They will provide installation and servicing.

Oxygen concentrator

If you have COPD you may have to use oxygen for at least 15 hours / day to gain benefit. You can use it overnight and at quiet times during the day to make up the 15 hours.

Portable cylinders can be obtained to enable you to leave the house.

Safety issues

Oxygen is safe when it is used properly. There are some safety issues to consider when using oxygen in the home. There should be no smoking around oxygen by anyone as clothing and hair can easily be ignited. Oil based creams for the face should be avoided.

Dry mouth, lips and nose

Oxygen therapy tends to dry up your mouth, lips and nose. Try to:

- Take frequent sips of water.
- Use a non-paraffin based moisturiser on your face.
- Apply water based lubricating jelly to the nose and lips. Do not use hydrogen based lotions such as Vaseline®.

Ear / nose protection

Another common problem is sore ears / nose where the tubing or strapping sits. This can cause quite nasty sores. You can get oxygen tubing ear protectors from your Dolby service engineer.

Remember oxygen is a prescribed drug, and you should always follow your prescription and directions.

See the CHSS booklet 'Understanding oxygen therapy' for more information.

Other drugs used in COPD

Oral steroids

The most common steroid tablet to be prescribed for COPD is prednisolone. Steroid tablets are prescribed to help you get over a flare up of your symptoms if they are not improving with the usual treatment. Steroids are usually prescribed at a higher dose and then reduced over a period of time before stopping. You should never stop taking your steroids suddenly without consulting your doctor.

Longer treatment

Sometimes it is necessary to be on steroids for longer periods of time. If this is the case it is advisable to carry a treatment card on you.

You may develop some side effects including:

- thin skin
- osteoporosis ('thinning of the bones')
- muscle wasting
- increased appetite
- increased weight / facial puffiness
- mood or behaviour changes
- bruising easily
- healing slowly after injury, e.g. cuts
- high blood sugar levels

Despite their side effects, steroids can be very useful drugs. Talk to your doctor if you are concerned about any side effects.

Antibiotics

Antibiotics are a group of drugs that fight bacterial infections. It is especially important to start treatment for an infection as soon as possible if you have COPD.

Usually you will be prescribed a course of antibiotics which will last between 7 and 14 days. Sometimes you may need antibiotics for a longer period.

- Always take your antibiotics as prescribed, spacing the doses accordingly.
- Take as recommended by the chemist on the label, e.g. with or without food or with milk.
- If you feel you are not improving by 3rd or 4th day, or getting worse, do not stop taking your antibiotics but contact your doctor. It might be necessary to change to a different antibiotic.

Side effects:

Antibiotics can upset some people more than others.

The most common problems are nausea, vomiting and diarrhoea. Some people are more prone to thrush during a course of antibiotics and treatment may be needed for this. Skin rashes are also quite common; you should let your doctor know as you might have to stop taking the antibiotic concerned.

Oral bronchodilators

Oral bronchodilators (e.g. theophylline) are usually only given to people who have not had effective relief from inhalers or who cannot use inhalers. They help to widen your airways by relaxing the muscles around them.

Side effects, which may be greater than with inhalers, include: headaches, nausea, insomnia, vomiting, irritability and stomach upsets. Your doctor will monitor your progress carefully.

Vaccinations

There are currently two vaccinations that people with COPD should have:

- Flu vaccine: you should have this every year; it is usually available from late September.
- Pneumococcal vaccine: you usually only need to have this once.

Acute exacerbations and hospital admissions

Sometimes in COPD your condition can suddenly deteriorate to such an extent that admission to hospital is vital and emergency treatment is needed. This is often referred to as an acute exacerbation. To minimise the risk of an acute exacerbation it is important that you report any sudden worsening of your symptoms to your doctor or nurse, e.g. increased breathlessness, cough, sputum production or change in sputum colour.

Hospital admission

On admission to hospital you are likely to:

- commence oxygen therapy
- be given some drugs (usually salbutamol) through a nebuliser
- be started on antibiotics

It is very important to assess how much oxygen your lungs are getting into your body and how well you are getting rid of the carbon dioxide from your body.

A variety of blood tests will be taken including an arterial blood sample (see tests section for details). This blood test will give your doctors the information they need to decide how best to treat you.

There are two options of treatment that may be tried:

- **Fixed oxygen**
  The oxygen mask that you have on may be changed to give you a fixed dose of oxygen. This ensures that you aren't being given too much or too little oxygen.
- **BiPAP (bilevel positive airway pressure)**
  This is also called non-invasive ventilation. It involves wearing a larger mask which forms a seal around your mouth and nose. The mask is attached to a machine which, as you breathe in, helps your lungs to expand. It does this by pushing air and oxygen in and, when you breathe out, it helps your lungs to empty. It does feel quite strange at first, and can be quite scary, but it can make a difference relatively quickly. BiPAP is generally only used for a short spell during your hospital admission but sometimes it can be used at home.

KEEPING WELL (SELF-MANAGEMENT)

Stop smoking

If you have COPD the most important thing you can do for yourself is to stop smoking.

The most common reason for your airways being irritated and damaged in COPD is smoking.

Unfortunately, you may not be aware of this damage occurring over the years until you develop symptoms which are bad enough to make you go to the doctor and a diagnosis can be made.

If you continue to smoke the damage will get worse and your symptoms will get worse. By stopping smoking, you will be giving yourself a real chance of having a better life. This may be a good enough reason to motivate you to stop. Don't feel guilty about the past. Think about the future. You can do it!

Support + Medication = x4 more likely to quit

Where to go to get help?

Stopping smoking can be very difficult, but there is a lot of help available. Ask your doctor about what support is available to help you. Most areas have specialist smoking cessation nurses who run groups and / or offer one-to-one support.

Different approaches to giving up smoking suit different people. You do not need to do it on your own. Seeking support is not a sign of weakness: it is a sign that you really do want to stop smoking.

