Bronchiectasis Empowerment Pack

A collection of resources for people with bronchiectasis and their clinicians

This resource has been developed in collaboration with the European Multicentre Bronchiectasis Audit and Research Collaboration (EMBARC) and the European Lung Foundation (ELF).

EMBARC
The European Bronchiectasis Registry

ELF EUROPEAN LUNG FOUNDATION

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Welcome to our Bronchiectasis Patient Empowerment Pack

This pack is a shared resource designed for **both patients and clinicians**. Its purpose is to support open communication, promote shared decision-making, and ensure that everyone involved in managing bronchiectasis has access to trusted, practical information.

For clinicians

This pack is a learning tool for bronchiectasis that can build knowledge. It supports informed decisions and encourages collaborative healthcare.

This pack offers clear information about bronchiectasis. It includes tips, tools, and resources to help you manage your condition and take an active role in your care.

For patients

Bronchiectasis remains an under-recognised condition but by working together, patients and healthcare professionals can change that.

We encourage patients to take this resource and share it with their doctors, and encourage doctors to share it with their patients, so you can learn about bronchiectasis and the available support together.

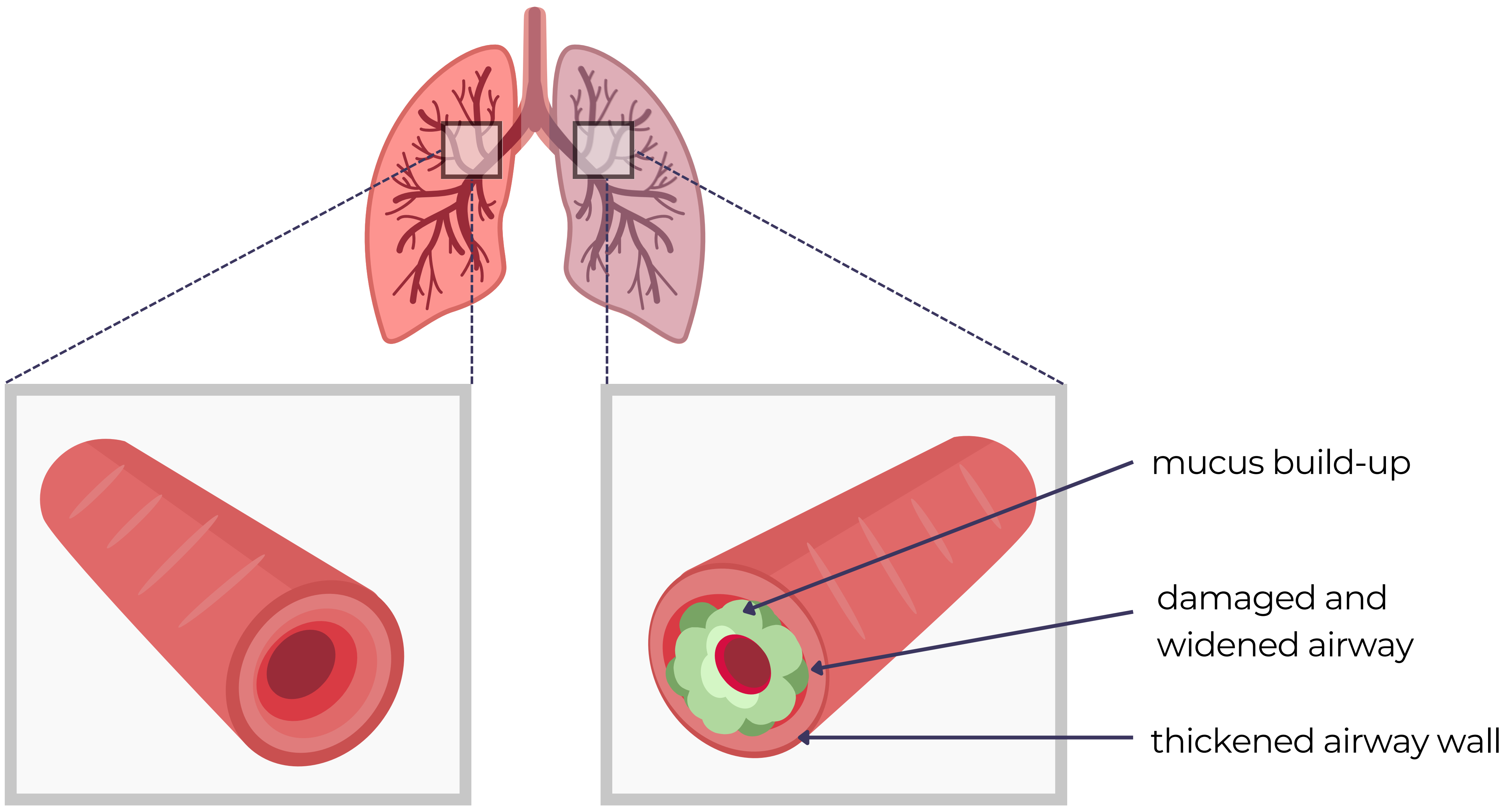
We hope this pack acts as a starting point for conversations, planning, and confidence-building on both sides.

