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LUNG UK

LIVING WITH BRONCHIECTASIS

Contents

This booklet is about bronchiectasis in adults. It covers what bronchiectasis is, what the symptoms are, and how it is diagnosed and treated.

Bronchiectasis is a long-term condition. If you have bronchiectasis, your airways are wider and inflamed, with thick mucus that gets trapped and is likely to get infected. Treatments help to reduce these infections, and keep you well. There are also lots of ways you can manage this condition yourself. You'll find tips about how you can look after yourself and deal with flare-ups in this booklet.

Remember, you are not alone: you and your health care team together can find ways to control your symptoms and manage your condition.

This information is for you, your family and carers. It's based on research that explored what information people living with bronchiectasis wanted. Health care professionals, people living with bronchiectasis and their families have worked together to develop it.

What is bronchiectasis?

Bronchiectasis is a long-term condition that affects the airways in your lungs.

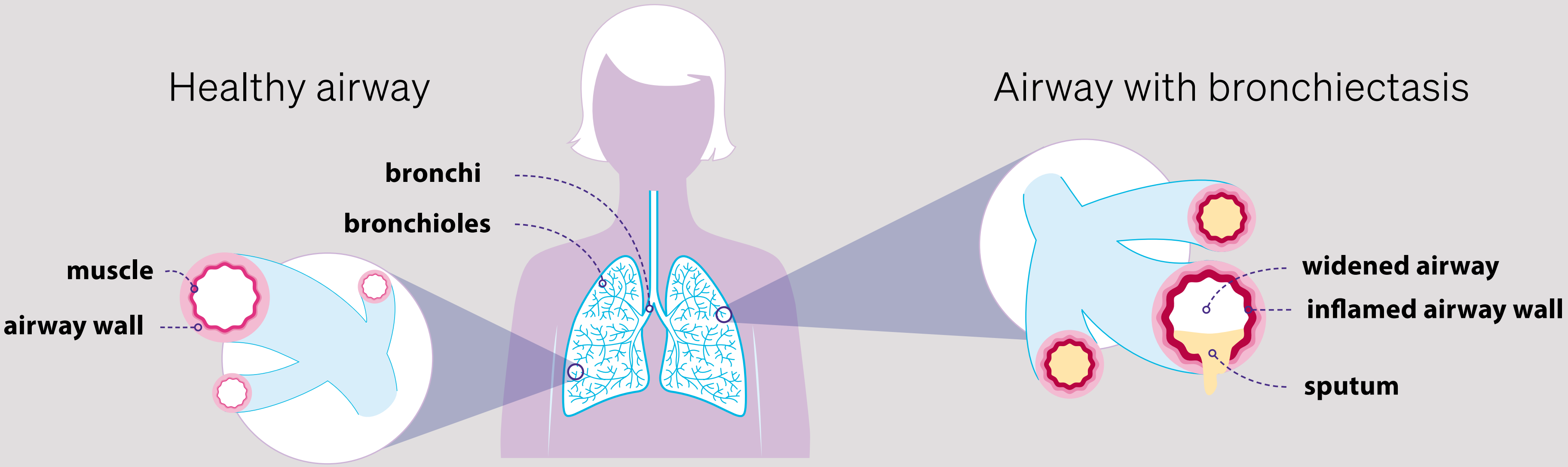
When you breathe, air is carried into your lungs through your airways, also called bronchi. The bronchi divide again and again into thousands of smaller airways called bronchioles. Your airways contain tiny glands that produce a small amount of mucus. Mucus helps to keep your airways moist, and traps the dust and germs that you breathe in. The mucus is moved away by tiny hairs, called cilia, which line your airways.

If you have bronchiectasis, your airways are widened and inflamed with thick mucus, also called phlegm or sputum. Your airways may not clear themselves properly.

This means mucus builds up and your airways can become infected by bacteria. Pockets in the airways mean that mucus gets trapped and is likely to get infected.

Sometimes, if the number of bacteria multiply, you'll get a chest infection or a flare-up of your symptoms. It's important to recognise and treat chest infections. If you don't get treatment, your airways may be damaged further. The changes to your airways can't be reversed, but there are ways you and your health care team can treat and manage bronchiectasis.

Bronchiectasis is sometimes called **non-cystic fibrosis bronchiectasis**. This is because **there is a different condition called cystic fibrosis**. People who have cystic fibrosis can have lung symptoms similar to those of bronchiectasis, but the treatments and outlook are different.