- Smokeline 0800 84 84 84 (9am-9pm): they can tell you the location of your nearest free stop smoking service, give you access to specialist counsellors and send you further information.
- www.canstopsmoking.com: online information and support to help you stop smoking. Also offers text phone support and live online chat with a Smokeline advisor.

Break the habit

Smoking is not only an addiction but it is a habit. Think about why smoking has been a part of your life. You may feel that it has helped you in some way, e.g. to relax or as a source of comfort or stimulation. How can you replace smoking? Find a distraction or another way to relax.

To break the habit you must first be aware of why you are smoking and when you smoke. Keep a smoking diary to tell you this then try and change your routine as you stop. Try and find a new activity to keep your hands occupied.

Nicotine Replacement Therapy (NRT)

When you smoke about 4000 chemicals are released. These include at least 80 cancer-causing chemicals; hundreds of poisons and nicotine. The nicotine is the addictive substance found in cigarettes, it is this that gives you the craving to smoke and the unpleasant withdrawal symptoms when you stop. Nicotine Replacement Therapy (NRT) can help with this.

NRT is available to buy from pharmacies and also on prescription. It comes in a variety of different styles and in various strengths, e.g. patches, gum, inhalators, micro tabs and nasal sprays. Always seek the help of your doctor or pharmacist before using NRT.

Zyban® and Champix®
Zyban® and Champix® are drugs that have been developed to help with smoking cessation. They are only available on prescription and treatment has to be monitored closely by your GP or specialist nurse. They have been found to be effective although they may have side effects and not be suitable for everyone.

See the CHSS factsheet 'Smoking' for more information.

Keep active

In COPD, you may be afraid that exercise will make you more breathless, or that breathlessness may be doing you some harm. This isn't true! By gradually building up the amount of exercise you do, you can help to improve your breathing. You will also strengthen your arms, legs, trunk and heart. This will in turn make everyday activities less tiring and less demanding of your energy.

This reverses the so-called 'cycle of inactivity' where the less you do the less you become able to do. Working the lungs through exercise can improve symptoms like breathlessness and energy loss.

The Borg scale can be helpful in teaching yourself how to adjust your activity depending on how you are feeling. Aim to be no more than moderately breathless (i.e. a Borg score of 3) in whatever you are doing. This will mean that you can be active but still in control of your breathing and you can recover comfortably when you stop. (See 'Degrees of severity of COPD' section earlier in booklet for details.)

What exercise should you do?

What form of exercise you do depends on your condition and symptoms. It is advisable to check with your GP before you start any new programme of activity. Try and do some form of activity most days. Build things up slowly, take your time, practice breathing control and remember that **you** are in control.

Your doctor who may be able to refer you to a respiratory (chest) physiotherapist for individual help / advice or refer you for pulmonary rehabilitation.

Pulmonary rehabilitation

Pulmonary rehabilitation is a structured programme of exercise and education for people with chronic chest conditions, e.g. COPD. It is designed to improve your level of fitness and quality of life and can help you learn to cope, and live, with your condition.

Individual programmes may differ, e.g. what exercises are used, duration of programme, amount of home exercise and how to be referred. Some programmes are run in hospitals but many are based in the community, where it may be easier for you to attend, such as community and leisure centres or church halls.

Programmes are usually 6 or 8 weeks, once or twice a week, depending on where you live. You will get the most benefit by committing yourself to the whole programme. Every programme is organised and coordinated by a health professional – usually a nurse or a physiotherapist. They will be at every class and do your initial assessment.

Pulmonary rehabilitation can lead to significant improvements in your quality of life and ability to exercise as well as improving symptoms such as breathlessness. Lasting benefits can be maintained if you continue to keep active after the programme has finished. If there is one in your area you may be able to get referred by your GP, nurse, physiotherapist or hospital consultant.

See the CHSS factsheet 'Pulmonary rehabilitation' for more information.

Monitor your symptoms and know when to get help

Look out for warning signs

Frequent uncontrolled chest infections can cause permanent damage to your lungs. Unfortunately, if you have COPD, you are more likely to get chest infections and the effect on you is much greater than on the general population. For people with more severe COPD, they can cause life-threatening situations. It is important that you learn about what symptoms are 'normal' for you and how to recognise if things are getting worse. Prompt treatment can stop you becoming very unwell and needing hospital treatment for an acute exacerbation.

Look out for warning signs

- generally feeling unwell
- increased breathlessness
- feeling feverish
- nasal congestion
- increased coughing
- changes in your sputum – increase in amount produced, change of colour and thicker consistency

Get help: don't ignore your warning signs!

- Do not ignore your symptoms. Call your doctor as soon as you notice any of the warning signs.
- It is best to start taking antibiotics within 24 hours of becoming unwell.
- Speak to your doctor about getting antibiotics and / or steroids to use during an exacerbation. This is referred to as the supply of rescue medication.

Minimise risk of an infection

- Make sure you are up to date with your flu and pneumonia vaccines.
- Complete the full course of any treatment you are prescribed, e.g. antibiotics.
- When you notice any of your warning signs try to avoid close contact with anyone who looks or sounds ill and minimise time you spend in small crowded places.

Take control of breathlessness

Coping with breathlessness

This section aims to give you some tips to help you deal with problems such as breathlessness and clearing your chest. Hopefully these ideas can help make living with COPD easier.

Breathlessness

Everyone gets breathless from time to time, e.g. when you exercise or run for a bus. This shortness of breath passes quite quickly when you stop and the feeling does not usually worry you. With COPD, however, the breathlessness tends to be uncomfortable, severe and can come on with very little or even no exertion.

Different people describe their breathlessness in different ways: “chest tightness”, “difficulty filling my lungs”, “not being able to catch my breath” or “gasping for air”. Learning to control your breathing will help you to control your breathlessness and so reduce the feelings of panic and anxiety that so often come with it.