All resources are available in multiple languages and are found on the European Lung Foundation's bronchiectasis information hub website.

URL: https://europeanlung.org/en/information-hub/lung-conditions/bronchiectasis/

What is bronchiectasis?

Bronchiectasis is a long-term lung condition where the airways become wider than normal and clogged with thick, sticky mucus (sputum).



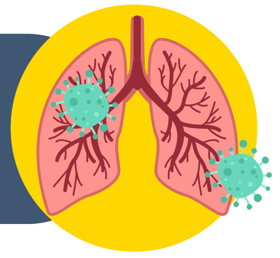
Healthy Airway

Airway in Bronchiectasis

The widening of airways and build-up of mucus can result in a variety of symptoms, including:

Cough (often producing large volumes of sputum)

Frequent chest infections



Breathlessness, wheezing and chest pain

Tiredness

Symptoms and their severity can vary between individuals which can make bronchiectasis a challenging condition to manage.

Understanding and managing bronchiectasis

Managing bronchiectasis in adults
Recommendations for healthcare professionals

The European Respiratory Society (ERS) created a set of guidelines for the management of adult bronchiectasis to help doctors treat the condition.

The current guidelines can be found **here**.

EUROPEAN
RESPIRATORY *journal*

ERS

Managing bronchiectasis in adults
Recommendations for patients

The European Lung Foundation (ELF) has written a patient-friendly version of the treatment guidelines to improve understanding of what is currently recommended in bronchiectasis care.

The recommendations cover:

- Tests after diagnosis: this may include blood tests and checking your sputum to help plan your treatment
- Ongoing treatments: these might be medicines that help clear mucus, treat infections or reduce swelling in your airways
- Treatment for chest infections: information about which antibiotics may be used and how long you might need to take them
- Support with breathing and movement: this includes ways to clear your chest and exercises to help you breathe more easily

The ELF patient-friendly recommendations can be found **here**.

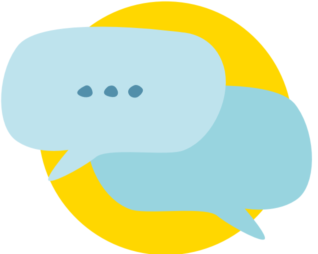
Patient Checklist

Supporting patients to advocate for their own health is essential. This is especially important for under-recognised conditions like bronchiectasis.

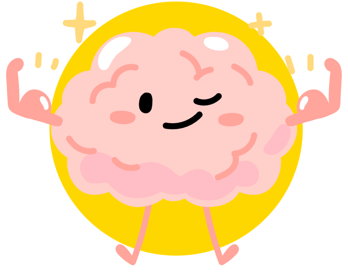
The Patient Checklist was developed by the ELF Bronchiectasis Patient Advisory Group in collaboration with EMBARC.

It outlines the main aspects of care that people with bronchiectasis should expect and empowers them with the knowledge to speak up for their health.

It can help to:



Support open communication between patients and their healthcare team



Give patients the knowledge to better understand their care

Build confidence to ask questions and ensure their needs are met

The Bronchiectasis
Patient Checklist

As a patient with bronchiectasis I should expect the following:

① I understand what bronchiectasis is and I know where to find additional information and support if needed ☐
② My doctor or nurse has performed tests to find out why I developed bronchiectasis. I have been told the cause of my bronchiectasis, or that no cause has been found despite testing ☐
③ I give a sample of sputum at least once per year to check for new infections and to help to choose the right antibiotic if I have an infection ☐
④ I understand how to recognise a chest infection [exacerbation], and I have been given advice about what to do when my symptoms get worse ☐
⑤ When I develop a chest infection, I am given antibiotics for 2 weeks ☐
⑥ I have been shown exercises [airway clearance techniques] to help me to cough up sputum ☐
⑦ If I have trouble with coughing up sputum despite doing airway clearance techniques, I have been offered extra help, such as seeing a physiotherapist or additional medication ☐
⑧ If I am having 3 or more chest infections per year, my doctor or nurse has spoken to me about medication or other treatments to help reduce the frequency of my chest infections ☐
⑨ If I suffer from breathlessness, I have been offered pulmonary rehabilitation [a series of classes that improve exercise capacity] ☐
⑩ If I suffer from breathlessness I have discussed with my doctor or nurse whether I need to take an inhaler ☐
⑪ I know what all of my medication is for, and I know when and how to take my medication ☐
⑫ I know the importance of taking responsibility for my own health by eating healthily, avoiding smoking, taking regular exercise and having an annual flu vaccination ☐

