



# Bronchiectasis self-care guide



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The European Bronchiectasis Registry



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# 1

# Introduction

This guide has been written by people with bronchiectasis to help people like you, who also have bronchiectasis, by sharing our experience of what works for us.

We know bronchiectasis is not curable but many of us live active and enjoyable lives by doing our own physiotherapy, exercising, eating healthily, staying vigilant of infection risks, and following medical advice on treatment.

Symptoms vary between individuals and could be mild, moderate or severe, but by taking an active role in looking after our own health we all hope to make our lives the best that they can be.

**ELF Bronchiectasis Patient Advisory Group**

# 2

## What is bronchiectasis and what symptoms can I expect?

Your airways are lined by a layer of sticky mucus. This is called sputum when it is coughed up. Bronchiectasis is a long-term (chronic) lung condition where your airways are abnormally widened and less effective at clearing this mucus.

It makes you more vulnerable to lung infections which can cause:

- a productive cough (a cough where you clear mucus)
- aches
- fever
- breathlessness
- tiredness
- chest tightness or pain
- blood in your sputum

Your most important task, as someone with bronchiectasis, is to lower your risk of infections, mainly by clearing as much mucus as you can, every day.

This will also help reduce flare-ups (sometimes called exacerbations), when your symptoms become more intense.

You can do a lot to improve your own condition with a combination of self-care and medical treatment.



# 3 What can I do about it?

First, if possible, see a specialist respiratory doctor and work out a treatment plan with them. Make sure you discuss:

- what to do if you get an infection, or a flare-up/exacerbation — and how to assess when you need medical help
- most importantly, ask them to refer you to a respiratory physiotherapist.

After medical treatment, this is where self-care takes over – accepting that you need to be active in caring for your own condition.

Self-care includes:

- Chest clearance — this is the top priority, getting rid of the mucus so it has less chance to breed infections.
  - The main method is **physiotherapy** using an **Airway Clearance Technique** (more on this later). A respiratory physiotherapist will teach you the best technique for your personal condition, then you can manage it by yourself.
  - Your physiotherapist may also recommend a plastic device known as an **oscillating positive expiratory pressure (O-PEP)** device. An O-PEP vibrates when you blow into it, which helps loosen the mucus (more on these later).
  - You could also ask your doctor about salt-water (saline) inhalation through a **nebulizer** — this is a machine that turns it into a fine mist that you breathe in through a mouthpiece or facemask. It loosens the mucus and makes you cough.
- Keeping as physically fit as you can by finding an exercise routine you enjoy and is appropriate to your physical condition. This might be dancing, jogging, lifting weights, whatever works for you — do it daily if possible.

A guide to what to ask about when you see your doctor can be found in the **Bronchiectasis Patient Checklist**.

Available at  
<https://www.europeanlunginfo.org/bronchiectasis/treatment/>

- Eating a healthy, balanced diet and keeping well-hydrated to help thin the mucus.
- Maintaining personal hygiene to avoid getting sick — this includes frequent hand-washing, hand-sanitisers, using face-masks in crowded places, avoiding people who are unwell. Oral health (toothbrushing) is also important, and some people use nasal rinse kits. These all help to reduce infection-risk.
- Getting the vaccinations recommended by your doctor, such as against flu and pneumonia — they can help prevent or lessen the severity of an infection.
- Protecting yourself from temperature extremes. Both hot and cold weather can worsen your symptoms.
  - In **winter**, viruses and bugs that thrive in the cold can increase your vulnerability. When it is freezing, keep warm indoors. And when outdoors keep your nose warm with a clean facemask or scarf so you breath warm air. Do not go out in extreme cold.
  - In **summer** the main thing is to avoid dehydration. Drink frequently (not alcohol), cool yourself down with ice-packs and fans, eat smaller, cooler meals and do your physical activities in the cooler part of the day. In public buildings or transport avoid staying too long in air-conditioned spaces that circulate air and may make it more likely to pick up an infection.
- Planning ahead when travelling. There is travel advice on the ELF bronchiectasis website at <https://europeanlunginfo.org/bronchiectasis/self-management/>
- Keeping other long-term conditions, if you have them, such as diabetes, under good control. It all helps self-care of bronchiectasis.