Breathing control

This is very useful to learn and master. It combines gentle relaxed breathing, using the lower part of your chest, with relaxation of the upper chest and shoulders.

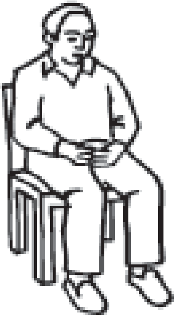
Practice breathing control

With practice you can use breathing control to regain your breath after activity or during an episode of breathlessness. You will be able to use it, for example, to help you if you are out for a walk and you need to stop for a rest. It also encourages a more normal breathing pattern and helps to get air into the lower part of your lungs.

How to do breathing control

- *Settle yourself into a chair in a comfortable position.*
- *Make sure your back is well supported.*
- *Rest one hand on your lower rib cage with the other hand on your upper thigh.*
- *Let your shoulders and upper chest relax, think about letting your shoulders go.*
- *Concentrate on letting the lower part of your chest move under your hand.*
- *Feel your hand rise and fall with your chest as you breathe gently in and out.*

- *Breathe at your own rate. Doing this should not tire you.*
- *Continue until your breathing is back under control once more.*
- *Once you feel happy about doing this, you may like to try resting both hands down on your thighs with the palms of the hands facing up.*

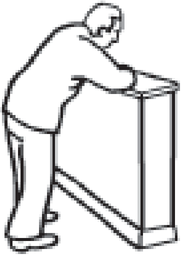


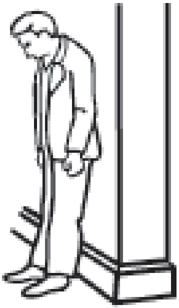
Other breathing positions

These are some different positions to use with your breathing control. Try them all till you find one that works best for you.

1. Sit on a chair and lean forward with both arms resting on your thighs with your wrists relaxed.

2. Stand leaning forward with your arms resting on a ledge, e.g. a windowsill, bench or banister rail.





3. Lean back against a wall with your shoulders relaxed and arms resting down by your side. Your feet should be 30cm away from the wall (or as far as is comfortable) and slightly apart.

Chest clearance

Chest clearance exercises help you to clear your chest of as much sputum as you can. This helps to reduce obstruction in your airways and improve the amount of air getting into your lungs. In the long-term, chest clearance can help to reduce the number, and frequency, of chest infections you may have.

There are several different techniques that can be used for chest clearance. Some people may find one technique works better than another, or is more convenient. It is important that you are shown how to do these exercises / techniques by a respiratory (chest) physiotherapist (physio). He / she will recommend how often you should use these techniques to get the maximum benefit.

Find a technique that works for you

The following pages explain 2 widely used chest clearance techniques for you to try: Active cycle of breathing and Autogenic draining.

Active cycle of breathing

There are 3 individual components to this technique combining:

- Breathing control.
- ‘Deep breathing’: also referred to as ‘Thoracic Expansion Exercises’ or TEE.
- ‘Huffing’: also referred to as ‘Forced Expiration Technique’ or FET.

Breathing control

This is very useful to learn and master (as explained earlier). It uses gentle relaxed breathing, using the lower part of your chest, with relaxation of your upper chest and shoulders. You shouldn’t feel that you are working at breathing and you should allow your tummy to rise as you breathe in and fall as you breathe out.

Deep breathing

As the name ‘Thoracic Expansion Exercises’ suggests this concentrates on expanding your chest as far as possible to allow maximum air into your lungs, by deep breathing and breath holding. This allows air to move behind trapped mucus and loosen it to enable it to be coughed out.

- Take a slow, relaxed deep breath in, as far as you can.
- Now hold your breath for the count of 3 (the deepest breath you can comfortably hold).
- Followed by a quiet relaxed breath out.
- Repeat 3-4 times.

Huffing

Also known as ‘Forced Expiration Technique’. As the name suggests this concentrates on pushing air out of your lungs (imagine you are steaming up a mirror.) The idea is to encourage the sputum up through your airways until it can be cleared out. Too short a huff may not be effective, too long can lead to bouts of coughing, so practise is essential.

- Take a normal breath in and then with your mouth open, squeeze the air out forcibly, making a ‘huffing’ sound. You should feel your stomach muscles contract strongly.
- Keep ‘huffing out’ until you can’t breathe out any more. (The huff should be long enough to move secretions from the smaller airways).
- Repeat 1-2 huffs then pause.

- Do breathing control in the pause to avoid wheeziness.*
- Repeat as necessary.
- When secretions reach your bigger airways, take a deep breath and huff again or cough to get the sputum into your mouth to clear out.

* The length of the pause will depend on how you are feeling. If you are wheezy, have or are recovering from an infection, you may find you tire easily, so 20 seconds rest between each huff should give you enough time to recover. If you are well, pauses can be shorter.

Here is an example of how these breathing exercises can be used together in a cycle for maximum chest clearance.

Breathing control
3-4 deep breaths with breath hold
Breathing control
3-4 deep breaths with breath hold
Breathing control
1-2 Huffs
Breathing control

This can be done sitting or lying but you may have to stay in one position for at least 10 minutes before changing your position to further clear your chest.

Autogenic drainage
This is another form of breathing exercise, which involves breathing right out as far as possible to loosen mucus from the small airways at the edges of your lungs. The mucus can then be moved to the larger more central airways making it easier to cough up.

To perform this breathing technique, choose a comfortable position, e.g. sitting upright and well-supported or lying down with a couple of pillows behind your head.

- Breathe in slowly, using your lower chest, as in breathing control.
- Hold your breath for 3 seconds, allowing air to evenly fill your lungs, resulting in air building up behind any trapped mucus.
- Push your breath out, for as long as you can manage, keeping going right to the end.
- Take a slow relaxed breath in, don't take a big breath or expand your chest too much.
- Breathe out all the way again, pushing all the air out of your chest completely.
- As you repeat the cycle, breathe in and out slowly to avoid pushing back the mucus you have just loosened back into your lungs.
- Continue with this cycle until you hear or feel the mucus collecting and moving upwards or you feel the urge to cough.
- When you feel this take a deeper breath in.
- Hold for 3 seconds.
- Breath out hard pushing as much air out as possible.
- Finally, when the mucus reaches the larger airways it can be cleared with a cough.

