

# LIVING WITH BRONCHIECTASIS





**NO LIFE HALF LIVED** 

The information contained in this booklet is based on guidelines and practice and is correct at time of printing. The content has undergone peer, patient and expert review.

## **LIVING WITH BRONCHIECTASIS**

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#### **ABOUT THIS BOOKLET**

#### Who is the booklet for?

The booklet is for people who have bronchiectasis. You may also find it useful if you are a friend, relative or carer of someone who has bronchiectasis.

#### What is this booklet about?

The booklet explains what bronchiectasis is, its causes and symptoms. It explains how bronchiectasis is diagnosed and managed and what you can do to help control your symptoms and keep yourself well.

The booklet also addresses some of the concerns you may have about living day-to-day with bronchiectasis and offers practical advice to help you continue to do the things that you enjoy.

#### How to use the booklet

The booklet is divided into different sections. These are outlined in the contents list. You do not have to read all of the sections at once. Some sections may be useful to you now, other sections you may want to come back to and read at a later time.

#### **Further information**

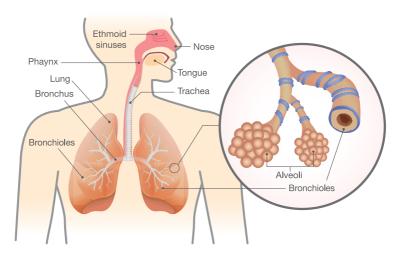
If you would like more information, we have a range of easy-to-read 'essential guides' on a number of different topics discussed in the booklet. These include guides on breathlessness, tiredness and fatigue, healthy eating, mental wellbeing, stopping smoking and physical activity. To see the full list of guides and other resources and to order, view or download them, go to www.chss.org.uk/publications or call the Advice Line nurses for more information on 0808 801 0899.

#### **UNDERSTANDING BRONCHIECTASIS**

## How do the lungs work?

In normal healthy airways, air travels into the lungs through the **trachea** (windpipe). The trachea divides into branches to supply your left and right lungs. These branches are called the left bronchus and the right bronchus. These bronchi divide further and branch into smaller and smaller air passages called **bronchioles**, that end in millions of tiny air sacs called alveoli. Around these air sacs are tiny blood vessels called capillaries.

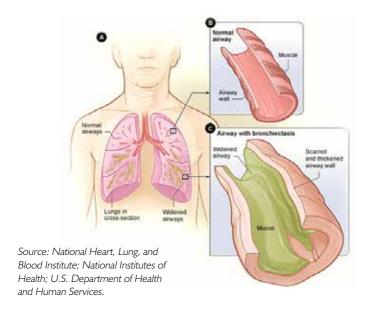
Oxygen from the air that you breathe passes through the thin wall of the alveoli into the capillaries, where it attaches to the red blood cells. The oxygen is then carried through the blood vessels to the rest of the body. At the same time, carbon dioxide (a waste product) passes from the capillaries into the alveoli and is breathed out.



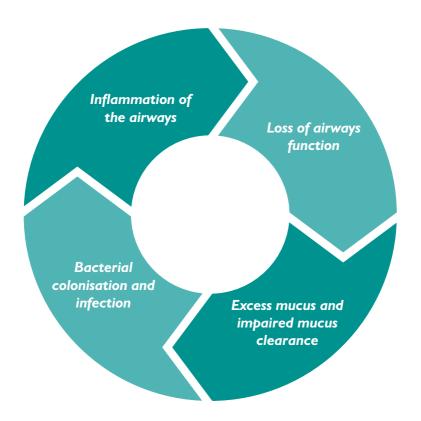
The airways are lined with glands that produce **mucus**. Mucus is a thick fluid that keeps the airways moist. It also helps to protect the lungs by trapping particles such as dust, allergens and bacteria, stopping them from going down into the lungs. Fine hairs called cilia that line the airways then brush the mucus and any particles trapped in it back up the airways towards the throat. The mucus is then either coughed up or swallowed. This mucus is often referred to as sputum or phlegm.

#### What is bronchiectasis?

Bronchiectasis is a long-term chest (lung) condition in which one or more sections of the airways become damaged and inflamed, causing them to become wider than normal. Extra mucus is produced, which becomes difficult to clear so it collects in the widened parts of the airways.



