

Breathing Better











**Understanding
and living with
a respiratory
condition**

**Chest
Heart &
Stroke**



Understanding and living with a respiratory condition

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Introduction



Over 165,000 people in Northern Ireland are living with chronic respiratory conditions including Chronic Obstructive Pulmonary Disease (COPD) and asthma. This booklet is designed to offer you guidance and support managing your lung condition day to day.

COPD is the name used to describe a number of long-term lung problems which can make breathing difficult such as emphysema, chronic bronchitis or a combination of the two.

Other respiratory conditions are:

- Asbestosis
- Bronchiectasis
- Lung cancer
- Obstructive sleep apnoea
- Pneumonia
- Pulmonary fibrosis
- Sarcoidosis
- Tuberculosis

A respiratory condition is not always obvious to other people – it is often referred to as an ‘invisible illness.’ People do not always realise the impact respiratory conditions can have on a person’s life and the lives of their families and carers. This means they don’t always receive the necessary support and understanding.

Northern Ireland Chest Heart and Stroke (NICHHS) Breathing Better Coordinators and members of the Breathing Better Support Groups do understand, and this understanding and empathy can help you!

In this booklet you will find information on:

- Respiratory conditions
- Recovering from Coronavirus
- Understand your condition
- Living with a respiratory condition
- Managing your respiratory condition
- How we can help you



Chronic Obstructive Pulmonary Disease (COPD)

COPD is the name used to describe a number of long-term lung problems which can make breathing difficult. Chronic Bronchitis and Emphysema are the most common conditions included under this umbrella term of COPD.

Chronic Bronchitis is inflammation and swelling of the air passages (bronchi), over a prolonged time. The body produces excess mucus or phlegm, which you have to try to cough up.

Emphysema occurs when the little air sacs (alveoli) in the lungs are damaged. As air sacs are destroyed, the lungs are able to transfer less and less oxygen to the bloodstream. This causes shortness of breath.

Both of these conditions can coexist and people can have symptoms which relate to both, hence the use of the general term COPD.

COPD cannot be cured but its symptoms can be treated and quality of life can be improved.



Asthma

Asthma is a condition that constricts the airways. People with asthma have sensitive airways which react to triggers. When an asthma sufferer comes into contact with one or more of these triggers, the muscles around the walls of the airways tighten and they become narrower. The lining of the airways also becomes inflamed and begins to swell. There are a range of symptoms, for example – breathlessness, wheezing, tight chest or a persistent cough – often at night, early in the morning or during/after activity. Asthma cannot be cured but its symptoms can be treated and quality of life can be improved.



Symptoms of a respiratory condition

Symptoms can include:

- A persistent cough
- Wheezing
- Production of mucus or phlegm
- Shortness of breath
- Chest infections

People living with a respiratory condition can be prone to chest infections because excess mucus in the lungs provides an ideal environment for bacteria to grow.

Recovering from Coronavirus

Coronaviruses are a common type of virus which can cause a wide range of respiratory infections, from the common cold and flu to more severe illness. COVID19 is the infectious disease caused by the most recently discovered coronavirus. This new virus and disease were unknown before the outbreak began in Wuhan, China in 2019.

As this is a new disease which impacts people in different ways treatment and recovery will differ for each person. The information provided in the following pages on understanding and managing a lung condition may help in your recovery.

Understanding your condition



How your lungs work

To survive your body needs oxygen from the air you breathe. The lungs are designed to absorb oxygen from the air and transfer it into the bloodstream and then to remove waste gases, such as carbon dioxide.

When you breathe air in, through your nose or mouth, it travels down the back of your throat (pharynx), passes through your voice box (larynx), and into your windpipe (trachea).

Your trachea is divided into two air passages (bronchial tubes). One bronchial tube leads to the left lung, the other to the right lung.

The right lung has three sections, called lobes, and is a little larger than the left lung, which has two lobes. The bronchial tubes divide into smaller air passages (bronchi), and then into bronchioles. The bronchioles end in tiny air sacs called alveoli, where the oxygen and carbon dioxide are exchanged in your blood.

After absorbing oxygen, the blood leaves your lungs and is carried to your heart. Then, it is pumped throughout your body to provide oxygen to the cells of your tissues and organs. When the oxygen is used by the cells, carbon dioxide is produced and transferred into the blood. Your blood carries the carbon dioxide back to your lungs and it is removed when you breathe out.

The respiratory system has built-in methods to prevent harmful substances from entering your lungs:



- Your nose moistens and warms the air.
- The hair (cilia) in your nose helps filter out large particles.
- Mucus produced by cells in the trachea and bronchial tubes keeps air passages moist and helps in trapping dust, bacteria, and other substances.
- Cilia hair in the air passages moves in a sweeping motion upwards towards the throat and mouth to get the mucus and bacteria etc out of the lungs.
- Healthy lungs are made of a spongy, pinkish-greyish tissue. Lungs that have become polluted with harmful particles, like smoke, appear to have blackened spots on the surface.
- Healthy lungs are elastic, so they can expand when you breathe in. In contrast, a disease such as emphysema causes the lungs to lose their elasticity. When a lung can no longer expand properly or transfer oxygen to the blood, the person has difficulty breathing and tires easily. Other difficulties can occur because the tissues and organs aren't getting the oxygen they need.

Treatment & Medication



Many different medications, which work in different ways, are used to treat and manage a respiratory condition. Your doctor will decide which medicine or combination of medication is best for you based on your medical history, symptoms and tests.

The different groups of medications are:

- **Bronchodilators/Relievers** – open up the airways in your lungs to relieve or reduce shortness of breath and wheezing.
- **Steroids/Preventers** – work over the longer term, to reduce swelling and inflammation in your airways.
- **Oxygen therapy** – raises oxygen levels in the blood.
- **Antibiotics** – treat chest infections.
- **Mucolytics** – break up mucus.
- **Vaccinations** – help prevent flu and pneumonia.