What are the symptoms of bronchiectasis?

Symptoms vary between people. You may have one or two on the list below, or you may have most of them.

The most common symptom is a **long-term cough, usually coughing up sputum**, sometimes called phlegm. The amount varies. For people with more severe bronchiectasis it can be quite large amounts, for example an egg cup full or more every day. Some people might have a dry cough or very little sputum.

Frequent chest infections are also a common feature of bronchiectasis.

Other symptoms you might have are:

- feeling very tired or finding it difficult to concentrate
- breathlessness: having difficulty breathing or feeling short of breath
- problems with your sinuses
- cough incontinence, also called bladder leakage
- anxiety or depression

Less common symptoms include:

- coughing up blood
- chest pain

Why have I got bronchiectasis?

For up to half of people diagnosed with bronchiectasis, there’s no clear underlying cause. This is called idiopathic bronchiectasis.

Some illnesses linked to bronchiectasis include:

- having had a severe lung infection such as pneumonia, whooping cough or tuberculosis (TB) in the past, for example when you were a child
- inflammatory bowel disease, also called ulcerative colitis and Crohn’s disease
- immune system deficiencies
- some types of arthritis, such as rheumatoid arthritis
- a problem with the normal structure or function of your lungs, such as primary ciliary dyskinesia

Other causes include:

- a severe allergic response to fungus or moulds such as Aspergillus
- gastric reflux
- a blockage of your airways, caused by breathing in a small item, such as a nut
- asthma, chronic obstructive pulmonary disease (COPD) or sarcoidosis

How is bronchiectasis diagnosed?

You doctor will ask lots of questions about you, your medical history and your symptoms. If your doctor suspects you may have bronchiectasis, you will be referred to a respiratory consultant.

You will have some tests, which are likely to include:

- a chest X-ray
- a computerised tomography (CT) scan. A CT scan uses a special X-ray machine to look at your lungs in more detail
- tests on your sputum to find out if any bacteria are in it
- blood tests
- lung function tests

In some circumstances, your health care professional might suggest a bronchoscopy – using a camera in a narrow tube – to look inside your lungs and take samples.

Sometimes you'll have further tests, including genetic blood tests, to try to find out why you've developed bronchiectasis.

Getting a diagnosis of bronchiectasis affects people differently. You might feel disbelief, worry or even relief at getting an explanation for your symptoms. Remember you are not alone, you will get help.

> **"I was shocked but sort of glad in a way, because it explained why I hadn't been well for so long."**
>
> Tom

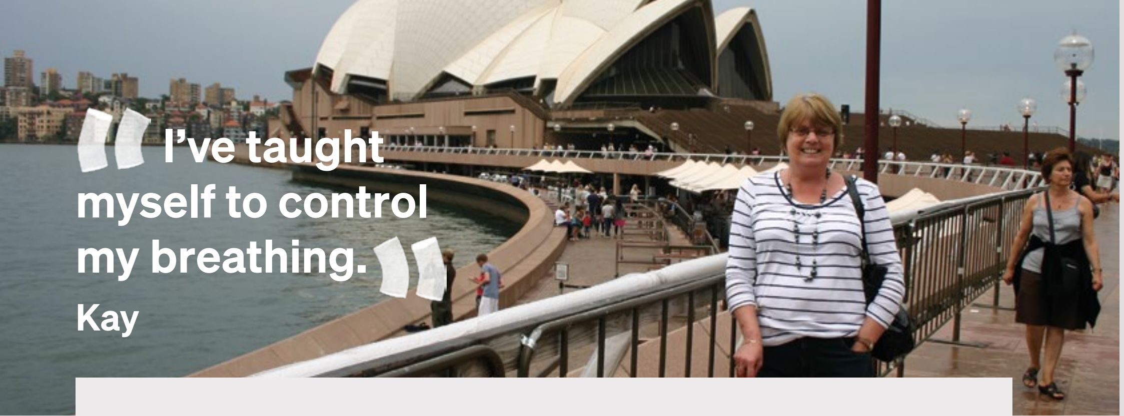
What is the outlook?