This build up of mucus in the airways can become infected by bacteria. Bacterial infection causes further inflammation and damage to the airways, which in turn causes more mucus to be produced that becomes more difficult to clear. This creates a 'cycle' of infection, inflammation and damage.



Good control early on is important in bronchiectasis to break the cycle and help prevent further damage. The advice that you will find later in this booklet can help you break this cycle.

#### What causes bronchiectasis?

Bronchiectasis is caused by inflammatory damage to the airways. In about half of all people with bronchiectasis the cause of the damage cannot be found. In the other half an identified underlying cause has damaged the airways, leading to bronchiectasis. Examples of underlying causes include:

- A severe lung infection such as pneumonia, tuberculosis or whooping cough, often in childhood or as a young adult – this is the most common cause
- Chronic obstructive pulmonary disease (COPD) with frequent flare-ups
- An obstruction or blockage of the airway an inhaled object (such as a peanut) or a tumour can cause damage to the airway
- Acid from the stomach (acid reflux) which travels back up towards the mouth and is breathed in to the lungs
- Conditions which affect the immune system can make a person more susceptible to infection and subsequent damage
- Conditions that cause inflammation in other parts of the body (such as rheumatoid arthritis, ulcerative colitis or Crohn's disease) can also cause inflammation in the lungs
- Some inherited conditions such as cystic fibrosis
- Ciliary defects such as primary ciliary dyskinesia or yellow nail syndrome (rare)
- An allergic reaction to a fungus called aspergillus. This is often seen in people who also have asthma

Smoking is not thought to be a direct cause of bronchiectasis but stopping smoking is important to prevent further damage to the airways. Smoking is also a cause of airways diseases such as lung cancer and COPD, which can contribute to bronchiectasis.

Damage can be limited to one area of the lung (more usual where there has been an obstruction or local infection) or it can be widespread (more usual if there is another inflammatory or immune disease present).

#### Who does bronchiectasis affect?

Bronchiectasis can occur at any age, but is more common in older adults.

It is more common in women than men, although it is not known why.

The number of people living with bronchiectasis is increasing:

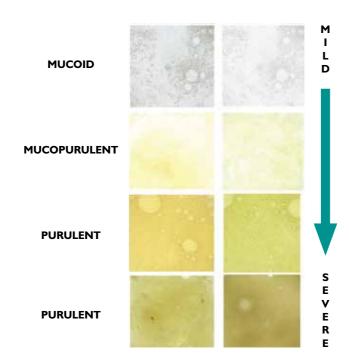
- For every 1,000 people in the UK, between 2 and 3 have bronchiectasis. That means that between 12,000 to 18,000 people in Scotland are currently living with bronchiectasis.
- About 3 out of every 10,000 people in the UK are newly diagnosed with bronchiectasis each year. That means that about 1,800 people each year in Scotland receive a diagnosis of bronchiectasis.

Bronchiectasis is responsible for 1.4% of deaths from lung disease. This is much lower than deaths from lung cancer (31%), chronic obstructive pulmonary disease (26%) or pneumonia (25%).

## What are the symptoms of bronchiectasis?

The main symptoms of bronchiectasis are coughing up sputum (phlegm) and repeated chest infections. The severity of symptoms varies depending on the severity of the disease:

- Mild disease: occasional cough producing small amounts of sputum and infrequent chest infections (less than 2 per year). Sputum is usually clear or light in colour.
- Severe disease: coughing up large amounts of sputum on most days and frequent chest infections. Sputum is usually dark yellow, green or brown and bacteria are found in the sputum even when the person is well.
- Most people with bronchiectasis have symptoms somewhere in between.



#### Other symptoms include:

- Tiredness
- Breathlessness, especially on physical exertion or exercising
- Wheezing
- Coughing up blood (usually just in small amounts, but sometimes a larger amount can be coughed up)
- Joint pain and chest pain

## How is bronchiectasis diagnosed?

Getting a diagnosis of bronchiectasis is not always easy and can take some time. Symptoms can be similar to other longterm lung conditions (such as COPD) and it can be difficult to distinguish between the two. Additionally, some people have both bronchiectasis and COPD, making diagnosis and management more difficult.