# 4 What are Airway Clearance Techniques and how can they help me?

Regularly clearing the mucus from your chest is probably the most important thing you can do to keep your health stable.

Even those who have 'dry' bronchiectasis (without excess mucus) need to know a chest-clearing technique for when they have an infection.

Coughing clears only the main airways, leaving mucus in the smaller airways untouched. So, you need to learn ways to get it moving from down there.

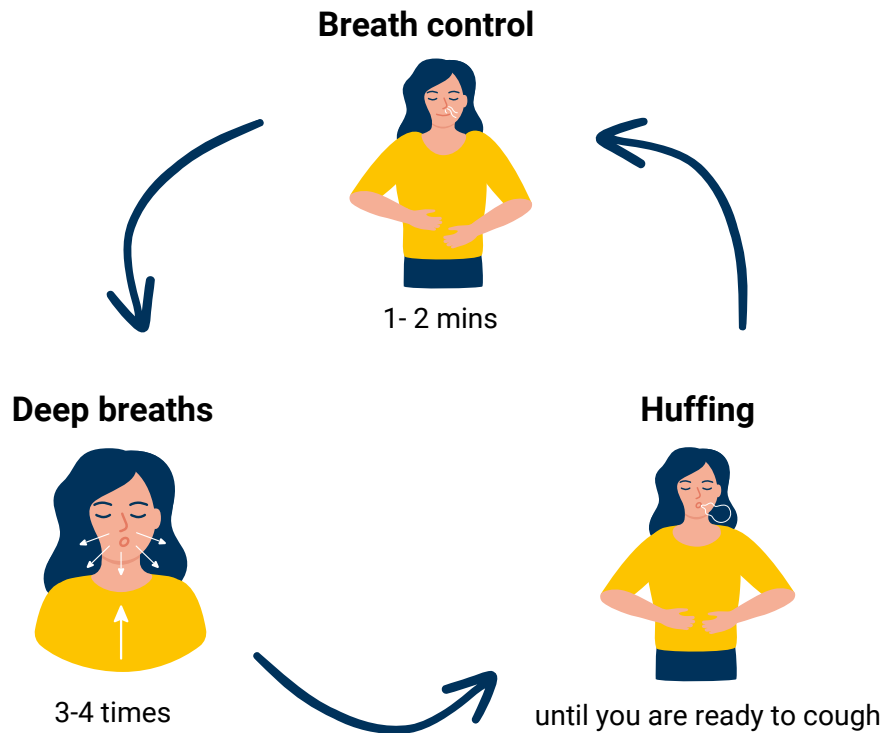
A respiratory physiotherapist will recommend the best technique for you (not all of them are suitable for everybody). If you cannot access a physiotherapist, there are video demonstrations online, including on the European Lung Foundation's bronchiectasis website:

<https://www.europeanlunginfo.org/bronchiectasis/how-to-help-yourself-videos/>

One of the most common techniques is the **Active Cycle of Breathing**.

This is a sequence of three breathing exercises that together help bring up the mucus as sputum. See description below and diagram on next page.

1. Breath control — breathe in gently using your nose and feeling your belly rise. Breathe out by your nose or mouth, feeling your belly fall. Try to slow the breath rate using as little effort as possible.
2. Deep breaths — breathe in slowly through your nose, as deeply as you can, feel your lower chest and abdomen (belly) expand. Hold it for 5 seconds. Then gently breathe out through your mouth — do not force it. Repeat 3–4 times (too many can make you feel dizzy).
3. Huff — breathe in, open your throat and 'huff' out forcefully through your mouth as though you are steaming up a mirror. Repeat until you feel ready to cough and clear sputum.



Repeat the cycle and stop when your huff is dry on two cycles in a row, and you can no longer hear or feel the mucus crackling in your chest.