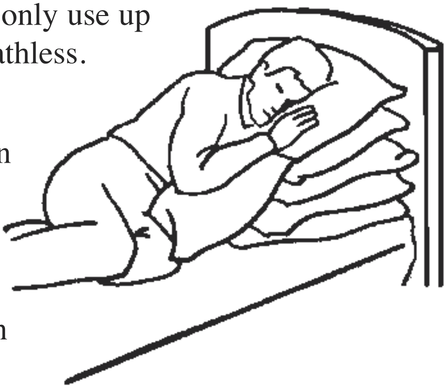
Be prepared – have everything you need close at hand

Breathlessness at night

Many people with COPD have breathing difficulties during the night. This can be very frightening and increases your anxiety, making your breathlessness worse. Being prepared can help to reassure you when it happens.

- If you wake up breathless, sit up and lean forward, e.g. sitting at the edge of the bed and leaning your arms on a bed table.

- Keep a fan by your bed and turn it on when you are feeling breathless.
- Keep your inhalers by your bed and take your reliever.
- Try and use your breathing control. Try not to force your breath out. This causes more air to get trapped in your lungs.
- Try not to fight your breathlessness. Relax your shoulders, tensing your muscles will only use up your energy and make you more breathless.



Suggestions for sleeping comfortably
You may find that you sleep better in an upright position.

Try sleeping on your side, as you are less likely to slide down the bed.

Putting a pillow under your knees when lying on your back also helps prevent sliding down the bed.

Conserving energy

As breathlessness can be brought on with the least effort and tiredness, and lack of energy is so common with COPD, learning ways to conserve energy is very important. Here are some tips to try:

- **Use breathing control**
  Exhale during the strenuous part of the activity.
  Don't hold your breath.
  If in doubt – blow out.

- **Eliminate unnecessary activities**
  Use a towelling bathrobe to dry off after showering.
  Let dishes air-dry.
  Sit for as many activities as possible.
  Use a perching stool in kitchen.

Don't be afraid to ask for help

- **Get assistance**
  Don't be afraid to ask for help.
  It doesn't mean you are being dependent it means you are using your energy to its best advantage.

- **Organise your time**
  Do most energy consuming tasks at the time of day / week when you have most energy – but be flexible and plan rest periods.
  Planning in advance will avoid having to rush.

- **Organise your methods**
  Use a trolley or shopper to gather things from around the house that you need to do something.
  Rest your arms on a surface while using your hands to do something.

- **Organise your space**
  Put most used items in drawers or shelves that are between waist / shoulder level.
  Keep items in the area where they will be used, to avoid unnecessary fetching and carrying.

- **Pace yourself**
  A slow steady pace consumes less energy.
  Alternate work and rest.
  Don't overdo it on a good day – you will be overtired the next day.

- **Maintain good posture**
  Avoid bending.
  Avoid lifting.
  Avoid doing things that involve raising your arms.

- **Relax**
  Give yourself time to do things.
  Lean on a shopping trolley, window shop, or lean on a stick to allow yourself to get your breath back.

See the CHSS factsheet 'Coping with tiredness' for more information.

Relaxation

Everybody needs to relax. It is a vital part of our lives. When you have COPD, it is even more important to relax as it loosens your shoulders and helps you to control your breathing. Sometimes you have to make a real effort to relax and need some help. There are many different relaxation 'exercises' and 'techniques' that can, with practice, help. You can obtain relaxation CDs from bookshops, music stores and some hospital therapy departments.

Here are some tips:

- Go to a quiet place. Get into a comfortable position with your arms and legs supported.
- Close your eyes.
- Concentrate on your breathing. Take deep breaths through your nose and exhale slowly through pursed lips.
- Learn to recognise tension. Make a fist and squeeze your hand tightly. Slowly open your fingers and feel the tension leave. Your hand will feel lighter and relaxed.
- Now you can relieve tension all over your body simply by contracting and relaxing each set of muscles in turn.
- Every time you breathe out think RELAX.

Coping with anxiety and panic attacks

One of the main symptoms of COPD is breathlessness. Because this breathlessness is not in relation to physical effort, it is often felt to be out of your own control and when severe can cause anxiety and feelings of panic. Unfortunately, these anxious and panicky feelings tend to make your breathlessness worse, which in turn increases your anxiety. Taking control of breathlessness and learning how to deal with anxiety and panic attacks will help you to get the most out of life.

Practising breathing control and relaxation techniques when you are feeling calm and relaxed will help you to cope with stressful situations when they arise. If you become confident about how to use these techniques, it will be much easier for you to use them when you actually need them.

Remember anxiety is a normal, healthy reaction

What is anxiety?

Anxiety is a normal healthy reaction. It happens to everyone at times of danger or in worrying situations to prepare us for action. A chain of events automatically occurs in your body causing real physical symptoms. If these physical symptoms come upon you unexpectedly in a normal situation, for example if you are pushing a trolley round a supermarket, it can be very frightening. The important thing to remember is that these very real physical symptoms are a biological response and are not harmful.

Effects anxiety can have on you

The symptoms of panic do not mean that you are going mad. They do, however, make you more tired. Being anxious and tense is a serious drain on your energy. Once you have learned how to manage anxiety you will find you have more energy for other things.

Physical symptoms of anxiety can include:

- breathlessness
- churning stomach
- sweating
- trembling
- racing heart
- desire to empty your bowel and / or bladder
- dry mouth
- problems concentrating, not feeling real

What do you fear?