Bronchodilators/Relievers



Your doctor may recommend medicines called bronchodilators, that work by relaxing the muscles around your airways. This type of medication is commonly prescribed by inhaler, so that the drug can be delivered directly to your lungs, and help open your airways to make breathing easier. Bronchodilators can be either quick acting or long acting.

- Quick-acting bronchodilators (Relievers) act quickly, within 5-10 minutes, to relieve breathlessness and last about 4 to 6 hours. Reliever inhalers are colour coded blue and it is important that you carry one with you at all times.
- Long-acting bronchodilators (Controllers) take about 30 minutes to act but last for 12 hours. These inhalers are not used to relieve immediate breathlessness, rather they are taken daily to reduce the symptoms of breathlessness. These inhalers are colour coded green or turquoise.

Your doctor may recommend regular treatment with one or more inhaled bronchodilators. Some people may need to use a long-acting bronchodilator and a short-acting bronchodilator. This is called combination therapy.

Bronchodilators can sometimes be prescribed in tablet form, in addition to inhalers, to keep the airways as open as possible. Bronchodilator tablets are also sometimes used if the person is unable to use an inhaler or has difficulty following a treatment plan with inhalers.

Steroids/Preventers



Steroids (Preventers) work to reduce the inflammation, swelling and mucus production that narrow the airways and cause breathing difficulties. The steroids work over the longer term to prevent these symptoms and will not give immediate or quick relief when you are breathless. Sometimes steroids and long-acting bronchodilators are used in combination. Steroids are also often prescribed as inhalers and are colour coded brown or orange.

Oral steroids can sometimes be prescribed if your symptoms suddenly get worse. Oral steroids are then usually prescribed at a higher dose and reduced over time before stopping completely. It is important to note you can become ill if you stop taking steroids suddenly. **Do not** stop taking any steroid medicines without talking to your doctor.

Inhalers

There are many different brands of inhalers made by many different companies. Generally they are colour coded in a similar way for clarity but it is extremely important that you know what kind of inhalers you have been prescribed and when you need to take them.

Inhalers are very effective if used correctly. It is very common to experience problems using inhalers and if you are having problems talk to your doctor or respiratory nurse. They will be able to check your inhaler technique or may give you a different inhaler.

There are two main types of inhaler:



- Pressurised Metered Dose Inhalers – These inhalers use an aerosol action to push the medication out of the inhaler as a fine mist for you to breathe in. The medication may be released by either pressing on the top of the inhaler or by breath activation.
- Dry Powder Inhalers – The medication comes as a powder stored in a small capsule, a disc or a compartment inside the inhaler. Dry powder inhalers require you to inhale more rapidly than you would with a traditional metered-dose inhaler to 'suck' the medication in.

Using Your Inhaler Different types of inhalers work in different ways but the general principles are the same:

1. Always make sure you are sitting upright or standing before taking your inhaler.
2. Shake the inhaler well.
3. Breathe out to empty your lungs.
4. Put the inhaler into your mouth and seal your lips around the mouthpiece.*
5. When activating the inhaler take a deep breath in.
6. After filling your lungs try and hold your breath for a count of 10 or as long as you can manage.
7. Breathe out.
8. If you need a second puff, wait 30 seconds, shake your inhaler again, and repeat steps 3-7.
9. If you use a steroid inhaler you may want to rinse your mouth or brush your teeth afterwards as these can sometimes cause oral thrush.

*Some of the dry powder inhalers require preparation prior to putting the mouthpiece in your mouth, in order to open the capsule or disc, so that the powder can be released. It is recommended you know the name of your inhalers, the colour codes and the mode of action.

Spacers



Sometimes people can have difficulty co-ordinating the actions needed to use the aerosol metered dose inhalers i.e. pressing down on the inhaler and taking a breath at the same time. A spacer is a large chamber which is fitted to an inhaler. Instead of inhaling directly from the inhaler, a dose is sprayed into the spacer then the medication is breathed in from the spacer through a mouthpiece.

Other advantages of a spacer are that it is easier to hold and you can breathe in and out several times from the chamber, so if your lungs aren't working very well you don't have to get all the medicine in one breath. The spacer also reduces the amount of medicine from the inhaler which hits the mouth and throat rather than going to the lungs. The benefit of this is that you will have fewer side effects in your mouth and throat, such as hoarseness or oral thrush from steroid inhalers.

Using Your Spacer

1. Shake the inhaler well.
2. Fit the inhaler to the inhaler hole in the opposite end of the spacer to the mouthpiece.
3. Breathe out to empty your lungs.
4. Put your mouth around the mouthpiece making sure there are no gaps.
5. Spray one puff into the spacer.
6. Breathe slowly and deeply from the mouthpiece of the spacer and hold your breath for 10 seconds if possible. Repeat two or three times with the mouthpiece still in your mouth. You can breathe out with the mouthpiece still in your mouth as most spacers have little vents to allow your breath to escape.
7. If your doctor has prescribed two doses, wait for one minute then follow steps 3 to 6. Never spray the two puffs into the spacer together as it is not as effective as doing them separately.

Nebulisers

A nebuliser is an electronic medical device which works by turning a solution of medication into a vapour which can then be breathed in. It is important to note that you should only be using a nebuliser if your doctor has advised it. The use of a nebuliser should be monitored to ensure it is beneficial and the medication is only available on prescription. Nebulisers may be prescribed for people who are unable to manage inhalers or whose symptoms are becoming worse.



A nebuliser consists of:

- An electrical air pump (or compressor) to pump the air at pressure.
- The nebuliser chamber where the medication is placed.
- A length of plastic tubing connecting the pump (or compressor) and the nebuliser chamber.
- A mouthpiece or facemask used to breathe in the medicine.