- In addition, some people blow into **O-PEP devices** which can help to loosen the mucus. These have trade names such as Acapella, Aerobika, or Flutter. When using these devices, be sure to exhale (breathe out) for as long as possible and clean them properly after each use.
- Some find that **Postural Drainage** helps to assist the flow of mucus. This means doing your airway clearance on a slope with your head lower than your chest. To do this, you could lie down with pillows under your hips or lie over the end of a low bed with your head on a cushion on the floor.
  - **Warning:** this is not suitable for everybody, particularly not people with back, neck or shoulder problems, rib/spinal injury, gastric reflux, heartburn, nausea or dizziness and increased breathlessness when in a lying position. Modified positions are now available to avoid head-down positions.





You can do the Active Cycle of Breathing in the above positions. Turning over to do one cycle on each side and once each on your back and front.

At the same time you could also clap on your chest with your cupped hand (not if your chest is painful). As the impact can help move the mucus.

Even just lying flat on your back on the floor with your knees bent will facilitate the movement of mucus and make airway clearance exercises quicker and easier.

If you are travelling or working and do not have anywhere to lie down, you can just bend forward from the waist to achieve some benefit from gravity.

Another popular technique is **Autogenic Drainage (self-drainage)** — your physiotherapist can teach you how to control your breaths in three stages, using different speeds and depths of breathing to move the mucus from the small airways.

You could add equipment to your physiotherapy routine, such as a **vibrating vest** (tradenames include AffloVest, SmartVest) to help dislodge mucus, but these are expensive. A **vibration plate** — which you can buy anywhere for general fitness — is a cheaper alternative. You stand on it to vibrate the whole body. It depends on your general physical condition whether you can tolerate it.

Some people find that going for a run or other vigorous exercise, or taking a hot steamy bath or shower is useful to get the mucus moving.

There is plenty of background information, including video demonstrations of the airway clearance techniques we have mentioned, on the ELF's Patient Priorities website at <https://europeanlunginfo.org/bronchiectasis/how-to-help-yourself-videos/>

# When should I do my airway clearance?

Once a day, or maybe two or three times depending on your condition and whatever suits your body and your timetable best.

Physiotherapists may recommend first thing in the morning and last thing at night and after taking nebulised saline if this is prescribed. But in practice this does not work for everybody, either in terms of convenience or effectiveness.

Lunchtime and evening is best for some. It depends if your chest fills up at certain times of day — do it then if you can.

The main thing is to do it, whatever time of day suits you, your lifestyle and your bronchiectasis.

We know it can be inconvenient, time-consuming and it sometimes feels like hard work, but **just do it**. Along with antibiotics, it is our main weapon against infection.

## What if I am out all day - at work or travelling?

Remember to carry enough tissues and plastic disposal bags (such as nappy/diaper bags or dog-poo bags).

During a working day, most of us would rather postpone airway clearance until we get home if we possibly can.

But if that is not possible, or you are on a long journey, you will have to find a private place to do your airway clearance – often the only place is public toilets. Yes, it is embarrassing if people can hear you deep breathing, huffing and coughing but it has to be done. **Tip:** Time it with other people's toilet flushes.

None of us like drawing attention to ourselves over personal health matters, but if fitting in airway clearance becomes a problem, perhaps you could talk to your manager about it and come up with a solution. Tell them you are more likely to take sickness absence if you do not do it.

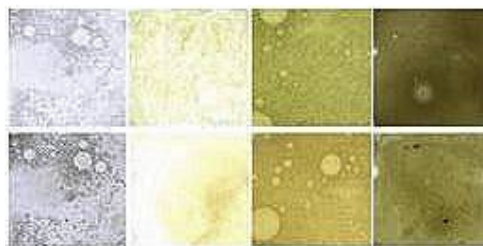
It can be difficult if colleagues make comments, such as 'you seem to have a lot of colds' or assume you have a smoker's cough. Just tell them truthfully that your condition is permanent, it is called bronchiectasis and emphasise it is not contagious. Most people will be sympathetic.

# 5 What if my symptoms get worse?

Bronchiectasis symptoms are variable between people. You need to work out what your personal 'normal' is — your **baseline** — in terms of quantity of sputum and general health. Then, if you notice significant changes you will know to seek medical help.

