

# **Patient Information**

# Bronchiectasis Symptoms, diagnosis and treatment

**Respiratory Department** 



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**Please note:** This booklet does **not** provide information about cystic fibrosis. Where it refers to 'bronchiectasis', it is referring to 'non-cystic fibrosis bronchiectasis'. Information about cystic fibrosis can be obtained from:

#### **Cystic Fibrosis Trust**

One Aldgate, Second floor, London EC3N 1RE

Tel: 0300 373 1000 or 020 3795 2184 Email: helpline@cysticfibrosis.org.uk Website: www.cysticfibrosis.org.uk

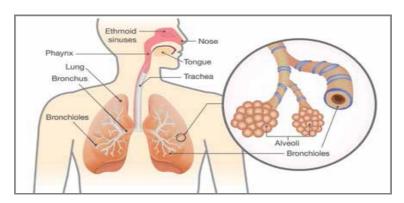
#### Introduction

Bronchiectasis is a long-term lung condition, in which the airways become wider than normal. The main symptom of bronchiectasis is a persistent cough, with lots of sputum (phlegm). People with bronchiectasis are more likely to get frequent chest infections.

This booklet provides information and advice for adults with bronchiectasis and their families, friends and carers. This booklet explains what bronchiectasis is, what the symptoms are, how it is diagnosed and how it is treated. It explains how to recognise a flare-up (exacerbation) of symptoms and what to do if your symptoms suddenly get worse. It also provides advice about what you can do to keep yourself as well as possible, and how to get the most out of living with bronchiectasis.

# How do the lungs work?

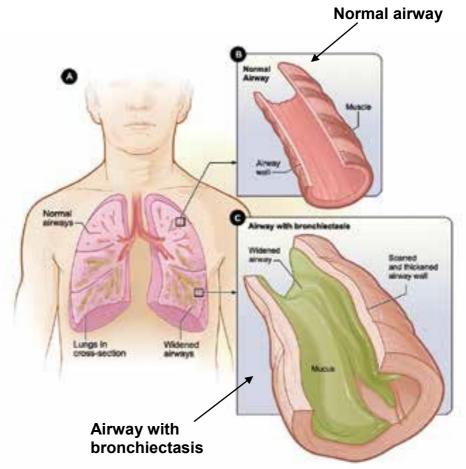
In normal healthy airways, air travels into the lungs through the trachea (windpipe). The trachea divides into smaller and smaller branches, like the branches of a tree, to supply your left and right lungs. These branches eventually end in millions of tiny air sacs called alveoli.



These alveoli are covered in tiny blood vessels so oxygen can be collected into the blood from the air you breath in, and carbon dioxide released from the blood, into the air you breath out. The oxygen is then carried through the blood vessels to the rest of the body.

#### Mucus

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 (dust, pollen and bacteria) and stop them from going deeper into the lungs. Fine hairs (called 'cilia') line the airways and 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 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 can cause further damage to the airways, which in turn causes more mucus to be produced that becomes more difficult to cough up. Once the damage has occurred, it is permanent.

#### Good control early on is important to prevent further damage.

#### What causes bronchiectasis?

In about half of all cases the cause is not found. This is known as idiopathic bronchiectasis. There are some known causes including:

- severe lung infection, especially during childhood, such as pneumonia, whooping cough or measles;
- underlying inherited disease, such as cystic fibrosis, where the mucus in the airways is too thick, or primary ciliary dyskinesia, where the hairs lining the airways do not work properly;
- lack of immunity to infection, i.e. a lack of disease-fighting cells called antibodies:
- severe allergic response to fungus (moulds such as aspergillus),
   which is often associated with asthma;
- gastric reflux, when stomach acid travelling up the food tube from the stomach is breathed in.

Bronchiectasis can also be associated with other diseases, such as ulcerative colitis or rheumatoid arthritis. It is also sometimes linked with chronic obstructive lung disease (COPD), but the two are separate diseases and it is important to correctly diagnose and treat both.