The pump forces air through the solution in the nebuliser chamber. This changes the liquid into a fine mist which you breathe in through a mask or mouthpiece.



Before using a nebuliser you must get your doctor or respiratory nurse to give you a demonstration of how it works. It is also useful to have a set of written instructions on how to use your nebuliser.

This written plan should include:

- How to set up the nebuliser.
- How to keep it clean.
- How to get it serviced.
- How to get it repaired.
- How much medicine to use.
- How to put the medicine in the nebuliser.
- When to use the nebuliser and how long for.
- How to recognise the warning signs that show you may be having an exacerbation.
- What to do in an emergency.

Note: It is extremely important that you are able to use your inhaler and/or nebuliser properly and know how to take care of them. Read all the instructions you are given and if you have any questions ask your doctor or respiratory nurse.



Oxygen Therapy

Oxygen therapy may be prescribed if tests show that there are low levels of oxygen in your blood due to lung damage. The air we breathe every day contains 21% oxygen. With oxygen therapy the percentage is higher therefore increasing the amount of oxygen in the blood and helping to reduce shortness of breath.

Oxygen therapy must be prescribed by a doctor. Your doctor will prescribe a specific amount of oxygen that is right for you. Some people may need to use supplemental oxygen for prolonged periods, while others may only need oxygen during exercise or activity.

You can get oxygen in:

- A cylinder containing either liquid oxygen or compressed gaseous oxygen.
- An oxygen concentrator which is a machine that takes oxygen out of the ordinary air in your home and concentrates it for you to breathe.

If you are prescribed oxygen for short periods of time you will likely be prescribed a cylinder. If you are prescribed oxygen for longer periods the oxygen concentrator is probably more appropriate, although you will also need a back up cylinder in case of power failures. Smaller portable cylinders are also available to enable you to leave the house with your oxygen supply.

You breathe the oxygen through a face mask or through tubes that go into your nose (called a nasal cannula). The nasal cannula tends to be most people's choice as it allows you to eat and drink whilst using the oxygen.



Note: It is important to remember that oxygen is a prescribed drug and you should always follow your doctor's advice, for example, never change the flow rate yourself. It is also important to treat the equipment with care and make sure there are no naked flames or heat sources nearby as oxygen could cause a fire to spread rapidly. Keep cylinders in a place where they won't get knocked over and do not carry liquid oxygen in a backpack or other enclosed bag. Special carrying cases, shoulder or hand bags, shoulder straps and backpack oxygen units are available which provide proper ventilation for the unit to ensure safety.



Antibiotics

Antibiotics are drugs that fight bacterial infections. It is especially important to start treatment for an infection as soon as possible if you have COPD. It helps to know the warning signs of an infection such as an increase in the colour, amount or stickiness of your mucus, an unusual increase in your shortness of breath or signs of fever. Colds and flu are caused by viruses (not bacteria) so antibiotics will not help.

It is important to take your antibiotics as prescribed, timing the doses accordingly and finishing the course of treatment, even if you feel better.

Mucolytics

A mucolytic medicine may be prescribed if you have moderate or severe COPD and cough up a lot of mucus or have frequent or bad exacerbations. This type of medication breaks down the mucus in your lungs, making it less sticky and easier to cough up. It may also make it more difficult for bacteria to settle in the mucus and cause infections.



Vaccinations

There are currently three vaccinations that people with a respiratory condition should receive.

Flu vaccine – this is available every year from about late September. This is manufactured to try and immunise the population for the strain of flu that will be around at the end of the year.

Pneumonia vaccine – given once in a lifetime unless you are immunocompromised.

Coronavirus vaccine – for further information visit: www.nhs.uk/conditions/coronavirus-covid-19/coronavirus-vaccination/coronavirus-vaccine/

It is important that you take any medication prescribed as directed. Your doctor, respiratory nurse or pharmacist will explain how to use your inhalers, nebuliser or oxygen equipment appropriately. Make sure and ask questions to help you understand your medication and how to use it. This will ensure every dose you take gives you the most benefit.



Living with a respiratory condition



Know Your Triggers

Some things can irritate your lungs and make your symptoms worse. For example, air pollution, smog, second-hand smoke, strong fumes, perfume and scented products, cold air or hot and humid air.

Tips to Avoid Triggers:

- Use unscented cleaning products
- Avoid wearing perfume or aftershaves.
- Avoid using aerosol sprays.
- Turn on the kitchen fan when cooking.
- Avoid smoke either from surrounding smokers or fireplaces.
- Stay indoors on days which have high air pollen or pollution counts.
- When you are outside in cold weather, breathe through a scarf that covers your nose and mouth.
- Avoid people who have the cold or flu.
- Get your annual flu vaccination.
- Avoiding your triggers and living a healthy lifestyle can help reduce exacerbations of your respiratory condition, which is when your symptoms suddenly become worse. But it is also important to recognise an exacerbation and take quick action.

You should contact your GP if you notice any of the following:

- Increased shortness of breath and/or wheezing.
- Chest tightness.
- Increased cough with or without mucus.
- A change in the amount, colour or 'stickiness' of the mucus.

Know How to Control Your Breathing and Breathlessness



There are various techniques for coping with breathlessness. If you practise these and use them every day, they will help your breathlessness. They will also help you manage if you get short of breath suddenly.

Breathing Control

Breathing control aims to encourage you to use the correct muscles when breathing. People with a respiratory condition have to work harder to breathe and tend to breathe using the muscles in their upper chest, rather than the muscles in their lower chest. This takes more energy and is tiring. Breathing control exercises will help your breathing be more efficient and encourage you to use the correct muscles, especially your diaphragm.