When you feel anxious, the more anxious thoughts you think. The more anxious thoughts you think, the more anxious you feel. Examples of the kind of things that may run through your head may include:

- What if I become ill in public?
- What will happen if I get physical symptoms of anxiety?
- What if there is something new physically wrong?
- What if people think I am making a fool of myself?
- What if I am not be able to help myself?
- What if other people won't know how to help me?

Thoughts about anxiety

If you are aware of frightening thoughts adding to your feeling of anxiety a useful tip is to count your breathing by slowly repeating to yourself over and over again 'in one thousand, out two thousand'. This will not only stop any 'what if' thoughts but it will help you to slow down your breathing and become in control of it by using your breathing control.

How to cope with anxiety and panic.

- Remember that what you are feeling is nothing more than an exaggeration of the normal bodily reactions to stress.
- These feelings are not in the least harmful or dangerous – just unpleasant. Nothing worse will happen.
- Stop adding to panic with frightening thoughts about what is happening and where it might lead.
- Focus on what is really happening in your body right now, not what you imagine might happen.
- Wait and give the fear time to pass without fighting it or running away from it. Just accept it.
- Notice that once you stop adding to it with frightening thoughts, the fear starts to fade away.
- Remember that every time you cope with fear (rather than avoiding it) makes it easier. So, this is an opportunity to make progress.
- Think about the progress you have made so far despite the difficulties and how pleased you will be when you succeed this time.

- When you begin to feel better, look around you and start thinking what you are going to do next.
- Then, when you are ready to go on, continue in an easy and relaxed way – there's no need for effort or hurry.

See the CHSS factsheet 'Living with stress and anxiety' for more information.

Coping with depression

It is very common for people with COPD to feel down or develop depression. The effect your illness has on your role in society and sense of self worth can be diminished by being unable to work or having to give up activities you previously enjoyed. Added to this are the physical limitations COPD can enforce. You may even feel isolated and trapped by your circumstances and have fears that prevent you from going out.

Depression affects your mood and how you feel about life - you may feel as if there is no point in anything. It can make you feel as if you don't want to get up in the morning or as if you don't want to go out or see family or friends. Often depression creeps up over a period of time.

Common symptoms of depression include: persistent sadness or crying spells; loss of self esteem and interest in life; mood swings; tiredness and loss of energy; difficulty concentrating; changes in appetite / weight gain or loss; lack of motivation; feelings of helplessness / hopelessness and sleeping problems. Some of these symptoms are similar to those caused by COPD itself.

Depression can be successfully treated. So, if you think you may be depressed it is important that you speak to your doctor. The longer you leave it the harder it can become to deal with it as you slide further and further down. Your GP may suggest that you try antidepressant drugs. These balance the chemicals in the brain responsible for these feelings. There are different types used depending on your symptoms and medical history.

Antidepressants are not the same as tranquilisers and they are not addictive. However, their use has to be monitored and they should not be stopped suddenly. If your doctor suggests antidepressants make sure you arrange a further appointment to see how things are.

Sometimes further support may be needed, e.g. from your doctor or nurse. Some kind of talking therapy (e.g. counselling), as well as antidepressants, may be helpful. Most people won't need to see a psychiatrist unless their depression is very severe or they are suicidal.

Relaxation, yoga, tai chi and reflexology are examples of additional ways to increase your feeling of well being and reducing stress.

The reason this is so important for people with COPD is that maintaining your health is very dependent on being proactive. This is made much more difficult if you have symptoms of depression or are feeling depressed. By addressing depression you will quickly feel the benefit and increase your quality of life substantially.

Controlling your environment

Irritants

There are many things around you in the air that you breathe that cause irritation to your lungs. It is almost impossible to avoid all irritants completely, but it is better to try and avoid the following as much as possible:

- smoke
- animal hair
- house dust
- strong odours / perfumes
- aerosol sprays
- paints, solvents
- gas fumes
- traffic fumes

Cigarette smoke

Try to make your house a ‘No Smoking Zone’. Don’t be polite about your health to your friends and family. If you smoke yourself, you have to think seriously about stopping.

Temperature

Another factor in your environment is the temperature. Cold air can be a real problem for some people with COPD. Try to keep the rooms of your house at the same temperature, especially your bedroom at night. Going into cold air from a warm living room can provoke an attack of breathlessness. In the winter, some people prefer to move their bed into the living area of the house. As well as keeping the temperature steady it can save money on heating. Try and aim for a constant temperature of 15ºC - 20ºC (60ºF - 68ºF). If you go out on a cold day, put a scarf over your mouth to help to warm the air as you breathe it in or buy a cold weather mask. (See ‘Useful addresses and websites’ section at end of booklet.)

Humidity

Some people with COPD are affected by damp or dry air. The weather may even have a great effect on how your day will be. Some central heating can make the air very dry. This can be corrected by putting bowls of water near the radiators, or by using a humidifier.

Damp houses

Unfortunately inside the house, damp conditions cause a more permanent problem. Moulds, mildew, dust-mites and bacteria depend on the damp to thrive. All of these things can cause irritation. If your house is damp, try and identify the source of the dampness and get it treated. Good ventilation and dehumidifiers can help. If the situation is beyond your control, contact your local council housing department, who may be able to help.

Work related COPD

Jobs or hobbies that expose you to dust can put you at a greater risk of developing COPD. Industries such as stone masonry, coal mining and iron foundries, cause the greatest hazards. If you think your problem may be related to your job you should ask your doctor to refer you to a specialist for an assessment. Once the diagnosis has been made you may be entitled to compensation through the legal system, or to a special pension from the Department for Work and Pensions.

Eating and diet

It is a good idea to be as close as you can to your ideal weight. Your doctor, practice nurse or dietician can advise you of what this should be.