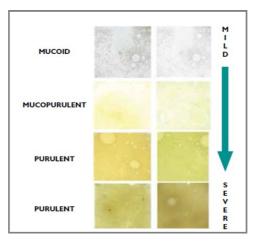
The exact number of people who have bronchiectasis is unknown, but some studies suggest there are at least 30,000 people in the UK with the condition.

# 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 two 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.



Sputum is a frontline defence mechanism of the lungs. It is a sticky substance that traps and destroys unwanted bugs from entering the respiratory system.

Sputum varies in colour and viscosity (thickness) and is different for each patient. It is important to know what your normal is and to monitor it.

Sputum samples are often collected and cultured in a laboratory to look for infection. The results are then sent to your GP or specialist.

# How is bronchiectasis diagnosed?

Getting a diagnosis of bronchiectasis is not always easy and can take some time. Symptoms can be similar to other long-term 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, they will arrange some tests for you. Depending on the results of these, you may be referred to a specialist respiratory 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:

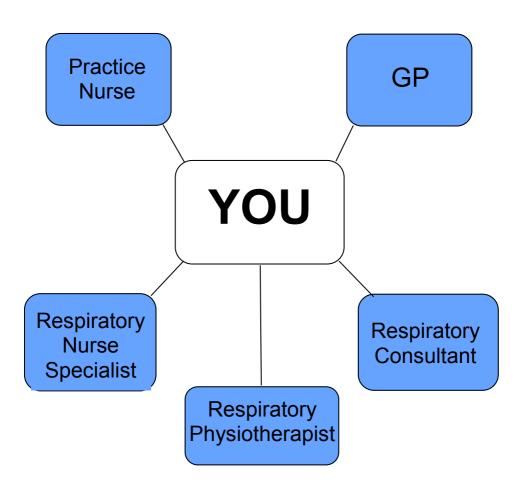
- High-resolution computed tomography (HRCT) scan this is a special type of X-ray that uses computers to make detailed images of your lungs to show if the airways inside your lungs are widened. Widened airways on a CT scan usually confirm bronchiectasis.
- Lung function tests to see how well your lungs 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.

# **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 managed?

Usually, the damage to your airways that causes bronchiectasis can't be reversed, so treatment is to help prevent further damage, infections and reduce your symptoms. The cause of your bronchiectasis, if it can be found out, should also be treated.

If you get an infection, it is treated with antibiotics. Some people who get a lot of infections take continuous antibiotics, either in tablet form or by inhaling them through a nebuliser. It is important that you see your GP if you think you have a chest infection so it can be treated quickly.

Your doctor should refer you to a respiratory physiotherapist, who will teach you various breathing exercises and techniques to help clear sputum from your lungs. It is essential that you continue to do this yourself regularly.

You may find your symptoms are reduced if you use an inhaler to open up your airways. There are different types of inhalers, including bronchodilators and steroid inhalers.

Some people use treatments to help remove mucus from their airways; these are sometimes called mucus clearance agents. They include hypertonic saline, a salt water solution that can be inhaled into the lungs through a nebuliser and keeps the airways hydrated, and carbocisteine, which makes mucus thinner and less sticky so it is easier to cough up.

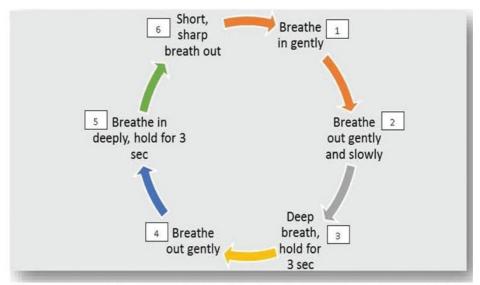
Very occasionally, in cases where bronchiectasis occurs in a single section of the lung, the damaged areas can be removed with surgery. This is only recommended in a very small number of cases when other treatments have not been successful.

# Airway clearance

It is important to clear as much sputum from your airways as you can. You should be referred to a respiratory physiotherapist who will teach you **airway clearance techniques** to help clear the mucus. Once taught you should continue to do these exercises regularly to prevent sputum building up and reduce your risk of getting a chest infection.