Tips for Breathing Control Exercises

- Sit in a comfortable position with your back well supported. Your upper chest and shoulders should be relaxed. Place one hand on your tummy between your lower ribs and navel.
- Breathe in through your nose, you should feel your tummy move out as you breathe in.
- Breathe out gently through your mouth, your tummy will move in as you breathe out.
- Concentrate on letting your tummy and the lower part of your chest move in and out under your hand as you breathe.
- It can sometimes help if you imagine the air is filling your tummy, like inflating and then deflating a balloon.
- Gradually try to increase the depth of each breath whilst staying relaxed.
- Practise this first when sitting. Then begin to practise while you are standing and then walking.

You should practise this breathing method several times each day (aim to do 5–10 breaths each time). The more you do it, the easier it becomes and your diaphragm will become stronger. A stronger diaphragm helps decrease your shortness of breath, strengthen your cough and remove mucus. Practising it every day also means that it comes more naturally to you if you feel breathless.



If you find breathing control difficult when you are feeling breathless then take slow, relaxed breaths, each breath a little deeper until you feel less breathless. Try to feel calmer with each breath.

Pursed Lip Breathing

Pursed lip breathing is another method that can help manage shortness of breath.

Tips for Pursed Lip Breathing

- Breathe in slowly. This should be a normal breath, not a deep one. It is best to breathe in through your nose, with your mouth closed, if you can.
- Pucker your lips in a whistling position. These are pursed lips.
- Breathe out slowly – as if you are trying to flicker a candle. Breathe out twice as long as you breathed in. Counting as you inhale and exhale will help you gauge this.
- Relax.
- Repeat these steps until you no longer feel short of breath. If you get dizzy, rest for a few breaths. Then begin again.
- If you get lightheaded you are breathing too quickly. Slow down and try again.

Again, you should practise this breathing method several times each day, so it comes naturally to you when you are breathless.

Learning to control your breathing will help you control and manage your breathlessness and reduce the feelings of panic and anxiety that come with shortness of breath.

Positions of Ease when Breathless

If you get breathless, there are several positions that can also help you get control of your breathing. These are often referred to as positions of ease. They allow your diaphragm muscle to work more effectively for you to use breathing control to reduce your breathlessness.



Relaxed Sitting Position

Sit leaning forward from the hips. Rest your forearms on your thighs with relaxed wrists and hands.

Forward Lean

Stand and lean forward from the hips onto something of a suitable height such as a wall, fence or banister.

Backward Lean

Lean back against a wall with your shoulders relaxed and arms resting down by your side. Your feet should be 12 inches away from the wall (or as far as is comfortable) and slightly apart.

The choice of position you choose may depend on where you are at the time or you may find one that works better for you than the others. Combine breathing techniques and positions of ease when you are feeling breathless.

Controlling Breathlessness at Night

Many people with a respiratory condition suffer from breathing difficulties during the night. This can be very frightening and increase your anxiety, making your breathlessness worse. Sleeping in an upright position can make you feel more comfortable; for example, lying on one side, rolled slightly forward with a slope of 45 degrees, using pillows to raise your shoulders. Also, being prepared to cope with breathlessness during the night can help to reassure you if it happens.

Tips for Controlling Breathlessness at Night

If you wake up breathless, sit up and lean forward, for example, sitting at the edge of the bed and leaning your arms on a bedside table. Relax your shoulder and neck muscles. Use the breathing techniques to control your breathing. 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.



Clearing Mucus from your Lungs

Some people living with a respiratory condition produce a lot of mucus in their lungs and may find it hard to get it up which can make breathing even more difficult. Changes in the amount, colour or 'stickiness' of the mucus may be a sign you have a chest infection and you should contact your doctor.

Tips for Clearing Mucus

Drinking fluids can help stop the mucus from getting too sticky. Try to drink 8-10 glasses of fluid every day such as fruit juice or water. Some people with a respiratory condition who also have heart problems might need to limit their fluids, so be sure to follow your doctor's guidelines. Use your reliever inhaler to open the tubes before trying to clear mucus.

Try the following breathing exercises, mornings and evenings:

- Do some breathing control exercises, as described earlier.
- Take 3 or 4 deep breaths, holding your breath to the count of 3 each time and breathing out gently.
- Follow this with some more breathing control exercises.
- Take 1 or 2 huffs, a huff is a small breath IN and a fast breath OUT through an open mouth like you were cleaning a spot off glass. Tighten your tummy muscles and chest as you huff.
- Do some more breathing control exercises.
- Repeat until the mucus reaches the bigger airways and then cough to clear it out.

How does Coronavirus (including COVID19) affect those with respiratory illness?

Coronaviruses are known to cause breathing difficulties and coughing, which can be extremely dangerous to those who already have a hard time breathing. The people most at risk of severe health impacts from coronavirus are those with pre-existing severe respiratory conditions including moderate to severe asthma, bronchiectasis and COPD, and those with compromised immune systems.



Are those with respiratory illness more likely to catch it?

People of all ages can be infected by coronavirus, but people who are over the age of 70, immunocompromised, or with underlying medical conditions such as moderate to severe asthma, are more vulnerable to adverse outcomes from the virus.

It is best to stay vigilant when out and about. Maintain physical distance from others if you can and keep up good hygiene practices.

Practical things you can do to stay safe from coronaviruses like COVID19 and colds and flu:

- Wear a face mask in public places.
- Keep a 2 metre distance from people you don't know in public places and take extra care with hygiene practices.
- If you are working and considered at risk of severe illness from coronavirus, talk with your employer about doing a risk assessment in your workplace to look at what the risk is for you and how it can be reduced.
- Keep up with your medication as prescribed, and always make sure these are well stocked.
- Regularly wash your hands with soap and water for at least 20 seconds and thoroughly dry.
- Avoid touching surfaces and wash your hands before and after you leave home.