Bronchiectasis is a long-term condition. When you have bronchiectasis you may have repeated chest infections. Medical and physiotherapy treatments aim to reduce the number and severity of these infections. These include airway clearance (clearing the mucus from your lungs using breathing exercises) and physiotherapy. Some people seem to be at risk of either more severe infections or more frequent infections. Scoring systems for bronchiectasis can help your doctor to identify if you're at higher risk and may need more treatments.

Most people diagnosed with bronchiectasis have a normal life expectancy with treatment tailored to their needs. Some adults with bronchiectasis developed symptoms when they were children and live with bronchiectasis for many years. Some people, who have very severe bronchiectasis, may have a shorter life expectancy.

We know people often worry about the outlook, so talk to your health care professional. You can ask them any questions you may have. Some people find it helpful to make a list. Remember – lots of people manage very well living with bronchiectasis.

> **"I had to think to myself 'I'm going to do the best that I can with it' you know, 'if these people can live with it, I can live with it'... and that really helped me to come to terms with it... you've got to help yourself... it's not the end of the world."**
>
> Celia



“I’ve taught myself to control my breathing.”

Kay

When I was four, I got whooping cough. No one explained the consequences to me. But afterwards, my mum did exercises with me to drain my chest every day.

When I was eight, I went to an open air school. Twice a day I did postural draining exercises so I could cough up sputum. I cried – the nurse wasn’t gentle.

When I left school, I stopped the exercises. Fifteen years later, I nearly died from pneumonia. This was a wake-up call.

I learned how to exercise to strengthen my breathing muscles and expand my chest. My husband and I became keen walkers. It took me a bit longer than most people – but I got up to Lanty’s Tarn on Helvellyn.

When I get an infection, I can end up in hospital on intravenous antibiotics. I can’t shake bugs off.

It doesn’t stop me. I was president of my local Women’s Institute for three years, took an Open University course, and flew to Australia to meet my grandson.

My condition has got me down at times. But I feel in control. That’s down to a lifetime of exercising and taking my medication.

Whatever age you develop bronchiectasis, don’t give up! There’s always new medication and treatments get better.

What treatments work?

Treatment aims to prevent further damage and infections in your lungs and reduce your symptoms. You’ll be given:

- **a personalised self-management plan** to help you control your symptoms
- **airway clearance techniques** (breathing exercises) to clear your sputum. Doing these regularly will reduce the number of infections you get and keep you well
- **treatment with antibiotics for flare-ups or chest infections**
- **annual flu vaccinations**
- **treatment for other conditions causing your bronchiectasis** – for example problems with your immune system.

Bronchiectasis treatment involves getting to know your body and what’s right for you. Make sure you agree a written self-management plan with your health care professional. This will help you manage your symptoms.

Antibiotics

If you get a chest infection or have a flare-up, you'll take a course of antibiotics, often for 14 days. It is important to take your antibiotics as directed. This includes completing the full course.

The antibiotics used vary depending on which bacteria are in your sputum. So it is very important to give a sputum sample at least once a year, even if you are well, and when you notice things changing. You'll start antibiotics without having to wait for the results.

The choice of antibiotics will be guided by what bacteria you had in the past or which antibiotics worked best for you. If analysis of your sputum shows new bacteria or bacteria that will not be treated by the antibiotics you've started, your doctor may prescribe another one.

People who have bronchiectasis sometimes have different bacteria in their sputum that can be more difficult to clear, such as Pseudomonas aeruginosa and non-tuberculous mycobacterium (NTM). If this is the case for you, your doctor will discuss the treatment options, which may include inhaled antibiotics.

You'll sometimes be given antibiotics into a vein in your arm. This may be done in hospital, or you can learn how to do this at home.

You may be offered long-term antibiotics, either as tablets or inhaled through a nebuliser, if you have:

- three or more infections a year, and
- recently been reviewed by a specialist physiotherapist to make sure your sputum is being cleared from your lungs as well as possible.

Clearing your sputum

Clearing sputum from your lungs is very important and can reduce the number of infections you have and reduce your cough.

Ask to see a respiratory physiotherapist.

They'll discuss ways you can remove sputum from your lungs and find airway clearance techniques that suit you.

Your physiotherapist will recommend how often, and when, to do them. They'll usually recommend a routine for when you are well, and changes to make when you're unwell. Some physiotherapy techniques work best when timed with your medications.

Tip: Try to keep hydrated and drink plenty of water.

Techniques include moving into positions so gravity helps sputum drain out of your airways and lungs. The physiotherapist might tap your chest to loosen the sputum and to help it start to move. Some people find it helps to blow into a small device to clear their chest.