If your GP thinks that you might have bronchiectasis, he or she will arrange some tests for you. Depending on the results of these, you may be referred to a specialist respiratory (chest) consultant.

Tests your GP may organise include:

- Chest x-ray to exclude any other conditions
- Sputum sample to see if there are any bacteria in your sputum
- Blood tests to look for possible causes of bronchiectasis

Tests your respiratory consultant may organise:

- High resolution computed tomography (HRCT) scan. This is a special type of x-ray that uses computers to make detailed images of your lungs to show if the airways inside your lungs are widened. Widened airways on a CT scan usually confirm bronchiectasis.
- Lung function tests to see how well your lungs are able to transfer air in and out.
- Various other tests to look for a possible cause of your bronchiectasis. These may include bronchoscopy, further blood tests and sputum sampling.

#### What is the outlook for someone diagnosed with bronchiectasis?

Once a diagnosis of bronchiectasis has been confirmed, the outlook for most people with bronchiectasis is good.

Prompt treatment with antibiotics when an infection occurs (or with regular antibiotics if needed) can reduce further damage and help to keep you well.

However, in some people, symptoms will gradually get worse over time as more of the airways become damaged. More severe disease results in daily symptoms, reduced lung function and a reduced life expectancy.

#### Complications of bronchiectasis include:

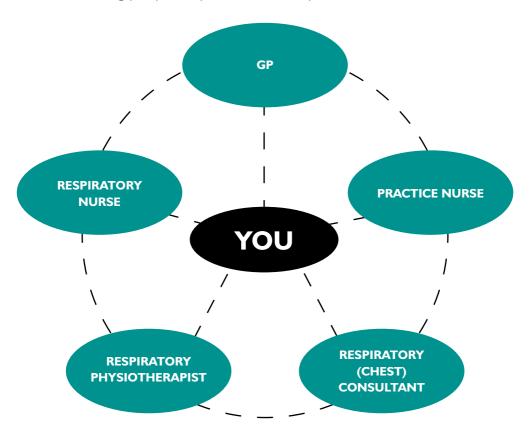
- Bleeding from a damaged airway this is usually just a small amount, but (very rarely) can be life-threatening
- Pneumothorax or 'collapsed lung'
- Heart failure (when your heart does not pump blood around your body as well as it should)
- Anxiety and low mood
- Self-conciousness, urinary incontinence, and / or sexual problems caused by chronic cough
- Chronic tiredness
- Poor appetite and weight loss
- Respiratory failure (when your lungs aren't able to exchange oxygen and carbon dioxide properly)

#### MANAGEMENT OF BRONCHIECTASIS

There is no cure for bronchiectasis. Damage to the airways cannot be reversed. However, treatment can help to prevent further damage, reduce infections and reduce symptoms.

#### Who will be involved in my care?

Depending on the severity of your bronchiectasis, the following people may be involved in your care:



#### How is bronchiectasis treated?

Early identification and management of chest infections is key to managing bronchiectasis. Other management options include:

- Finding and treating any underlying cause
- Airway clearance techniques and exercises
- Pulmonary rehabilitation
- Treatment to open up the airways (sometimes)
- Surgical management (rare)

#### Find and treat any underlying cause

If the cause of your bronchiectasis can be found, treatment may help to control your symptoms and reduce further damage to your lungs.

#### Airway clearance techniques and exercises

It is very important to clear as much mucus as you can from your airways. Ideally, your doctor will refer you to a respiratory (chest) physiotherapist who will show you how to use airway clearance techniques to help you clear the mucus. In some areas a respiratory physiotherapist may not be available. In this case, your doctor may give you a written guide showing you how to do these techniques and exercises. You can also watch short video clips that demonstrate some of these techniques on the CHSS website (www.chss.org.uk/chest-information-and-support).

Once you have been shown how to do these, you should continue to do these exercises regularly to prevent the mucus building up in your airways and to reduce your risk of getting a chest infection.

If you are finding it difficult to clear your chest and you have not seen a respiratory physiotherapist, ask your doctor about a referral.