Do not be alarmed if you see occasional blood-streaks in your sputum, it happens with bronchiectasis. Contact your physiotherapist to discuss the best airway clearance technique for you or if you need to stop for a while. But if it turns bright red with blood coming up rather than mucus (this is rare), seek medical help immediately.

Also consult your doctor if your sputum looks particularly dark in colour — greenish or brown is a sign of inflammation or infection; white, cream or pale yellow is normal. The picture shows different sputum samples from bronchiectasis patients varying in colour from clear to dark green/brown):



You may also produce excessive sputum and feel more tired, achy, breathless, even feverish. These are all symptoms of a flare-up where you need medical intervention.

You will probably be asked to provide a sputum sample to decide what treatment you need, but until your doctor gets the result they could prescribe a broad-spectrum antibiotic. Some doctors may prescribe a 'rescue pack' of antibiotics to keep at home in case you need them at short notice.

**Many people are dealing with other conditions alongside bronchiectasis, such as gastro-intestinal problems, asthma, sinusitis, rheumatoid arthritis, primary ciliary dyskinesia and aspergillosis. Each will need their own care, and that can have an impact on your ability to cope and on common symptoms such as breathlessness and tiredness.**

# 6 How can I manage breathlessness?

When short of breath, stand still or sit, and try to control your breathing by relaxing your shoulders and neck and taking a slow breath in through your nose.

Take the air right to the bottom of your lungs, feel your lower belly expand so you know the smaller tubes are opening.

Breathe gently out through pursed lips as if you are blowing out a candle. Try to empty your lungs to create space for the next breath in.

If you are walking, or climbing stairs or a hill, try to use your breathing control in time with your stepping.

- Breathe in – 1 step
- Breathe out – 1 or 2 steps.

If you need to take a rest, sit down or lean with your back against a wall. Or lean forward with your hands on your knees, or your elbows on a windowsill, until you can control your breathing again.

If you are in a room, look for a rectangular shape such as a door, window or picture. Move around the sides of the rectangle with your eyes, breathing in on the short sides and out on the long sides.

In the heat, use a hand-held fan or cool your mouth and nose with a wet cloth to reduce the sensation of breathlessness.

If breathlessness affects your daily life, ask about a course of pulmonary rehabilitation – exercise classes tailored for people with a lung condition.



# 7

## How can I manage tiredness/fatigue?

### Use the three Ps - Plan, Pace, Prioritise

**Plan** – work out what time of day you have the most energy so you can do your most demanding tasks when you are least tired.

Some people find it beneficial to eat smaller meals every three or four hours to keep energy levels up instead of a large meal less often, which can make you more tired.

You could consider cutting out caffeine to combat tiredness.

Avoid taking naps during the day and relax before bed to give yourself the best chance of a good night's sleep.

Take your healthcare professional's advice on your best position for sleeping – some people (eg. with gastric reflux) find it helpful to be propped up on pillows, others to lie flat with a single pillow. It can depend on your individual condition and comfort.

But either way do your airway clearance regularly to reduce the chance of being woken up by coughing.

**Pace** yourself during the day, allow plenty of time so you do not have to rush. Spread out tasks so you can rest in between.

Some people find the 'spoons' metaphor useful: imagine you have 10 spoons each day, this may vary on how you are feeling and your base energy levels. If you sleep badly or are unwell take away some of your spoons. Each activity uses one or more of those spoons. So getting out of bed is one spoon, but walking the dog might be three spoons. Try to balance your day so you only use the spoons you have. This can help you to prioritise which activities you do each day.

Spend some time outdoors each day if you can. Regular exercise has been proven to help tiredness and breathlessness.

It may be the last thing you want to do, but even a 15-minute walk, done regularly, will help, and you can slowly extend your range.

Tai chi, gentle yoga or pilates can also be therapeutic.

**Prioritise** – decide what really needs to be done and what can wait. Ask a family member or friend to help with household chores.

Remove unnecessary tasks or look for shortcuts so you can spend more time on enjoyable activities that are good for your mental health.