Examples are the Acapella and Aerobica flutter valves and the positive expiratory pressure (PEP) valve. These devices aren't always available on the NHS. Talk to a health care professional before you buy one – or you might end up with something that isn't right for you.

Your physiotherapist can tell you about the active cycle of breathing techniques to do daily at home. They include:

- **breathing control** – breathing gently, through your nose if you can. Keep your shoulders relaxed.
- **deep breathing** – taking a long, slow, deep breath in through your nose, if possible, holding your breath for two or three seconds and breathing out gently, like a sigh
- **huffing** – breathing out through an open mouth instead of coughing. To huff, you squeeze air quickly from your lungs, out through your mouth and throat as if you're trying to mist a mirror

If your sputum is sticky and hard to cough up or if you have more than three flare-ups in a year, your health care professional may suggest:

- a check-up with a respiratory therapist
- a mucolytic, a drug to break up the sputum and make it easier to clear from your lungs
- a nebuliser to breathe in a salt solution called saline. This may help if you have frequent infections and find it difficult to clear sputum from your lungs by physiotherapy. The salt water helps break up the sputum and makes it easier to cough up

How to cope with breathlessness

Some people don't get short of breath at all, for others it's the main symptom. Becoming more breathless can be a sign of a chest infection. Over time you'll learn what level of breathlessness is normal for you. Feeling out of breath can be frightening – get medical help if you're concerned about a change in your level of breathlessness.

If you do get breathless, pacing your activities can really help. Talk to your physiotherapist about this.

It might be daunting, but exercise can help with breathlessness too. Muscles that are stronger use oxygen more efficiently so your lungs have to work less hard when you're active.

Help to stop smoking

If you smoke, stopping is very important. The NHS offers a free stop smoking service – your GP can refer you. Find out more at **blf.org.uk/smoking**

If you get breathless, ask your health care professional about attending a breathlessness management class called pulmonary rehabilitation or PR.

PR is a six to eight week course led by a qualified respiratory professional that covers:

- a physical exercise programme designed for people living with lung conditions and tailored to you
- looking after your body and lungs, managing your condition and coping with feeling short of breath

Reducing bladder leakage or cough incontinence

Living with a long-term cough puts extra pressure on your bladder, bowel and pelvic floor muscles. Many people living with bronchiectasis tell us they have problems with stress incontinence – leaking urine (and rarely faeces) during forceful movements such as when they're coughing or laughing. Evidence suggests doing pelvic floor muscle exercises is an effective treatment.

Don't be embarrassed if you have problems with your bladder or bowel. Discuss this with your health care professional as soon as you can – they're used to helping. They can give you exercises and refer you to a specialist, who can help with training in exercises to strengthen your pelvic floor muscles and other techniques.

Vaccinations

Make sure you get your flu jab every year. The NHS offers it for free to people living with long-term conditions like bronchiectasis. Your doctor should also offer you a vaccination against pneumococcal infection – a bacterial infection that can cause pneumonia and other illnesses. You only need to have this once.

If you have bronchiectasis, you may find that if you are around people who have colds or chest infections, you're more likely to get unwell. If you do get signs of an infection, make sure you treat it quickly. There is more on page 18.

Other treatments

Surgery

Today, surgery in bronchiectasis is quite rare, as it helps only a few people. It's sometimes considered for people who have bronchiectasis in a limited area of one lung and have not responded to other treatments.

Embolisation

If you cough up blood, you may have a scan called bronchial angiography to look at the blood vessels in your lungs.
If this shows blood vessels cause bleeding, a procedure called embolisation can block off the blood vessels causing the trouble.

Lung transplantation

Lung transplantation is rarely needed in bronchiectasis. It's for people who have very severe lung disease and no other treatment options.

Oxygen

Your oxygen saturation levels will be checked as part of your breathing tests. Most people with bronchiectasis do not require oxygen.

Vitamin D

There is some evidence that people with bronchiectasis can have insufficient levels of vitamin D, needed for healthy bones, teeth and muscles. Your health care professional might test your vitamin D levels, especially as current government advice is that adults should have 10 micrograms of vitamin D every day.

Check-ups: Make sure you review your treatment with your health care professional at least once a year. You'll give some sputum for analysis and review how often you have flare-ups.