There are different techniques that can be used for airway clearance. These include:

- Positioning (also known as postural drainage) changing your position, which can make it easier to remove mucus from your lungs.
- The use of hand held devices to help with airway clearance.
   Generally, these use a combination of vibrations and air pressure to make it easier to cough out any mucus.
- Active cycle of breathing (see below)



Phase 1: Steps 1 and 2. Repeated for 4-6 breaths, Phase 2: Steps 3 and 4. Repeated for 4-6 breaths, Phase 3: Steps 5 and 6. Repeated for 4-6 breaths

# **Pulmonary rehabilitation**

Pulmonary rehabilitation is a structured programme of physical activity and education specifically designed for people with long-term lung 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.

Pulmonary rehabilitation courses usually last for 6 - 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.

# What can I do to keep myself well?

Unfortunately, there is no cure for bronchiectasis. However, there are things that can be done to manage it and for you to continue to live an active life:

- Monitor symptoms and follow your personalised management plan
- Stop smoking
- Keep as active as you can
- Eat healthily and keep hydrated
- · Avoid air pollution
- Attend pulmonary rehabilitation
- Do regular airway clearance techniques
- · Have the 'flu vaccine each year
- Pneumococcal vaccine this is usually a single one-off injection

# **Avoiding air pollution**

Air pollution can be particularly harmful to people with a long-term lung condition like bronchiectasis. High levels of pollutants can irritate your lungs and cause breathlessness and cough, and make exacerbations more likely.

### **Examples of air pollutants include:**

- Traffic pollution
- Wood or coal smoke
- Industrial pollution, i.e. 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
- Avoid main roads and busy junctions where possible
- If you cycle, run or walk to work, try to take the back roads to avoid traffic pollution
- Levels of air pollution on busy roads are higher inside cars than outside, so it's still better to walk than drive if you can
- 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

For information regarding areas that may have higher levels of pollution, please visit the government website:

https://uk-air.defra.gov.uk

#### What is an exacerbation?

An exacerbation is a flare-up of your condition when a worsening of symptoms is experienced. You could have one or more of the following symptoms:

- Getting more breathless
- More coughing
- Increase in sputum volume/quantity
- Increased thickness of sputum
- Change in sputum colour
- Generally unwell
- More fired
- Fever

# If you have any of these symptoms contact your GP and follow your personalised management plan.

- Start standby medication as prescribed
- Take a sputum sample to the doctors so they can find out what bacteria (if any) is causing the infection. You will need a sterile pot which can be obtained from your GP
- If your symptoms do not begin to improve after 48 hours of starting the antibiotics or you are feeling worse, contact your GP for further advice

# You can help manage a flare-up by:

- Increasing the use of your bronchodilator
- Use airway clearance techniques more often
- Rest
- Stay hydrated

# Living with bronchiectasis

If infections are treated promptly and you can cough up sputum, you will probably be able to live with your condition quite normally.

### Coming to terms with a diagnosis of bronchiectasis

Living with bronchiectasis and its symptoms, such as regular coughing and breathlessness, isn't always easy. It can feel frustrating if you can't do some of the things you used to be able to do. Some people become socially isolated because it's difficult for them to get out and about or they feel self-conscious 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.



The Wellbeing Team can help you work out how to feel better...

www.hpft.nhs.uk/wellbeing-service

Call: 0300 777 0707



to your GP today to see if the NHS Wellbeing Team could help you

The Wellbeing Service - offering free and confidential support to people over 16 years and registered with a GP in Hertfordshire.

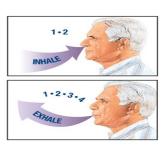
# **Managing your breathlessness**

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 and, 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 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' This 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.

# **Urinary incontinence**

Urinary incontinence is the unintentional passing of urine. It's a common problem thought to affect millions of people, and occurs in up to half of all women with bronchiectasis. It is due to the pressure on the bladder increasing suddenly when coughing.

This isn't a problem for everyone but for some people the combination of a persistent severe cough and weak pelvic floor muscles can mean that urine leaks out from the bladder.