- Clean and disinfect frequently touched surfaces and objects, such as doorknobs, keys, handrails.
- Do not touch your eyes, nose or mouth if your hands are not clean.
- Cough or sneeze into your elbow or by covering your mouth and nose with tissues.
- Put used tissues in the bin or a bag immediately.
- Avoid passing around your mobile phone to other people.
- Follow the UK Government guidelines www.nidirect.gov.uk for updated information.

Managing your respiratory condition



Secondary prevention

You can also make changes to your lifestyle to help such as:

- If you smoke, STOP.
- Eat a balanced diet.
- Take more exercise.
- Conserve your energy.

If you smoke, STOP

If you stop smoking, this alone will help improve your cough and mucus and slow the rate at which you become breathless. It is not easy to stop smoking but there is help out there.

People who quit smoking:

- Have fewer chest infections.
- Have fewer hospital admissions.
- Slower decline in lung function and have less lung damage.
- Respond better to the effects of inhalers and other medication than smokers.
- Reduce their risk of stroke, heart and vascular disease.

For help to quit smoking:

- Go to www.nhs.uk/smokefree for a QuitKit.
- Go to www.want2stop.info/stop-smoking-services for local Stop Smoking Services.
- Text QUIT to 70004 for SMS support.

Ask your GP for information on nicotine replacement products. Many local hospitals run smoking cessation clinics and there are some GPs who also provide this service. You can also find out more at: www.stopsmokingni.info/ways-quit/local-help-and-support

Tips to Help Give up Smoking

Set a goal each day to make it through without smoking.



- If you tell yourself you're quitting for good it may be too overwhelming to think about. The key is to take one day at a time.
- Stay away from your triggers. Coffee, tea and alcohol are well known triggers for smokers. So if you find they weaken your resolve, avoid them completely or drink fruit juice, water or decaffeinated versions instead.
- Reward yourself! One of the great side effects of stopping smoking is the extra money.
- Treat yourself - it's good to have something to show for your efforts and it will spur you on.

Eat a Balanced Diet

If you have a respiratory condition, eating regularly and eating healthy foods is important because:

- Food provides you with energy, including the energy you need to breathe.
- Nutrients are necessary for a healthy immune system. A healthy diet and strong immune system can help you prevent and fight infections.
- If you are overweight, your heart and lungs have to work harder, which makes breathing more difficult. Eating healthy foods can help you lose weight.
- If you do not eat enough or are underweight, you generally feel tired, which in turn makes it more difficult to perform everyday activities. Being underweight may also increase your chance of getting infections. Eating healthy foods can help you gain or maintain your weight.

If you are Overweight



- Aim to lose weight sensibly, about one pound per week is ideal.
- Choose low fat foods such as semi skimmed milk or low fat spread and cheese.
- Eat plenty of fruit and vegetables.
- Limit your sugar, salt, caffeine and alcohol intake.
- Steam, bake, boil and grill foods rather than frying.

If you are Underweight

- If you are not eating well or have lost weight you may need to include nutritional or high energy supplements in your diet.
- A wide range of products are available, from high energy drinks like milkshakes or smoothies, which can be bought at the supermarket, to nutritional supplements which are prescribed by your doctor or dietician.
- Eat small amounts as often as possible throughout the day.
- You could also try high calorie snacks throughout the day such as wholemeal toast, crackers and cereal, natural yoghurt and fruit, hummus and raw vegetables, nuts and seeds and rice or oat cakes.
- Speak to the dietician for more specific information.

If you get short of breath at mealtimes, you can:

- Eat small, frequent meals throughout the day instead of three big meals.
- Rest before eating.
- Eat slowly and chew foods well, taking plenty of time to eat.
- Breathe evenly when chewing.

* Reference <https://researchbriefings.files.parliament.uk/documents/CDP20160220>
CDP20160220.pdf (page4)

Take more Exercise

Exercise is good for everyone as it helps to contribute to our general well-being. For someone who is living with a respiratory condition, exercise is beneficial as it can strengthen the breathing muscles which means they don't have to work as hard to get air into and out of the lungs.



Exercise also strengthens the muscles in your legs and arms making you stronger meaning you tire less easily. It has also been shown to help people feel more relaxed, and can help with the symptoms of moderate depression. Exercise also helps you sleep better at night and so you feel more refreshed and have higher energy levels the following day.

People who have a respiratory condition will benefit from exercise but you should be aware of your own ability and it is advisable to consult your doctor before increasing your activity levels. Walking and swimming are good aerobic exercises and also help to strengthen your upper and lower body. Even chair bound people can do some arm and upper body movements. Check with your GP or local respiratory team before starting on an exercise programme.

Tips for Exercising

- Consult your doctor or respiratory nurse and ask advice on a suitable exercise programme.
- Make a commitment to a regular exercise programme, vary your activities and have fun.
- Start slowly and build up your exercise programme, setting yourself goals.
- Do light warm-up and cool down stretches.
- Take adequate rest periods during your exercise session.
- Use breathing control techniques during exercise.
- Pace yourself, avoiding sudden bursts of activity.
- Exercise sensibly in moderation.

Conserving Energy

Many people who have a respiratory condition may suffer from tiredness and lack of energy. Exercise can help increase energy levels but learning ways to conserve energy can be very helpful, especially for those unable to exercise.



Tips for Conserving Energy

Get good quality sleep. It is important to get as good a quality of sleep as possible. Lying in bed for hours but not sleeping well is worse than getting a few hours deep and restorative sleep. Get into a routine before bed to prepare your mind for sleep. Have a warm bath to relax and take a hot malt or sweet drink. Don't start jobs before going to bed or think about things that upset or worry you.