Coping with flare-ups

Being able to spot a change in your lung health early means you can get treatment sooner to prevent a severe flare-up.

The signs to look out for are when, **for more than 48 hours or two days**, you:

- feel unwell
- cough up more sputum
- have a change in the colour of your sputum
- are more breathless

Agree a plan with your doctor about what to do.

When you spot signs of a flare-up:

- clear your chest more often – at least twice daily
- take your regular medication as usual
- drink plenty of fluids
- collect a sputum sample and give it to your GP or hospital as soon as you can. If you can't hand it in that day, store the sample in your fridge overnight.
- contact your GP or health care team for advice – you may need to start antibiotics
- sometimes your GP may issue an emergency pack of antibiotics for you to keep at home. This is in case you need to start antibiotics at a time when you can't contact your doctor, for example when you're on holiday.

“I feel in control because I have a personal plan.”

Lynn

After 18 months of chest infections, I was diagnosed with bronchiectasis. When I realised it was a long-term condition that would progress, I grieved for the life I had imagined. To deal with the diagnosis, I learned all about bronchiectasis and how I could help myself.

Twice a day, I clear my chest, even if I feel well – mostly by huffing and nebulising with saline. At pulmonary rehab I learned how to clear my chest and devices that could help.

I walk a lot and have an exercise bike. But I listen to my body about when to push myself and when to rest. I still work full-time, flexibly. My employer has been great and has listened to my ideas about how I can continue to work and keep well, like working from home in ‘flu season.

Every six months, my mucus turns a dark yellowy green. That's the start of a flare-up: my breathing gets worse and I cough up more sputum. I nebulise with inhaled antibiotics and have emergency antibiotics and steroids at home. As I also have Pseudomonas, I send a sample in straightaway in case I need another type of oral antibiotic.

I feel in control because I have taken control and have a personal treatment plan.

What can I do?

You know your body better than anyone else, so you're key in managing your condition. Over time, you'll recognise what is normal for you and the start of a flare-up.

Being able to work in partnership with your health care team is important. Agree a personalised self-management plan with them, to cover:

- keeping your chest clear as advised by your physiotherapist
- being active and exercising so you keep fit
- drinking plenty of fluids and eating healthily
- thinking about avoiding contact with people who are unwell with a cold, flu or chest infection
- if you smoke, stopping smoking
- avoiding air pollution as much as possible
- knowing how much sputum you normally have and its colour. You might like to keep a diary of your symptoms (see next page)
- taking your medicines as prescribed and not allowing them to run out
- agreeing a flare-up plan with your health care professional, and keeping stand-by antibiotics at home
- submitting a sputum sample at least once a year or at every hospital appointment
- getting a flu jab every year
- having an annual check with your health care professional

Symptom diary

My usual symptoms are:

Cough

☐ I normally cough most days of the week
☐ I normally cough one or two days of the week
☐ I normally cough a few days a month
☐ I normally cough only when I have a chest infection
☐ my cough is dry
☐ my cough is wet
☐ my cough is both dry and wet

Sputum

☐ I normally cough up sputum most days of the week
☐ I normally cough up sputum one or two days of the week
☐ I normally cough up sputum a few days of the month
☐ I normally cough up sputum only when I have a chest infection

My sputum is

☐ clear ☐ white ☐ light yellow or green
☐ dark yellow or green ☐ brown

I cough up this amount of sputum in a day

☐ 1 teaspoon ☐ 1 tablespoon ☐ half an egg cup ☐ 1 egg cup

My sputum is

☐ thin and easy to clear ☐ thick, sticky and hard to clear

I get breathless when

☐ I walk around my home
☐ I walk outside on the level
☐ I walk up a slope or a flight of stairs
☐ I exercise or play sport
☐ I only get breathless when I have a chest infection
☐ I never get breathless

My other usual symptoms are

☐ wheezing ☐ fatigue ☐ tiredness other . . . .

Exercise

Any form of exercise that makes you a little breathless, such as walking and swimming will help you. It can help to clear your chest and improve your overall fitness. A respiratory physiotherapist can help you to find the right exercise for you and also advise you on managing any breathlessness, pacing yourself and conserving energy. Pulmonary rehabilitation can also help, see page 15.

Eat healthily

What you eat is also important. A balanced and varied diet can help you maintain your strength and fitness. If your body is well nourished, you'll be more able to fight infections. For some people with bronchiectasis, energy requirements from food will be higher.