There are several different techniques that can be used for clearing your airways. These include:

- Specific breathing techniques
- Positioning to help the mucus drain
- The use of hand-held devices to help with airway clearance

Your physiotherapist will work with you to decide which technique will be best for you and how often you should use these techniques. It is important that you are able to continue these on your own at home, so finding the right technique for you is vital. Do these exercises regularly, even when you feel well. Usually they should be done for 20 to 30 minutes once or twice a day if you produce sputum every day. If you only cough up sputum occasionally, you may need to do them less frequently.

For some people, inhaled treatments before airway clearance techniques can help to improve clearance of sputum. There is not much evidence for these treatments, so your specialist team will work with you to decide what is best for you.

#### **Pulmonary rehabilitation**

Pulmonary rehabilitation is a structured programme of physical activity and education specifically designed for people with long-term chest conditions. It is designed to improve your level of fitness and quality of life and can help you manage your symptoms of breathlessness, cough and tiredness on a day-to-day basis. If you are having difficulty with daily tasks because of your breathlessness you should be referred for pulmonary rehabilitation.

Pulmonary rehabilitation courses usually last for 6 to 8 weeks, with sessions once or twice a week. Individual courses will differ as they will be tailored to your specific needs. Every programme is organised and co-ordinated by a healthcare professional – usually a nurse or a physiotherapist. They will be at every class and will do your initial assessment. Some programmes are run in hospitals but many are based in the community, such as community and leisure centres or church halls, where it may be easier for you to attend. In some areas there may be an option for pulmonary rehabilitation exercises to be delivered at home if a class is not appropriate.

#### Treatment to open up your airways

For some people with bronchiectasis, especially those who get very breathless, using an inhaler to open up your airways can help to improve your symptoms. You may be offered a trial of an inhaler called a **bronchodilator**, which opens up (dilates) the airways (bronchi) by relaxing the muscle, making it easier to breathe. If your lung function and symptoms improve with inhaler treatment, your doctor may advise that you should continue to use it.

Inhaler devices come in many different shapes and sizes. Different devices will suit different people and it is important that you can use your inhaler properly to get the most benefit from it.

Your doctor, nurse or pharmacist should show you how to use your inhaler and make sure that you can use it properly, even when you are feeling breathless. If you find your inhaler difficult to use or you feel it is not working, tell your doctor or nurse. They will help you find a device that is more suitable for you.

For more information about the different types of inhaler and video clips showing how to use them correctly, see the My Lungs My Life self-management website (www.mylungsmylife.org).

Steroid inhalers are not usually recommended for bronchiectasis, unless you also have underlying asthma or COPD.

#### **Lung surgery**

Very occasionally, lung surgery may be an option for people with a small local area of lung damage whose symptoms are not controlled by usual treatment. Your respiratory consultant will discuss the options with you.

#### How can I tell if I'm getting a chest infection?

Sometimes you may notice your symptoms getting worse over a couple of days. This is often referred to as a **flare-up** or an **exacerbation** and is usually due to a chest infection. It is important that a chest infection is treated as quickly as possible to prevent further damage to your airways.

## If you notice any of the following, contact your GP as soon as possible so that treatment can be started if necessary:

- Increased coughing
- Sputum becomes darker, usually yellow or green
- Increase in the amount or the thickness of sputum you are producing
- Blood in your sputum
- Increased breathlessness
- Generally feeling unwell
- Fever, aches and pains
- Increased tiredness and lethargy

## How is a chest infection managed?

If your GP thinks you have a chest infection, he or she will take a sputum sample and prescribe you a course of antibiotics.

Sometimes you may have already been given a course of antibiotics to keep at home and start if you notice your symptoms getting worse. If this is the case, it is important that you take a sputum sample before you start taking the antibiotics so that the doctors can find out what bacteria (if any) are causing your infection. To do this you will need a sterile specimen pot, form and specimen bag. You can get these from your doctor's surgery. If you cannot get to the surgery that day, keep the sample in the fridge overnight and take it to the surgery as soon as possible.

The course of antibiotics will usually last for 14 days. It is important that you keep taking the antibiotics as prescribed until the course has finished.

If your symptoms do not begin to improve within 48 hours of starting to take the antibiotic, or you are feeling worse, contact your GP for further advice.