If you are tired for a long time, check your **nutrition** with a dietitian – you may need to adjust your diet or take a dietary supplement.

Ask about a course of **pulmonary rehabilitation**. These are exercise classes tailored for people with a lung condition to improve your stamina, helping you stay active in a way that is right for you. And ask if you can see an **occupational therapist** to help you cope with the practicalities of life, whether at work, school or home.





# 8

## Does diet really make a difference?

Some people believe that cutting out dairy foods reduces mucus but research does not back this up. Neither are there any 'miracle foods' to do the same unfortunately. However, a well-balanced diet should make a difference to your overall health, wellbeing and resilience to infections.

Protein is a priority to help your body recover from infection, plus enough energy or calories (kcal), vitamins and minerals to help the process along.

Vitamin and mineral supplements should not be necessary with a well-balanced diet. Some groups are more likely to experience certain deficiencies, people who menstruate for example, are more prone to iron deficiency. If you do not get very much sunshine on your skin, or you live in a northern country, especially in winter, it may be advisable to take Vitamin D. You should always speak to a healthcare professional before taking any supplements.

Keeping your weight within healthy limits is important - being overweight puts more strain on your heart and lungs, being underweight can lower your resistance to infection.

The **Mediterranean diet** is often recommended. If you have gastro-intestinal problems, food intolerances or allergies, adapt it if you need to. Vegans can find plenty of protein in nuts, beans, pulses and seeds, tofu, fortified soya milks, and vegetables. People with conditions like Irritable Bowel Syndrome may prefer to eat small meals, little and often to reduce bloating.

Everyone needs to keep well-hydrated to help thin the mucus, so drink lots of non-sugary fluids. Some people recommend tea with anti-inflammatory elements like turmeric, cinnamon and ginger although there is no evidence to show these are effective. Alcohol will dehydrate you so limit your alcohol intake.

### **The Mediterranean diet typically includes:**

- fruits and vegetables – ideally five handfuls of different coloured fruits and vegetables a day,
- beans, chickpeas, lentils,
- nuts and seeds,
- fish, two portions a week, one of them oily – such as sardines, salmon, herring, trout, mackerel,
- whole grains (including wholegrain rice, pasta, bread, oats)
- unsaturated fats such as olive oil or rapeseed oil,
- a moderate amount of dairy – cheese, yogurt, milk – also eggs,
- a limited amount of red meat (avoid heavily salted or processed meat) and saturated fat, such as butter.

# 9 How can I cope with anxiety, low mood, loneliness?

A chronic condition like bronchiectasis can be difficult to deal with, especially when you are first diagnosed or have had a series of infections – but remember you are not alone. We all have times when we struggle to cope with it mentally, but there are ways to get through it.

- Talking about your feelings, either with someone sympathetic, a doctor, nurse or counsellor. In many countries there are helplines run by lung or mental health charities who can give support, advice and point you to sources of help.
- See a therapist or counsellor trained to help with anxiety and depression.
- If you are struggling with your mental health, medication to manage this may be helpful. Speak with your doctor about this.
- Walking in the outdoors, preferably close to nature, can lift your spirits.
- A gentle exercise class such as yoga or tai chi will get you out of the house with other people. Make sure you do your airway clearance first. If you are anxious about coughing too much, try an online exercise class.
- Music is a natural mood-changer, put on some music you enjoy and dance around the kitchen or living room.
- Get creative – drawing, decorating, writing, gardening, craftwork, woodwork, knitting, learning a musical instrument – anything you enjoy or want to try so you forget your worries. If you can do it with a like-minded group, like singing in a choir, so much the better.
- Phone or text a friend, arrange to meet for coffee or see a film.
- Try not to focus on things you cannot change, you will only go round in circles – focus your time and energy on helping yourself feel better, doing things that give you a sense of achievement.

# 10 Tips for dealing with social issues – coughing, incontinence

Coughing comes with having bronchiectasis and it can be embarrassing in social or work situations.

The only way to reduce it is to make sure your chest is clear before that important meeting, job interview or social engagement. You may still cough, but not as loudly or frequently.