Some find incontinence embarrassing to talk about but do speak to your GP, physiotherapist or other member of your healthcare team about it. This could be the first step towards finding a way to effectively manage the problem as there are a number of things that can help. These include:

- Using your airway clearance techniques to reduce excessive coughing.
- Maintaining a healthy weight.
- Avoiding tea and coffee (including decaffeinated) try herbal tea instead.
- Avoid alcohol and fizzy drinks.
- Learn and do regular pelvic floor exercises. The pelvic floor muscles support the bladder and give you control when you urinate.

#### Sex and breathlessness

Living with a lung condition that leaves you breathless can get in the way of sex and relationships. Sex is an important part of life for many people, and this doesn't have to change for you and your partner because you have a lung condition. Here are some suggestions to try to help you enjoy a normal love life:

- Have sex when you feel rested and your breathing feels most comfortable. If you're feeling tired or stressed this could make your breathing worse.
- You might want to try clearing your chest before you have sex, or avoid having sex in the morning when many people are more likely to produce and cough up sputum.
- Taking one or two puffs of your salbutamol prior to sexual activity may relieve shortness of breath. Keep it to hand in case you need to use it again.
- Try positions that require less energy for you. The main thing is to avoid positions that put pressure on the chest.
- If you get short of breath, have a break to pause and take some slow deep breaths - use your breathing techniques.

For more information visit the British Lung Foundation website: www.blf.org.uk/support-for-you/sex-and-breathlessness

Please also feel free to discuss this with your specialist nurse or doctor as well.

# Working

Most people with bronchiectasis are able to continue working without any problems.

If you are finding it difficult to continue working as normal due to your bronchiectasis talk to your GP, your respiratory consultant and your occupational health department at your work. Alterations to your working hours or role may be possible to allow you to continue working.

# **Travelling**

With preparation, you should still be able to travel as normal. Ensure your vaccinations are up-to-date and speak to your GP in advance about taking a supply of antibiotics with you in case you get a chest infection. You should also make sure you have appropriate travel insurance.

If your bronchiectasis is stable you should be able to fly without any problems. However, you may need clearance to fly if your fitness is in doubt or if you need a special service or equipment. This may involve a 'flight assessment'. If you are unsure, talk to your doctor and airline before travelling.

# Practical advice for travelling:

- Have a letter from your doctor with details of your condition and treatment. Keep this in your hand luggage.
- Take your medication rescue pack with you.
- Do your airway clearance techniques before flying and during stopovers on long haul flights.
- Keep hydrated.
- If you have an inhaler make sure it is easy to get to. Inhalers are safe to use when flying.

# Further help and information



# British Lung Foundation Helpline **2** 03000 030 555 Monday to Friday, 9am - 5pm.

www.blf.org.uk

# **Breathe Easy Support Group**



To find your nearest support group contact the British Lung Foundation on the number above

**Bronchiectasis help** - provides education and self-help.

www.bronchiectasishelp.org.uk

**NHS Choices** - NHS website providing further information.

www.nhs.uk/conditions/Bronchiectasis

# **Hertfordshire Wellbeing Service**

NHS service offers free and confidential talking therapy and practical support for Hertfordshire residents experiencing a wide range of mental health problems, such as worry, low mood, insomnia and stress.

www.hpft.nhs.uk/services/community-services/wellbeing-service



# **Hertfordshire Stop Smoking Service**

You can refer yourself to the service

23 0800 389 3998 or



Or go online: www.hertsdirect.org/stopsmoking

**UK-AIR: Air Information Resource** - Pollution forecast provided by the Met Office.

https://uk-air.defra.gov.uk

# **Useful telephone numbers**

For support and advice you can contact the Respiratory nurse team at the Lister Hospital:

#### **23** 01438 285621

Monday to Friday, 9am - 5pm

#### NHS 111 service - 23 111

111 is the NHS non-emergency number.

NHS 111 is available 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones.

Call 111 and speak to a highly trained adviser, supported by healthcare professionals. They will ask you a series of questions to assess your symptoms and immediately direct you to the best medical care for you.

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www.enherts-tr.nhs.uk

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