If you are overweight:

- The best way to lose weight is slowly. A gradual weight loss of around 0.5-1kg (1-2lb) a week is recommended. If you lose weight too quickly you will be far more likely to put the weight back on again.
- Choose low fat foods such as semi – skimmed milk, low fat spread and low fat cheese.
- Watch your sugar intake. Try artificial sweetener instead of sugar and go for diet / sugar free drinks.
- Eat plenty of fruit and vegetables. Aim for 5 portions a day.
- Bake, steam, boil or grill foods rather than frying.
- Limit your alcohol intake, as it is high in calories.
- Take as much exercise as you can manage.
- Take time to enjoy your meals.

If you are underweight

This is more likely to be a problem if you have COPD. The exertion of eating even a medium sized meal can make you very breathless, and this can put you off eating. As a result you may not be meeting your energy needs.

- Eat small amounts as often as possible.
- Have high-calorie snacks to nibble on throughout the day. Nuts, crisps, dried fruit, cheese and biscuits, yoghurts, puddings, ice cream, sweets and chocolate are good.
- Drink fluids with a straw as this can be less tiring than using a cup. Include high-calorie fluids. Try fruit juice, high-energy drinks, milk, and milk-based drinks for coffee, chocolate or diet supplement drinks – available from your local Chemist.

Keep well hydrated

Fluid intake

It is very important to keep your body well hydrated. This stops your sputum from getting too sticky and makes chest clearance easier. Try to drink 8-10 mugs of non-alcoholic fluid a day, even if it means an extra visit to the toilet. Remember if you are underweight try to make these high-energy, not diet, drinks. Limit your alcohol intake as alcohol causes dehydration.

Also watch how much coffee and tea you drink, as both contain caffeine which has a diuretic effect, i.e. makes you go to the toilet more.

Stress incontinence and COPD

Stress incontinence in COPD is when urine leaks due to the pressure on your abdominal organs increasing suddenly when coughing.

It tends to be worse in women who have had children because the muscles keeping urine in the bladder may be weaker. Going to the toilet regularly throughout the day will ensure your bladder is never full. You can get pads from your GP, practice nurse or pharmacy shop. These can give you some extra protection, avoid you having to change your clothing and may help your confidence. You can also get practical help and advice from a continence advisor if necessary.

Although it can be embarrassing to speak about, this is a relatively common problem. Your COPD treatment should also be reviewed to see if it can be improved at all as this might alleviate the problem of incontinence also.

Sex and loving relationships

COPD does not diminish sexual ability. However, problems with lack of energy, coughing and breathlessness may affect your stamina and interest in sex. You may even avoid sexual intimacy because you are scared you may cough or get breathless. Depression and anxiety can also have an affect on your sex drive.

Partners may feel it is better to avoid sex. However, maintaining or resuming intimacy and closeness in a relationship is important in combating the loneliness and isolation that you may feel with COPD.

Talking to your partner about how you feel and any worries you may have will make it easier for you both to deal with the situation before it becomes a problem.

Some drugs, such as those for high blood pressure and some antidepressants, can have an effect on your sex drive. Speak to your doctor if your drugs have this side effect.

Remember breathlessness is in your control and it will not harm you. Planning ahead and using the coping strategies below will give you the confidence to keep sexually active if this is what you and your partner want.

If you have COPD you should plan all physical activity.

Don’t attempt sexual activity:

- immediately after a heavy meal
- after consuming alcohol
- in an uncomfortable room temperature
- when under emotional stress

Do prepare:

- clear any chest secretions using your chest clearance technique
- use your bronchodilator inhaler or nebuliser prior to sexual activity
- use the same amount of oxygen during sex as you would during physical activity
- use breathing control as you would with any other activity and have rests as necessary
- choose a position that is less energetic and avoids pressure on the chest, for example,

lying on your side during intercourse may be more comfortable and less tiring

- encourage the more able bodied partner to assume a more active role

Flying advice

If you have any concerns about your health you should contact your airline's medical department before travelling by air. This will allow the airline staff to help you with early boarding and ensure that you get the best in-flight care.

Who needs medical clearance to fly?

You will need medical clearance to fly if any of the following criteria apply to you:

- If your fitness is in doubt as a result of a recent illness, a period in hospital, surgery or if you have a condition that is unstable.
- If you need any special service or equipment, e.g. oxygen.
- If any of the above criteria apply, you and your doctor will need to complete a Medical Information Form (MEDIF), which is available from the medical department of your airline or your travel agent.

Can you fly?

There is slightly less oxygen in an aircraft cabin than at ground or sea level. If you already have low blood-oxygen levels because of your chest condition this could cause breathlessness and discomfort. In this case your doctor might suggest having some further tests to predict if this is likely to be a problem for you. (This effect can also happen in highaltitude destinations from 6,000ft upwards). However, most people with chest complaints have no difficulty flying. If you can walk more than 50 metres on the flat without getting breathless you should be able to fly as long as you have your doctor's permission.

How to arrange oxygen for a flight
If you use oxygen continuously you will need it during the flight. You will have to let your airline know your requirements before you book to ensure your needs can be met. Each airline will have its own policy regarding the supply of in-flight oxygen, e.g. what flow rates are available and what charges, if any, are applicable. Some airlines now prohibit in-flight oxygen during take off and landing. Ask your airline what its policy is.

Most airlines will only provide oxygen for the flight. If you need oxygen on the ground you will need to provide your own for any transfer between flights.

Other equipment
You will also need permission to take on board and use any other equipment such as a nebuliser. Equipment must be battery driven and you will not be allowed to use it during take off or landing.

During the flight

- Your sputum will become stickier in the dry plane atmosphere. Drinking plenty of non-alcoholic fluids will help loosen your sputum, which will allow you to keep your chest clear.

- It is quite safe to use any of your inhalers in the pressurised cabin.
- Try to remain as mobile as possible throughout the flight.

Plan ahead

You should arrive early at the airport and avoid carrying heavy luggage. You can ask for wheelchair transportation within the airport if you arrange it in advance. Make sure you have all your medication including your preventative and reliever inhalers in your hand luggage. This ensures you have a supply in the event of missing luggage, delays etc. You may wish to bring a supply of antibiotics and steroids with you in case you develop a chest infection while you are abroad. Have a letter from your doctor to keep in your hand luggage with details about your condition and medication.