Ask your specialist, doctor or nurse to go through the list and make sure that you understand your condition.
Please note that not all of these recommendations will apply to all patients.

The Bronchiectasis Patient Checklist is based on the European Bronchiectasis Guidelines 2017 which was developed by a team of expert doctors, physiotherapists, other healthcare professionals and patients. The recommendations above reflect what most patients with bronchiectasis should expect from their care according to these guidelines. In some cases, the treatments described above may not be suitable for you. Your doctor or nurse will explain which apply to you.

This document does not contain detailed information on bronchiectasis and should be used in discussion with your doctor.

EMBARC The European Bronchiectasis Registry
ERS European Respiratory Society
ELF European Lung Foundation
British Lung Foundation
European Reference Network for rare or low prevalence complex diseases
Network Respiratory Diseases (ERN-LUNG)

The Patient Checklist is available in multiple languages on the [ELF website](#).

The English translation is available to download [here](#).

Airway clearance

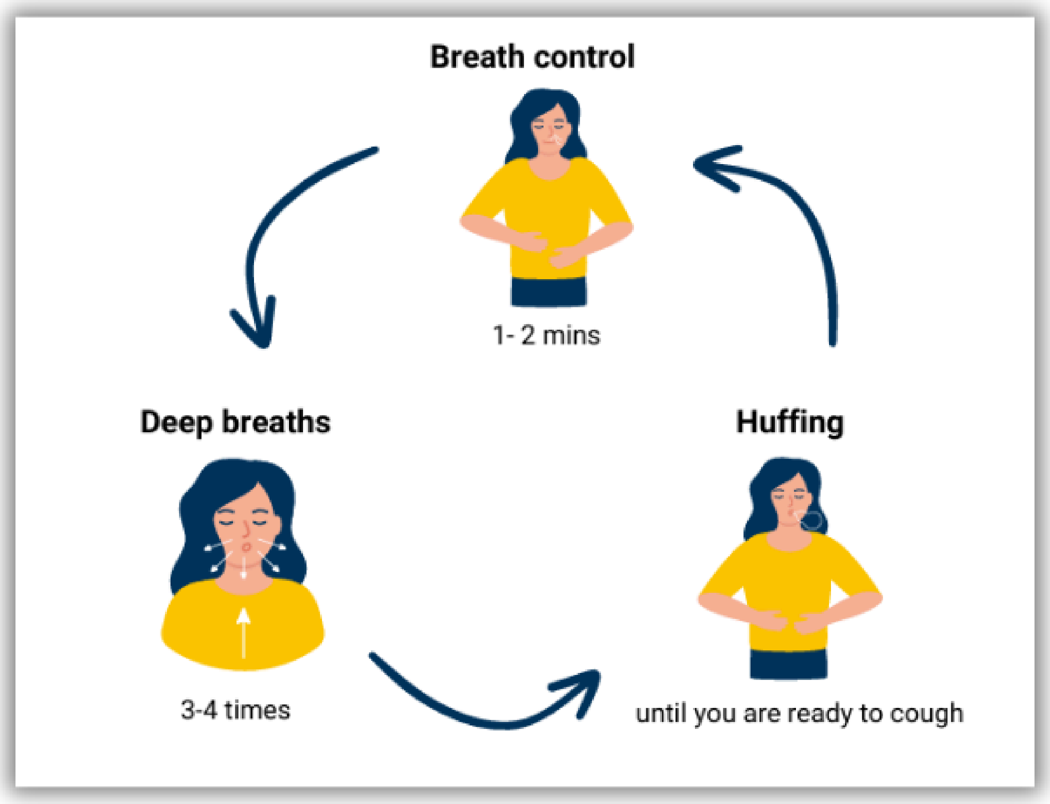
For most people with bronchiectasis, clearing the airways is an important part of managing the condition.

Many patients find staying active and taking part in regular, moderate-to-high intensity exercise - which causes them to huff or cough - beneficial for clearing their airways.