- Avoid movements that use lots of energy. Avoid bending and lifting too much.
- Organise how you go about things. Do energy consuming tasks at the time of day/week when you have most energy, but be flexible and plan some rest periods too.
- Good planning in advance will prevent you having to rush.
- Set priorities and make choices about what you want to use your energy for. Sit for activities that can be tiring, for example, washing or preparing meals.
- Organise your space. Put the items you use in a drawer or shelves that are between waist and shoulder level. Keep items in the area where they are going to be used to avoid unnecessary walking or carrying. Ask someone to help you reorganise your space.
- Eliminate unnecessary activities. Let dishes drip dry. Use a towelling bathrobe to dry off after a bath or shower.
- Pace yourself. A slow steady pace uses less energy. Give yourself time to do things. Rest before and after energetic activities, for example washing or preparing meals. Don't be tempted to overdo it on a good day as you will be overtired the next day. If you are overtired one day, look back to what you did the previous day. If you did too much, learn to adjust this.
- Ask for help. Household chores use up a lot of energy and you could get help with them. Friends and family could help with shopping or housework or social services may be able to get help for you.

Coping with Difficult Emotions

A person who has just been diagnosed with a chronic respiratory condition may feel a lot of things. Some people feel vulnerable, confused, and worried about their health and the future. Others feel sad or disappointed in their bodies. For many, the situation seems unfair, causing them to feel angry at themselves and the people they love.



Everyone's reaction is different, but they're all valid.

It is also important to remember that whilst you may be the one with a respiratory condition, the people around you who care about you are also affected by your condition. They suffer because they hate to see you unable to do the things you enjoy or worry when they see you unwell.

Depression

A chronic respiratory condition can make you feel tired and you may not be able to do the things you once enjoyed such as hobbies or work. You may use oxygen and be reluctant to go out in public or have a chronic cough and be conscious in front of other people. All these things can socially isolate you and put you at an increased risk of developing depression.

Many people who have a chronic respiratory condition can suffer from depression at some time or another and it is important to act quickly. When depression is left untreated, it drains both your emotions and your body. You not only feel bad, but you also have less energy to do the things you want to do, including taking care of yourself and managing your condition.

Symptoms of depression can include:

- Feeling down more often than not.
- Interrupted sleep or trouble getting to sleep.
- Sleeping much more than usual.
- Lack of interest in people or activities.
- Decreased motivation.
- Difficulty concentrating.
- Changes in appetite.
- Crying much more easily and more frequently than usual.
- Feeling irritable with everyone and everything in your life.



If you think you are depressed it is very important to talk to your doctor as it is a condition that can be managed. There are successful drug treatments for depression as well as relaxation techniques or activities such as yoga, tai chi, or reflexology. Meeting or talking to friends, getting out of the house, reading a book, listening to music and gentle exercise are also ways to manage feelings of depression.

Anxiety

Breathlessness can be a frightening experience, especially when it is severe, leading to feelings of anxiety and panic. You may become anxious about becoming breathless or coughing in public or at night time. Unfortunately feelings of anxiety and panic cause physical symptoms such as a racing heart, sweating, feeling a need to go to the toilet, loss of concentration and irritability as well as increased breathlessness.

If you start to feel anxious it may help to try some breathing techniques such as pursed lip breathing or breathing control exercises. This will help your breathing and take your mind off your immediate worries.

If you do feel anxious or depressed talk to your loved ones about your

fears and anxieties, as it can help. Talking will also help them as they will have their own concerns about you. It can also help to talk to other people who understand what you are going through.



Making time for yourself to relax can help prevent feelings of anxiousness and depression. For some listening to music will help, for others a bath is relaxing.

Tips for Relaxation

- Go to a quiet place where you won't be interrupted.
- Make yourself comfortable, either sitting or lying down.
- Start to breathe slowly and deeply, take deep breaths in through your nose and out through pursed lips.
- Gently tense, then relax, each part of your body, starting with your feet and working your way up to your face and head.
- Push any distracting thoughts to the back of your mind and imagine them floating away.
- Stay like this for a time, then take some deep breaths and open your eyes, but take a few moments before you get up.

Mindfulness

Mindfulness practice helps us to live in the present moment by using the natural tools of our breath, our body and our senses as anchors. Mindfulness can be practised at any time at all – while you are walking along, driving, cooking, eating, or even just breathing. If you are focusing on the present moment and paying deliberate attention to the activity you are currently doing, then you are not thinking about the past or the future with all the associated worries, regrets, panic and negative thoughts.

5, 4, 3, 2, 1

This is a technique that can be used when driving, walking, commuting etc. It is a means of distracting your brain from the past or future and forcing it to focus on the present by finding things in your immediate environment. In this technique you are looking for:



5 things you can see

4 things you can hear

3 things you can touch

2 things you can smell

1 thing you can taste

3 Actions you can take!

1 Medication

Many different medications, which work in different ways, are used to treat respiratory conditions. Your doctor will decide which medicine or combination of medication is best for you based on your medical history, symptoms and tests.

You may also want to visit your pharmacist and book a Medication Use Review (MUR). This 20 min appointment with a qualified pharmacist is a great opportunity to understand your medication fully and check your inhaler technique.

Action: Contact your local pharmacy for more information

2 Pulmonary Rehabilitation

Also known as Pulmonary Rehab, is an exercise and education programme that helps improve the wellbeing of people who have chronic breathing problems.



Pulmonary Rehabilitation has many benefits. It can help:

- Improve your tolerance to exercise
- Your ability to function, decrease breathlessness, and improve your quality of life. It results in people seeing their doctors less often and spending less time in hospital. Even if you have advanced lung disease, you can still benefit from pulmonary rehabilitation.

Action – Contact your GP or respiratory nurse and ask to be referred to Pulmonary Rehabilitation and they will advise if you this programme is available to you.

3 Self-Management

Living with a long term condition requires careful self-management. On average people living with a long term condition spend 4 hours per year with a health professional.* This leaves 8,756 hours per year when you must take control and manage your own daily activities plus your mental and physical health.