Other things that you can do to help manage a flare-up of symptoms include:

- Increasing the use of your bronchodilator inhaler (if you have one) to help control your symptoms
- Using your airway clearance techniques more often to clear extra mucus from your airways

- Resting more if you feel tired
- Making sure you drink plenty of fluids (but if you have another medical condition that means you need to limit your fluid intake, seek advice from your doctor or nurse).

Most people can be treated at home if they have a chest infection, but some people will need to go into hospital. Where you are treated will depend on how severe your symptoms are and how well you would be able to cope at home. If you are not able to take medicines by mouth, or you have already had a course of antibiotics that hasn't worked, you may also have to be treated in hospital with intravenous antibiotics (given directly into a vein).

## Can frequent chest infections be prevented?

If you have more severe bronchiectasis, you may have more frequent chest infections, which may return quickly once the antibiotic course is finished. In this case, you may need to take regular antibiotics to prevent infections from recurring. There are several ways that you can do this:

- Pulsed antibiotics: regular short courses of antibiotics with breaks in between courses.
- Regular oral antibiotics: a low dose of an antibiotic taken every day or every second day.
- Daily nebulised antibiotics: a nebuliser is a device that turns the antibiotic into a fine mist that you can breathe in using a mouthpiece or a face mask. This means that the antibiotic goes directly into your airways, reducing side effects.

## What follow-up should I receive?

Your bronchiectasis should be reviewed at least once a year. If your disease is stable this may be done at your GP surgery, often by the practice nurse. However, if you have recurrent chest infections, your symptoms are getting worse or you have moderate or severe disease, a respiratory specialist should review your bronchiectasis.

You may find it helpful to keep a diary noting the number of chest infections you have had, when they were and what medication you took.

At your review appointment, your doctor or nurse may ask you about:

- The number of flare-ups you have had and which antibiotics you took
- Your usual daily symptoms of cough, breathlessness, tiredness and how they affect your daily activities
- Whether you are managing to do your airway clearance exercises, as advised by your doctor or physiotherapist
- The frequency, amount, colour and thickness of sputum that you produce
- Whether you smoke if you do, you will be offered help to stop
- How well you are coping with your bronchiectasis
- Any specific concerns that you may have

## WHAT CAN I DO TO KEEP MYSELF WELL?

While there is no cure for bronchiectasis, there are lots of things that you can do to manage your bronchiectasis and live an active life.

- Monitor your symptoms and know when to get help
- Reduce your risk of getting a chest infection
- Keep as active as you can
- Stop smoking
- Eat healthily and keep up your fluid intake
- Keep your your chest as clear as you can
- Avoid air pollution

## Monitor your symptoms and know when to get help

## One of the most important things you can do is monitor your own symptoms.

It is important that you know what is 'normal' for you and that you can recognise when you have an infection so that you are able to get it treated promptly and avoid further damage to your lungs.

Warning signs of a chest infection include:

- Feeling increasingly unwell over a few days
- Change in sputum colour, quantity or thickness
- Increased coughing and difficulty clearing your chest
- Feeling more breathless than usual
- Increased tiredness and lethargy

If you have any of these symptoms it is likely that you have a chest infection and you will need to start a course of antibiotics.

## Reduce your risk of getting a chest infection

Reducing your risk of getting a chest infection can reduce further damage to your airways and help to stop your bronchiectasis becoming more severe.

- Make sure you are up to date with your vaccinations.
  - Flu vaccine you should have this every year.
  - Pneumococcal vaccine this is usually a single one-off injection.
- Try to avoid contact with people with colds and chest infections.
- Get into the routine of good hand hygiene and encourage visitors to do the same.
- Exercise frequently, as this can boost your immune system, which will help avoid infections.

## Keep as active as you can

Keeping physically active is an important part of staying well if you have bronchiectasis.

Some people may be worried that exercise could make them feel more breathless and that this will cause more harm. However, this is not the case; keeping active can help to:

- Clear sputum from your lungs
- Improve your breathing control
- Increase your general strength and fitness, making everyday activities less tiring
- Improve your mood
- Improve your sleep quality

The type of exercise you do will depend on your condition. Exercise that gets you moving about and makes you slightly out of breath and feeling warmer is best. This might be taking a brisk walk, cycling, swimming or gardening. Try to do some form of exercise everyday and build it into your routine.