Food is the fuel used by your body for all its activities and functioning, including breathing.

- If you are overweight, your heart and lungs have to work harder to supply you with oxygen.
- If you are underweight, you may be more at risk of infections.

The eatwell guide is a useful way to check your diet is healthy and balanced. Visit **blf.org.uk/eating-well**. Ask to see a dietician who can help you with a specific plan to meet your individual needs.

Emotions and enjoying life

The impact of living with a long-term condition like bronchiectasis can vary from person to person. It can also vary over time – you may have times when you have few symptoms, and times when your symptoms are more troublesome.

Research with people who have bronchiectasis and their families found that living with the condition has emotional and physical impacts.

Remember that you are not alone: there are lots of others who have similar feelings. Don't bottle things up – talking to a friend, relative or health care professional can help. It helps to stay active and sociable, and to learn about bronchiectasis to help you understand and manage your condition.

> **“Mine fortunately is mild… generally I'm feeling so well that it hasn't made any impact on me, but I think it has had an emotional impact on me, to find that there is something wrong.”**
>
> Julie

You can get support from your family and friends, other patients, your health care team, or even information resources.

Our support groups support people living with a lung condition and their families. To find your local group, visit **blf.org.uk/breathe-easy** or call our helpline. You could also join our web community at **healthunlocked.com/asthmalunguk-lung** where you can talk to others in similar situations.

> **“My experience has been greatly helped over the last two or three years, or two years, since I've met the bronchiectasis nurse… He personally has helped me a lot, both psychologically and obviously as a patient.”**
>
> Chris

Carers and families

If you support someone who could not manage without this help, then you are a carer. Not everyone thinks of themselves as a carer – you might feel you're doing what anyone else would do to look after their loved ones.

People with bronchiectasis may not have any care needs at all. Caring for someone with bronchiectasis will vary depending on their specific needs, but at times being a carer can be tough, physically and emotionally.

Things you may be able to help with include medications such as nebulisers which require washing after every use, or sometimes taking antibiotics intravenously at home.

You may also provide practical support with things that are now difficult to do alone, or simply emotional support. You may find that you can help with self-management. For example, you may be the first one to recognise signs of a chest infection.

If you are a carer, having support from family members, friends and also the health care team is essential. You may be entitled to financial or other support. Call our friendly helpline team on **0300 222 5800** to find out more.

Information and support

Our friendly helpline team on **0300 222 5800** are ready to answer your questions. For example, if you live with bronchiectasis, or care for someone who does, you may be entitled to welfare benefits to help you live with a long-term condition. We can also put you in touch with your local support group. Our team can tell you more.

Online

There's more information about bronchiectasis including videos of people living with bronchiectasis at **www.bronchiectasis.me**

Find out more about breathing techniques from the Association of Chartered Physiotherapists in Respiratory Care at **www.acprc.org.uk/publications/patient-information-leaflets**

For advice on the bladder and bowels, go to **www.bladderandbowelfoundation.org**

Our website

We have more information about bronchiectasis and living with a lung condition at **blf.org.uk/support-for-you**:

- keeping active and pulmonary rehabilitation
- eating well with a lung condition
- breathlessness and how to manage it
- sex and breathlessness

Get help

Call our helpline on **0300 222 5800**

We are here to help if you want:

- answers to your questions – whether it's about coping with symptoms, your rights or finding equipment
- clear and trustworthy information about breathing problems and living with a lung condition
- to get in touch with your local support group

Our friendly team are here Monday to Friday 9am to 5pm. Ringing will cost the same as a local call. It's usually free, depending on your call package, even from a mobile.

Or visit **AsthmaAndLung.org.uk** to find support and information or to join our web community

■ get support and information	**blf.org.uk/support-for-you**
■ sign up to our newsletter	**blf.org.uk/signup**
■ find your local Breathe Easy group	**blf.org.uk/breathe-easy**
■ join our web community	**healthunlocked.com/ asthmalunguk-lung**

Help others like you

You can help us to fund more research to find cures and new treatments, and make sure everyone has the support they need. We're the only UK charity looking after the nation's lungs, and we rely on your donations. Visit **AsthmaAndLung.org.uk** or call **0300 222 5800**.

Together we fight for lung health

Helpline: **0300 222 5800**

AsthmaAndLung.org.uk

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