If your coughing is a nuisance during a normal working day, take yourself off to the toilets and do some airway clearance. If your throat is irritated sip water or suck a cough sweet.

Some people take half-breaths to stop their chest crackling, for instance in a quiet meeting, but that is not medically advisable or sustainable for more than a minute or so.

If anyone notices, tell them you have a long-term lung condition, it is called bronchiectasis, and – most important to them – it is not catching.

Sometimes we should stop worrying too much what other people think – concentrate on living our best life with the lungs we have.

But most importantly, never leave the house without tissues and disposal bags.

**Mild incontinence** can affect both men and women because the physical stress of coughing puts pressure on your bladder. Incontinence is when you pass urine without meaning to. This may happen more often when you cough. Some people may also avoid doing airway clearance because of this.

Speak to your doctor if you are having incontinence issues. There are lots of ways they can help you.

You can also strengthen your pelvic floor muscles with exercises – frequent, simple, everyday exercises you can do anywhere, such as standing in a queue or sitting at your desk and no-one will notice.

These exercises involve squeezing your pelvic floor muscles as though you were stopping the flow of urine midstream. Do it 10 to 15 times, two or three times a day. Do not hold your breath or tighten your stomach, bottom or thigh muscles at the same time.

As you get used to it, hold each squeeze for a few seconds. Each week, build up more squeezes, and after a few weeks you should start to notice a difference.

Try squeezing every time you cough, so that it becomes a habit you don't even think about.

Some people find that apps are useful to help with technique and remind you to do the exercise. Search online for 'pelvic floor exercise apps'.

If you are still experiencing symptoms, you can ask to be referred to a specialist pelvic floor physiotherapist. They can give you advice on any additional techniques that might help and check that you are performing them correctly.

Improving your pelvic floor can increase sensitivity during sex, strengthen orgasms and reduce the symptoms of erectile dysfunction.

To help you while you are working on your incontinence you can buy products to absorb the urine. There are lots of products that include pads, liners and underwear that vary in how much urine they can absorb.

# 11 Further sources of help

Have a look at the European Lung Foundation (ELF) website:  
<https://europeanlung.org>

Working in partnership with patients, it has an Information Hub dedicated to a range of lung conditions including bronchiectasis, translated into different languages. It has factsheets, patient stories, advice on dealing with your condition, air travel and much more.

ELF also:

- brings patients and healthcare professionals together – it is where they engage with us to help draw up care guidelines and research projects.
- has organised several online **Bronchiectasis Patient Conferences** in which patients, clinicians and physiotherapists engage with hundreds of people from around the world. You can watch the recordings on their YouTube channel at <https://www.youtube.com/user/lungfoundation>.

In addition, most countries have their own organisations – often charities – dedicated to supporting people with respiratory conditions generally. Search the ELF patient organisation network directory at <https://europeanlung.org/en/people-and-partners/elf-patient-organisation-network/>

Remember, bronchiectasis may not be as well-known as asthma or COPD – most people have never heard of it until they get it – but you are definitely not on your own.

And after a long period of slow progress in the treatment of bronchiectasis, medical researchers are now working hard to develop new medications that will eventually make our lives easier.

We hope you find this guide useful and we would love to hear what you think. You can email [info@europeanlung.org](mailto:info@europeanlung.org) with any feedback.

**"Bronchiectasis is hugely impactful. Putting in a lot of effort to move the lungs on a regular basis, and keeping the whole body fit, has made a big difference throughout my 40+ years of living with bronchiectasis."**

**Donna, Switzerland**

**"I would prioritise airway clearance above everything for people with bronchiectasis. You've just got to regard it as a part of normal body maintenance every single day, like brushing your teeth or having a shower. It's the most important thing we can do for the health of our lungs to keep as free of mucus as possible and as free of infection as possible"**

**Barbara, United Kingdom**



This guide was written by Barbara Crossley in partnership with members of the ELF Bronchiectasis Patient Advisory Group and physicians and scientists from EMBARC - the European Bronchiectasis Collaboration.

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