## Stop smoking

Although smoking is not a direct cause of bronchiectasis, smoking will cause damage to your lungs and make your symptoms worse. Stopping smoking can help to prevent further damage to your lungs and improve your symptoms.

Giving up smoking is never easy, but there is plenty of help and it is never too late to guit. You are 4 times more likely to stop smoking if you have specialist support. So speak to your GP, nurse or pharmacist for advice and support, or contact Smokeline (Scotland's national stop-smoking helpline): telephone FREE on 0800 84 84 84 or visit www.canstopsmoking.com.

## Eat healthily and stay well hydrated

When you have a condition like bronchiectasis, it is important to eat well. A good diet not only helps you to keep strong, fit and healthy but it will also help you to be better at fighting and avoiding infections. Aim to eat a healthy balanced diet and drink plenty of fluids. Try to be as close as possible to your ideal weight - your doctor, practice nurse or a dietitian can help you work out what this might be. Being overweight increases the demand placed on your heart and lungs, which can make you feel more breathless.

General guidelines on eating a healthy balanced diet suggest following a diet that is low in sodium (salt), fat (particularly saturated fat) and added sugar, but high in whole grains and protein.



It is also very important to keep well hydrated by drinking plenty of fluids. Aim to drink at least 6-8 glasses of fluid every day. Water, lower-fat milk and sugar-free drinks including tea and coffee all count. Keeping hydrated helps stop your sputum from getting too sticky and makes it easier to clear your chest.

Note: if you have another medical condition that means you need to limit your fluid intake, seek advice from your doctor or nurse.

## Keep your chest as clear as you can

Use your airway clearance techniques daily, as advised by your respiratory physiotherapist. If you are having difficulty clearing your airways and you have not seen a respiratory physiotherapist, ask your GP about referral.

## **Avoid air pollution**

Air pollution is particularly harmful to people living with a long-term chest condition, like bronchiectasis. High levels of pollutants can irritate the lungs and increase symptoms such as breathlessness and cough.

Examples of air pollutants include:

- Wood or coal smoke
- Traffic pollution
- Industrial pollution, for example from factories

Try to reduce your exposure to air pollutants as much as possible:

- If you are in a busy area, try not to be out during rush hour, when levels of traffic pollution will be at their highest.
- Keep away from main roads and busy junctions.
- If you cycle, run or walk to work, try to take the back roads to avoid as much traffic pollution as possible.
- Avoid spending long periods of time near sources of industrial pollution.
- If you have a wood or coal fire, make sure that the room is well ventilated.

#### LIVING WITH BRONCHIECTASIS

If you get your infections treated quickly, and you can cough up mucus, you will probably be able to live with your condition guite normally. Here are a few tips to help you manage living with bronchiectasis.

#### Coming to terms with a diagnosis of bronchiectasis

Living with bronchiectasis and its symptoms such as regular coughing and breathlessness isn't always easy. People can feel frustrated that they can't do some of the things they used to be able to do. Some people become socially isolated because it is difficult for them to get out and about or they feel selfconscious about their cough when they are with other people. All these things can get you down. Feeling down for some of the time is a natural reaction as you adjust to life with bronchiectasis. However, if you feel you are struggling emotionally, it can really help to talk to a family member, a friend or a healthcare professional about how you are feeling.

## Managing a troublesome cough

Constant coughing in public can make you feel self-conscious. However, you can often manage this by planning ahead. For example, make sure you clear your chest thoroughly immediately before you meet others, and take opportunities wherever you can to clear it again.

## Dealing with urine leakage when you cough

Urinary incontinence or leakage of urine occurs in up to half of all women with bronchiectasis.

When you cough, the pressure on your bladder increases suddenly. For many people this is not a problem, but for some people, the combination of a persistent severe cough and weak bladder muscles can mean that urine leaks out from the bladder. Although this can be embarrassing to talk about, speak to your GP, physiotherapist or other member of your healthcare team, as there are a number of things that can help. These include:

- Doing your airway clearance techniques to reduce excessive coughing
- · Losing weight if you are overweight
- Avoiding caffeine-containing drinks (such as tea and coffee) and alcohol
- Learning and doing pelvic-floor exercises

If you find that you are affected by the leakage of urine when you cough, speak to your respiratory physiotherapist.