Realising this fact is daunting – however at NICHHS we have a free 6 week programme which will start you on the right path. Further information on page 39.

Action – Contact NICHHS on 02890 320184 or chestsupportni@nichs.org.uk to find out more.

How we can help you



Living with a long-term health condition such as chest, heart or stroke illness, affects you not just physically, but also emotionally and socially. Whilst timely and effective medical intervention is essential, people with long term health conditions also need support and guidance to manage their conditions, and lives, on a daily and ongoing basis.

Breathing Better Service

People living with chest, lung or respiratory conditions can avail of our Breathing Better Service, where our trained Coordinators will listen, understand, advise, and support you. Our service includes an initial phone call assessment. Our support will include:

- Information and advice on living with a respiratory condition. or caring for someone with a respiratory condition.
- A listening ear and emotional support.
- Signposting to other local services who can help.
- A key point of contact.
- Fast Track Referral to Advice Space for support with benefits.

NICHS's Breathing Better Service also:

- Allows people to share experiences.
- Provides information on living with a respiratory condition.
- Provides information on healthy lifestyles.
- Encourages proactive Self-Management using NICHS services. e.g. "Taking Control" Self-Management Programme.
- Promotes continued rehabilitation.

Self-Management – Taking Control



The NICHS "Taking Control" Self-Management Programme will help you develop the skills and confidence you need to better manage your condition and help you feel stronger and better equipped to deal with daily life.

The programme is a weekly workshop of 2.5 hours over 6 weeks. It is free of charge and covers the following:

- Getting a good nights sleep.
- Managing symptoms.
- Medication "how-to."
- Working with your health care team.
- Setting weekly goals.
- Effective problem solving.
- Better communication.
- Handling difficult emotions.
- How to relax.
- Tips for eating well.

The programme will also enable you to meet other people who share similar experiences and who understand what it's like to live with a long-term condition.

Caring for someone with a chronic respiratory condition



If you are close to or caring for someone with a respiratory condition, you will find it helpful to learn about the condition yourself. The more you understand about the condition, its management and treatment, the more you will be able to help the person you are looking after. You will have a better understanding of their needs, and are also less likely to become impatient.

Things Carers May Have to Help With

People living with a respiratory condition can get breathless very easily, and they may rely on other people to do things for them. The things they will ask you to do will depend on their level of breathlessness. Some of the things you may be asked to help them with can include:

- Getting in and out of bed.
- Climbing up and down stairs.
- Household chores such as shopping, cooking and cleaning.
- Washing or dressing.
- You may also need to be familiar with the medication the person you are caring for takes.

If you are living in the same house, there is a lot you can do to help:



- Make sure you make every effort to reduce indoor pollution, for example, asking people not to smoke in your home, avoid wearing perfumes or aftershaves, avoid using aerosol sprays, vacuum the house regularly especially if you have a pet and try to maintain a constant comfortable temperature.
- Make sure you include them in things you do. They may get out of breath easily, but they can still join in with a lot of everyday activities and outings.
- Encourage them to keep a positive attitude, and continue making time for the things they enjoy.
- Be sensitive about their need for extra time to catch their breath.
- Get into a daily routine that suits you both.
- Learn to recognise an exacerbation and encourage quick action.

Looking after Yourself

Caring for someone who is dependent on you is a big responsibility. It is realistic, not selfish, to think carefully about taking care of your own health and organising support for yourself. If you don't look after yourself, you run the risk of becoming so stressed or exhausted that you are no longer able to care for them.

Think about what you can do to look after your health. Common problems are stress, tiredness and depression.

To reduce stress levels and tiredness it is important that you get some time for yourself, and that you get a break from caring. Many carers say that getting a regular break is invaluable. Plan some time

for yourself into your daily routine. You could try some of the tips for relaxation, go for a walk, read a book or do something else that interests you. Ask other family members or friends for some help. People often want to help - you just need to let them know how.



Many carers go through feelings of loss and grief for the way their life, and that of the person they care for, has changed. It is not unusual to have feelings of anger, resentment, guilt, anxiety and depression. Finding someone you can talk to about how you feel can help. Every carer is an individual, and each caring situation is unique. You are likely to find that most people who do not have experience of caring for another adult have no idea what it involves. But carers do have a lot in common, and it can be very helpful to meet and talk to other people who understand exactly what you're going through.

You might want to think about talking to one of our Breathing Better Coordinators or joining one of our Support Groups to meet other people with similar experiences.

How our support has helped others



**Ivan's
story**



**Ivan would have described himself as “relatively fit”.
The Belfast man was working in Tesco and had spent
28 years working in a bakery.**

He went through chemotherapy but in his recovery, he was experiencing problems with his lungs. It was during Pulmonary Rehabilitation that he was introduced to a Breathing Better Coordinator from Northern Ireland Chest Heart & Stroke. We met with Ivan and talked him through the support that we offer. It wasn't long after this when Ivan took part in the NICHS Taking Control Self-Management Programme.

Taking Control is designed for individuals with long-term health conditions and aims to help those individuals develop the skills and confidence they need to better manage their condition. “Setting aims each week was great,” Ivan says.

Before attending Taking Control, Ivan would very rarely leave his home. Previously Ivan would have been very social, but this changed due to his condition. **“I thoroughly enjoyed Taking Control. My Breathing Better Coordinator really helped me get out of my shell. She spoke to me at my level and was very helpful”.**

As well as the physical differences Ivan was feeling, he also found great social benefits from attending the group. He was able to make lasting friendships and continues to meet up outside of group times. “I found it really relatable as these people had gone through similar circumstances.”

Ivan describes a mental barrier being one of the biggest challenges in his recovery. He says, “It's very frustrating when you can't do small jobs that you used to be able to do. The cold weather really affects



me, too. It becomes a new normal and you have to get used to a different lifestyle.”