Insurance

Your travel insurance should cover you for any medical costs that may arise in connection with your chest condition, including the costs of travel in an air ambulance if you were to become too ill to travel on a commercial flight. Your doctor may also have to supply a fitness to fly letter.

See the CHSS factsheets 'Holidays', 'Insurance companies' and 'Air travel' for more information.

Take all medication and a doctors letter in your hand luggage and plan ahead

Information for carers

You can achieve a lot by being honest and open with your partner and with yourself. Try not to be overprotective. You are not in charge of your partner's COPD. You can't make him / her healthy but, if you're overprotective, you can make him / her feel like an invalid. Get the facts about COPD and keep reminding yourself of them.

Be positive

There will be bad days. Don't be discouraged. Remind yourself that negative thoughts are just that: thoughts, not facts. Be determined not to let the illness take over both your lives. Your partner is not a victim; neither are you. Make a list of activities both of you could enjoy. Plan to do at least one every day.

Think positive thoughts

Encourage independence

Make bargains with your partner, e.g. 'If you do your exercises, I'll make the tea'.

If your partner is afraid to do something that you know he or she can actually do, don't do it. Ask yourself 'Am I doing this for my partner or am I doing it for myself, so I can feel useful?'

Make time for yourself

Find things to do at home that will take your mind off worrying about your partner.

Take a break, away from the house. Ask family or friends to stay if you are anxious about leaving your partner alone.

Understanding help in the community

The idea behind community care is to give you the support that you need to continue to live in your own home. Family and friends who help to care for you (carers) can also receive support. There are various agencies involved in providing community care including: your local social work (or social care / social services) department, the NHS, private and voluntary organisations and your local council's housing and education departments.

What sort of help is there?

Local services may vary depending on where you live in Scotland. There may also be a charge for some services, depending on your circumstances.

- help with the housework
- help with the shopping
- provision of meals
- lunch clubs
- day care provision
- sitter services / care attendants
- residential and supported accommodation
- a break away, to give your carer a rest (respite care)
- equipment and housing adaptations
- alarm systems
- benefits assessments
- advice on personal finance
- advice about leisure and recreation

Your GP's surgery will have a team of nurses (including a Practice Nurse, Health Visitor, District Nurse and Health Care Assistant) who can also help. You can make an appointment with the Practice Nurse yourself, but you will need to ask your GP to refer you to the district nursing or health visiting services.

Are you getting all the benefits you are entitled to?

It is important that you, and your carer, receive all the benefits that you are entitled to. It can be helpful to speak to your social worker, or a welfare rights officer, at your local social work centre. You can also get information from the Benefits Enquiry Line as well as a Citizen's Advice Bureau, local carers centre or money advice centre (see 'Useful addresses and websites' section for details).

See the CHSS factsheet 'Understanding help in the community' for more information.

PALLIATIVE CARE SERVICES

What does palliative care in COPD mean? To nurses and doctors it means support and management of symptoms at every stage of the disease.

COPD and other chronic chest conditions can, and do, progress for a variety of reasons:

- age
- repeat chest infections
- continuing to smoke

These can all speed up the disease process.

In time, if the symptoms of your COPD become more difficult to control, your doctor or nurse may mention palliative care services. As the disease can not be cured the emphasis is to find ways to support, and control, your symptoms and provide you with all the help you may need. A palliative care assessment will involve a full assessment of your symptoms and how they are impacting on your day-to-day life, what treatment you are on at the moment and discussion around any other treatment that maybe useful. It may also include looking at:

- Your weight and dietary intake: you may see a dietician if necessary.
- Your mobility: you may be referred to other services such as physiotherapy, occupational therapist or district nurses.
- What benefits you are on: to check you are receiving all the benefits that you are entitled to.

You will have plenty of opportunity to talk about your disease, how you feel you are coping with it and also to explore what may happen in the future and talk about your particular wishes or fears.

USEFUL ADDRESSES AND WEBSITES

Action on Depression
11 Alva Street, Edinburgh EH2 4PH
Information service: 0808 802 2020
(2pm - 4pm Wednesdays)
Tel: 0131 226 1803
Email: info@actionondepression.org
Website: www.actionondepression.org

Age Scotland
Causewayside House
160 Causewayside
Edinburgh EH9 1PR
Tel: 0845 833 0200
The Scottish Helpline for Older People:
0845 125 9732
Website: www.ageuk.org.uk/scotland

Provide wide range of information and advice topics older people.

Assist UK
1 Portland Street
Manchester
M1 3BE
Telephone: 0161 238 8776
Email: general.info@assist-uk.org
Website: www.assist-uk.org

Assist UK provides details of locally situated Disabled Living Centres which provide impartial information and advice on products and equipment for easier living.

There are Disabled Living Centres in Dundee, Edinburgh, Elgin and Grangemouth.

Benefits Enquiry Line
Tel: 0800 882 200
Monday - Friday 8.30 am - 6.30 pm

Bladder & Bowel Foundation
SATRA Innovation Park
Rockingham Road
Kettering, Northants NN16 9JH
Helpline: 0845 345 0165
General enquiries: 01536 533255
Fax: 01536 533240
Email: info@bladderandbowelfoundation.org
Website: www.bladderandbowelfoundation.org

The Bladder and Bowel Foundation provide information and support for people with bladder and bowel disorders.

Blue Disc Parking
The blue disc is issued to disabled drivers or passengers with certain medical conditions and to registered blind people.

Contact your local council for an application form.

British Lung Foundation Scotland
Suite 110-111 Baltic Chambers
50 Wellington Street, Glasgow G2 6HJ
Helpline: 08458 50 50 20
(Mon - Fri 10.00am - 6.00pm)
Tel: 0141 248 0050
Email: scotland@blf-uk.org
Website: www.lunguk.org

BLF Scotland works to provide support, advice and information to those living with lung disease across Scotland. They run ‘Breathe Easy’ groups across Scotland.