There are also a number of products you can use such as absorbent pads (specially designed for urine leakage) to give you protection. These are available through your GP or practice nurse. Practical help and advice can also be given by a continence advisor – ask your GP for more information and a referral if appropriate.

## Managing your breathlessness

Learning how to control your breathlessness is an important part of living with bronchiectasis. Learning and practising breathing-control techniques is one of the best ways to control your breathlessness and reduce the feelings of panic and anxiety that often come with it.

Breathing control involves gentle breathing, using as little effort as possible. These techniques are often easier to practice when you are not breathless. With practice you can use breathing control to regain your breath after activity or during an episode of breathlessness.

Examples of breathing control include:

- Relaxed slow breathing. It is always important to breathe at a pace that suits your breathing rate at the time – if you are very breathless it may take time to gradually reduce your breathing to a relaxed slow pace.
- 'Blow as you go', which is when you breathe out during the most effortful part of an activity. For example, if you are getting up from a chair, breathe out as you stand up.
- Pursed-lips breathing, as if whistling but with no sound.
- Paced breathing or using a rhythm that keeps in time with the activity you are doing. For example, when climbing stairs breathe in as you put your foot on the step and breathe out as you push up.

#### Working

Many people with bronchiectasis are able to carry on working without any difficulty. Whether you are able to continue to work will depend on the severity of your bronchiectasis and on the type of job you do.

If you are finding it difficult to continue working as normal because of your bronchiectasis, you should discuss this with your GP, occupational health at your work and your chest consultant. It may be possible to make changes to your current role (for example working fewer hours or working from home more) that would enable you to continue working.

## **Travelling with bronchiectasis**

With proper preparation you should still be able to travel and enjoy going on holiday. Make sure your vaccinations are up to date and speak to your doctor in advance about taking a supply of antibiotics with you in case you get a chest infection. You should also make sure you have adequate insurance cover.

If your bronchiectasis is stable, you should be able to fly without any problems. However, you may need medical clearance to fly if your fitness is in doubt or you need any special service or equipment. This may involve a 'fitness to fly' assessment. If you are not sure whether it is OK for you to fly, contact your airline before travelling.

Practical advice for flying if you have bronchiectasis:

- Have a letter from your doctor with details of your condition and treatment. Keep it in your hand luggage.
- Do your airway clearance techniques before flying and during stopovers on a long-haul flight. You may need to do some additional airway clearance exercises on the plane too.

- Drink plenty of non-alcoholic fluids to loosen your sputum and help keep your chest clear.
- If you use an inhaler, keep it with you in your hand luggage. It is safe to use inhalers when flying.
- The risk of cross-infection from other passengers is minimal because of the air filtration system.
- Try to remain as mobile as possible throughout the flight.

## **Sex and intimacy**

Sex is an important part of life for many people, and this doesn't have to change because you have bronchiectasis. You may be worried about feeling breathless or coughing during sex or that it might make your symptoms worse. Feeling tired, anxious or low can also have an effect on your sex life.

If you have concerns, being open with your partner about how you feel can help put you both at ease. The best thing you can do is make sure you continue to communicate with your partner and stay open-minded about what you can and can't do.

Planning ahead and using ways of coping will give you the confidence to keep sexually active if this is what you and your partner want:

- Try doing your airway clearance techniques before having sex.
- Use breathing control, as you would for any other physical activity.
- Try different positions and avoid positions that might put extra weight on your chest or stomach.
- Choose a time of day when you feel at your most awake and relaxed

Remember there are also other ways to express physical intimacy such as touching, holding hands, kissing and hugging.

#### Contact with friends and family

Contact with friends and family can, and should, continue as usual.

Try to avoid contact with people who you know have a cold or flu, as you will be more likely to develop a chest infection.

If you have a chest infection, it is unlikely that you will pass it on to your family or friends if you take sensible precautions:

- Clear your chest properly before any intimate contact
- Throw away used tissues in the bin
- Wash your hands frequently

#### **HELP AND SUPPORT FROM CHSS**

#### **CHSS** support groups

It can be very helpful to hear how other people with a longterm chest condition cope. To find out if there is a CHSS support group in your area call the Advice Line nurses on 0808 801 0899.