He says himself that he is very fortunate to have the caring support of his wife, Margaret. The couple are an example of how respiratory affects not only the person with the condition, but their family, too. “You never think you're going to be ill,” Margaret says. “It changes everything.”

In this way, the support from NICHS also had an impact on Margaret, who says she noticed a big difference in Ivan as a result. “We only row once a day now instead of 6!”

Ivan is now on oxygen, which can limit some of the things he can do. He hasn't been able to go on holiday as he can't fly with his oxygen tank. However, he does get out and about to visit family and continues to go to the support groups. He now has a portable, battery charged oxygen tank which allows him to get around more freely. “NICHS told me about this piece of kit. It makes things a bit easier,” Ivan says.

Ivan and Margaret continue to manage his condition each day, and thanks to the support and encouragement and the knowledge gained from NICHS, he has been able to take on and achieve many challenges.

“Six months after Taking Control, I aimed to take part in a sponsored walk at Stormont Estate,” he says. “I completed this walk and members from the Breathing Better Support Group joined me. It was a very proud day!”

A portrait of Fionna Henry, a woman with short grey hair and glasses, wearing a dark blue shirt with white heart patterns. A red speech bubble on the left contains her name and 'story'.

Fionna's story



My name is Fionna Henry, I am a Northern Ireland Chest Heart and Stroke service user. I have COPD, sleep apnea and arthritis and have suffered a mild stroke.

I first met my local Breathing Better Coordinator at the end of my pulmonary rehabilitation programme; she offered me a home visit to discuss further opportunities that could possibly benefit me. During the pulmonary rehab class I huffed and puffed my way through the exercise programme, and struggled with my arthritic knees. I did enjoy the classes, but sometimes it really was an effort. If I hadn't met the NICHS Breathing Better Coordinator that day I would have walked away unaware of the potential opportunities that could be achieved.

Recently someone said to me, "You don't look sick" – that's a good thing. But in order to prevent the hidden illnesses coming to the surface, that requires work and effort, and I need all the help I can get, so the NICHS Breathing Better programme fits the bill completely. It is the perfect continuation on from pulmonary rehab. If I hadn't had this programme after finishing pulmonary rehab I wouldn't be in such a good healthy place.

The programme provided a wide array of topics to help manage various long-term illnesses. During the programme we were able to purchase a book which deals with long-term illnesses. This book is very useful, and I have referred to it several times. It also provided an opportunity to make new friendships and we continued to learn about the tools we can use to help our conditions.



To say something is life changing is a bit dramatic, but the Breathing Better Programme has certainly involved lifestyle changes, which I have now embraced. I am enjoying my new found health benefits, such as weight loss and breathing better. I feel better, both physically and mentally. My skin, hair and nails are in better condition and I have gained a new found confidence, which isn't a bad thing either. This programme is not a miracle cure, you get as much or as little out of this programme as you wish to take, but there's no limitation to what you can achieve.

Six months ago, if anyone had said to me, that today I would be going to the gym, eating sensibly and taking care of myself, I would have laughed, but here I am, proof that you are never too old to learn. Who would have thought such a transformation was possible?

Certainly not me..."



Paddy's story



Belfast father-of-two Paddy Lynas once thought his life was over. He suffered from depression over his newly diagnosed lung disease, the resulting loss of his job and the death of several close family members.

Now, just a couple of years later, he walks 12 miles a day and is off all medication. He no longer takes drugs to control his chest condition, bronchiectasis, and has been officially discharged by his consultant. And he puts it all down to the help he received from Northern Ireland Chest Heart & Stroke.

"A few years back, my father, who was my hero, died. Then I lost three more of my family, my mother and two sisters, within 18 months of each other," he said. "Meanwhile, I was struggling with this lung disease that I was told would not improve. It seemed to me that I was in a pit with no way of getting out. My GP referred me to NICHs and I was offered a place on the Taking Control Programme."

"To be honest, I wasn't sure it was going to work. I was depressed, I found it hard to breathe and my skin was grey. But part of the idea of self-management is that you make a promise about what you hope to achieve. I said I would walk three miles, and I did. Then I promised I would walk six. After that I managed nine and decided I should extend it to 11. Everybody said I would never manage it, but I felt great. I started to walk into the country, then to the zoo. I'd meet people I knew miles away from the house, and they'd ask me if I needed a lift home, but I told them I was walking."

"Before too long, I'd lost more than two stones in weight and stopped all my tablets. Walking is my medicine now. But if it hadn't been for NI Chest Heart & Stroke, I simply wouldn't be here today. They saved my life."



To give something back, Paddy did the Belfast City Marathon to raise funds. People were not sure he would manage the full 26 miles, but he said: "I told them I would run it, walk it or skip it. And when I finished, I felt as if I could do it all over again. When I thought of how I used to be, I felt as if all my Christmases had come at once."

"I don't ever want to go back to the way I was. The doctor tells me my lung function has improved. I never get a taxi or a bus – I just walk everywhere. I used to be a chef, and since my health has improved I've started cooking again. Last year I finally got discharged from the respiratory clinic. The consultant used to call me the Marathon Man – now he calls me the Miracle Man! It's like a new lease of life."

"That's why I've decided that from now on, I'm going to live my life for others. Northern Ireland Chest Heart & Stroke gave me my life back, so I'm going to do everything I can to help anyone else who might find themselves in a similar position."

If you need help, get in touch chestsupportni@nichs.org.uk



Every year we support over 4,000 people in Northern Ireland like Ivan, Fionna and Paddy. But we can't do this without your help.

Almost 90% of NICHs's care services and research are funded exclusively by public donations.

To help us continue our vital work, visit nichs.org.uk/donate

For more information on any of these conditions, our support services or other programmes, please contact us or visit **nichs.org.uk**

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