The Princess Royal Trust for Carers
Glasgow Office, Charles Oakley House
125 West Regent Street, Glasgow G2 2SD
Tel: 0141 221 5066
Fax: 0141 221 4623
Websites: www.carers.org
www.youngcarers.net

The Princess Royal Trust for Carers provides comprehensive carers support services throughout the UK including independently run Carers centres.

Carers Scotland
The Cottage, 21 Pearce Street
Glasgow G51 3UT
Tel: 0141 445 3070
Advice Line Tel: 0808 808 7777
(Wednesday and Thursday
10am-12pm and 2pm-4pm)
Website: www.carersuk.org/scotland

Carers Scotland is provides information on all matters relating to caring.

Chest Heart & Stroke Scotland
Rosebery House, 9 Haymarket Terrace,
Edinburgh EH12 5EZ
Tel: 0131 225 6963
Fax: 0131 220 6313
Advice Line: 0845 077 6000
Email: adviceline@chss.org.uk
Website: www.chss.org.uk

Chest Heart & Stroke Scotland improves the quality of life for people in Scotland affected by chest, heart and stroke illness, through medical research, influencing public policy, advice and information and support in the community.

Citizens Advice Scotland (CAS)
www.cas.org.uk

Online advice and contact details of your local citizens advice bureau.

Cold weather masks
www.healthy-house.co.uk

Health Facilities Scotland
The service covers the whole of Scotland. They organise the provision of oxygen to you at home and pass you on to Dolby's Medical Ltd if you need an oxygen concentrator. They can answer queries about your oxygen, the refund of costs for electricity and the supply of equipment.

Tel: 0131 275 6860

Motability
City Gate House, 22 Southwark Bridge Road
London SE1 9HB
Tel: 0845 456 4566 | Textphone: 0845 675 0009
Website: www.motability.co.uk

Oversees the motability scheme which enables disabled people to lease a car, powered wheelchair or scooter by using their government-funded mobility allowances.

NARA
Moulton Park Business Centre, Redhouse Road
Northampton NN3 6AQ
Tel: 01604 494 960 | Fax: 01604 494 960
Email: info@thebreathingcharity.org.uk
Website:www.naratbc.org.uk

NARA can provide nebulisers (including servicing) for a refundable £25 deposit and £5 per month voluntary contribution. Ask for an application form for your doctor to complete.

NHS 24
This phone service is designed to help you get the right help from the right people at the right time.

Tel: 08454 24 24 24
Textphone: 18001 08454 24 24 24
Website: www.nhs24.com

Smokeline
Tel: 0800 84 84 84 (9am-9pm.)

Smokeline offers initial and ongoing telephone support and encouragement to callers wishing to stop smoking or who have recently stopped and want to stay stopped. Can also tell you the location of your nearest free stop smoking service, give you access to specialist counsellors and send you further information

Website: www.canstopsmoking.com: information and support to help you stop smoking. Offers text support and live online chat with a Smokeline advisor.

The information contained in this booklet is based on current guidelines and is correct at time of printing. The content is also put out to peer, patient and expert review. If you have any comments about this booklet please contact Lorna McTernan, Health Information Manager, at the address on the facing page.

CHEST PUBLICATIONS

Booklets	
C1	Living with COPD
C2	Understanding oxygen therapy
C3	Tuberculosis in the 21st century
C4	Living with bronchiectasis

Factsheets	
F1	Smoking
F6	Holidays
F7	Insurance companies
F8	Suggested booklist
F13	Air travel for people affected by chest, heart and stroke illness
F18	Coping with tiredness
F22	How to make the most out of a visit to your doctor
F23	Living with stress and anxiety
F24	Healthy eating
F26	Understanding help in the community
F30	Just move!
F32	Pulmonary rehabilitation FAQs

'Remember to take your inhalers' fridge magnets

A full publication list is available from Head Office.
Rosebery House, 9 Haymarket Terrace, Edinburgh EH12 5EZ
Tel: 0131 225 6963

ORDER FORM

Please send me the following:

TITLE	No. of copies

Up to 100 booklets free, up to 100 factsheets free

If you wish to order more than 100 booklets or factsheets please contact the Health Information department at the above address.

Name: ____

Address: ____

____

Postcode: ______________ Tel: ____________________

WHERE TO FIND US

Head Office
Tel: 0131 225 6963
Fax: 0131 220 6313
Rosebery House
9 Haymarket Terrace
Edinburgh EH12 5EZ
Open Mon – Fri

Glasgow
Tel: 0141 633 1666
Fax: 0141 633 5113
103 Clarkston Road
Glasgow G44 3BL
Open Mon – Fri

Inverness
Tel: 01463 713 433
Fax: 01463 713 699
5 Mealmarket Close
Inverness IV1 1HT
Open Mon – Fri

www.chss.org.uk

Chest Heart & Stroke Scotland is a wholly independent Scottish charity. We receive no core funding from Government or any public body or private agency.

We need your help to achieve our aim of improving the lives of those in Scotland with chest, heart and stroke illness. You can help by volunteering your time with our services, by supporting your local Regional office or as a fundraiser. You can help by giving now and in the future, by making a donation, organising a local fundraising event, leaving us a gift in your will or by setting up a regular Direct Debit.

Designed by Creative Link, North Berwick

If you would like to speak to one of our Advice Line nurses, in confidence, phone Chest Heart & Stroke Scotland Advice Line.

Monday – Friday
9.30am – 4.00pm

0845 077 6000

Fax us: 0131 220 6313
Email us: adviceline@chss.org.uk
Text us: text chss followed by your message to 07766 40 41 42
There is a text relay service for the hearing-impaired.

Chest
Heart &
Stroke
Scotland

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