#### **Advice Line**

Call our confidential Advice Line on 0808 801 0899. Staffed by nurses, the Advice Line is open Monday to Friday 9.30am - 4.00pm and provides confidential, independent advice on all aspects of living with a long-term health condition such as bronchiectasis. Whether you need someone to talk to or you are looking for details of local services, the Advice Line nurses will help with any information you or your family needs. All calls are FRFF from landlines and mobiles.

#### **Health Information**

CHSS have a range of booklets and easy-to-read 'essential guides'. To see the full list of guides and other resources and to order, view or download them, go to www.chss.org.uk/ publications or call the Advice Line nurses for more information on 0808 801 0899.

#### **USEFUL RESOURCES**

#### **Chest Heart & Stroke Scotland**

www.chss.org.uk

Tel: 0131 225 6963

Email: adviceline@chss.org.uk

Advice Line nurses: 0808 801 0899 (free number)

(Monday to Friday 9.30am-4pm)

Resources include the self-management website for people with COPD and asthma, My Lungs My Life: www.mylungsmylife.org

#### **Bladder & Bowel Foundation**

www.bladderandbowelfoundation.org

Helpline: 0845 345 0165

Email: info@bladderandbowelfoundation.org

Provides information and support for people with bladder and bowel

disorders.

#### **Bronchiestasis**

www.bronchiectasis.scot.nhs.uk

A patient's guide to managing and living with bronchiectasis.

Includes a self-management plan for people with bronchiectasis.

#### **Cystic Fibrosis Trust**

www.cysticfibrosis.org.uk

Tel: 0300 373 1000 or 020 3795 2184

Email: helpline@cysticfibrosis.org.uk

#### NHS24

www.nhs24.com

Tel: free on: 111

This phone service is designed to help you get the right help from the right people at the right time. The website provides comprehensive up-to-date health information and self-care advice for people in Scotland.

#### Scottish Disability Equality Forum (SDEF)

www.sdef.org.uk

The Scottish Disability Equality Forum (SDEF) works for social inclusion in Scotland.

#### **Quit Your Way Scotland**

www.canstopsmoking.com

Tel: 0800 84 84 84 (8am - 10pm, Mon-Sun)

Quit Your Way Scotland 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.



**Chest Heart & Stroke Scotland welcomes your comments** and feedback on this resource to help us to develop the best information for you and others with bronchiectasis.

If you have any comments regarding this booklet or any of our other publications you can contact us through:



www.chss.org.uk



healthinformation@chss.org.uk



Rosebery House, 9 Haymarket Terrace Edinburgh EH12 5EZ

#### PERSONAL STORIES

We would also like to hear from you if you would like to tell us about your experience of living with bronchiectasis, or of caring for someone with bronchiectasis.



## Advice Line Nurses



For confidential help, support and advice, call our specialist nurses or visit

www.chss.org.uk



Chest Heart & Stroke Scotland (CHSS) is a wholly Scottish charity

## OUR **PUBLICATIONS**

We hope this information has been useful to you.

Our publications are free to anyone in Scotland who needs them

To view, download or order any of our resources, visit **www.chss.org.uk/publications** 

If you'd like more information about our publications, please contact our Health Information team:











**Chest Heart & Stroke Scotland** is a Scottish charity. Our ambition is to make sure that there is no life half lived in Scotland.

After a diagnosis of a chest or heart condition or a stroke, many people experience fear and isolation and struggle with the impact on their lives. **Chest Heart & Stroke Scotland** won't stand for that. The care and support we deliver every day ensures everyone can live the life they want to.

We offer our resources free of charge to anyone in Scotland who needs them. To help us to continue to do this, and to help provide vital services to people in Scotland affected by chest, heart and stroke conditions, you can donate at: www.chss.org.uk/supportus/donations

#### **CONTACT US**

For confidential advice, support and information call the CHSS Advice Line nurses on:
Freephone 0808 801 0899 or email adviceline@chss.org.uk

#### **Head Office**

Chest Heart & Stroke Scotland Rosebery House, 9 Haymarket Terrace, Edinburgh EH12 5EZ Tel: 0131 225 6963 | Open Mon – Fri

www.chss.org.uk

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