Alongside regular exercise, there are specific methods which can improve airway clearance. Such methods can be recommended by a respiratory physiotherapist. Referrals to a physiotherapist can be made by a general practitioner or a healthcare professional from a specialist respiratory team.

These additional airway clearance methods include:

- Active cycle of breathing (ACBT)
- Positive expiratory pressure (PEP) devices
- Autogenic drainage
- Postural drainage - moving into different positions to help mucus drain from different parts of the lung



Watch the NHS University Hospital Plymouth physiotherapy videos above or visit the ELF website for written guides for each clearance method **here**.

Pulmonary rehabilitation

Pulmonary rehabilitation (PR) can be offered to people living with long-term lung conditions that are affected by breathlessness. PR is a treatment programme designed to:

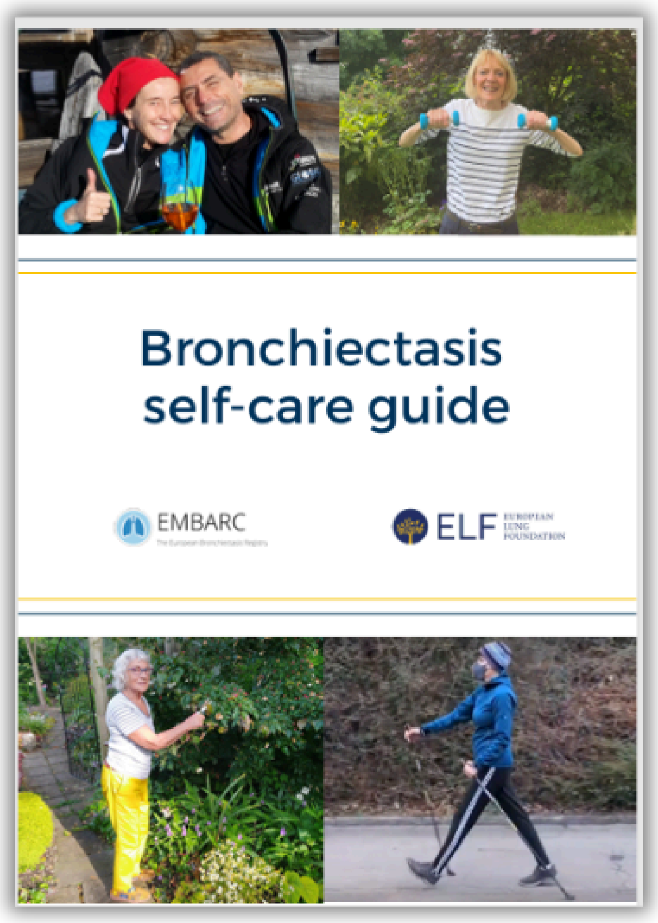
- Improve muscle strength and fitness through exercise
- Provide advice from professionals on managing breathlessness
- Provide mental health support

Learn more about pulmonary rehabilitation and its benefits **here**.

Practical tools for self-management

Self-care guide

While treatments are available, most of the day-to-day management of bronchiectasis happens at home.



Bronchiectasis
self-care guide

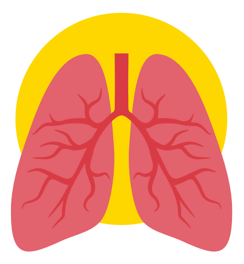
EMBARC

ELF

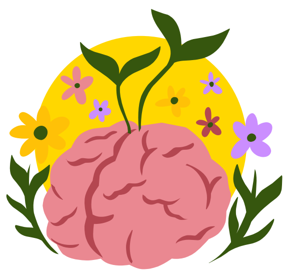
The ELF Bronchiectasis Patient Advisory Group produced a self-care guide to support others living with the condition by highlighting the best ways to self-manage the condition and live a full life.

The guide has been written by patients for patients.

It details different areas of bronchiectasis management including:



Symptom management



Mental health

Airway techniques

Exercise

Signs of exacerbation

Nebulisers

Diet

Physiotherapy

Travel

The full self-care guide is available in multiple languages on the [ELF website](#).

The English translation is available to download [here](#).

Self-management plans

Self-management plans help patients monitor symptoms, track daily medications and manage exacerbations. An exacerbation is a time when bronchiectasis symptoms worsen or flare up, requiring a change in treatment.

Most will follow a similar format highlighting:

- Usual daily symptoms
- Daily medications
- Medications to take during an exacerbation
- Advice on when to seek help

Discuss your self-management plan with your doctor so you are both clear and agreed on your treatment approach.

TIP

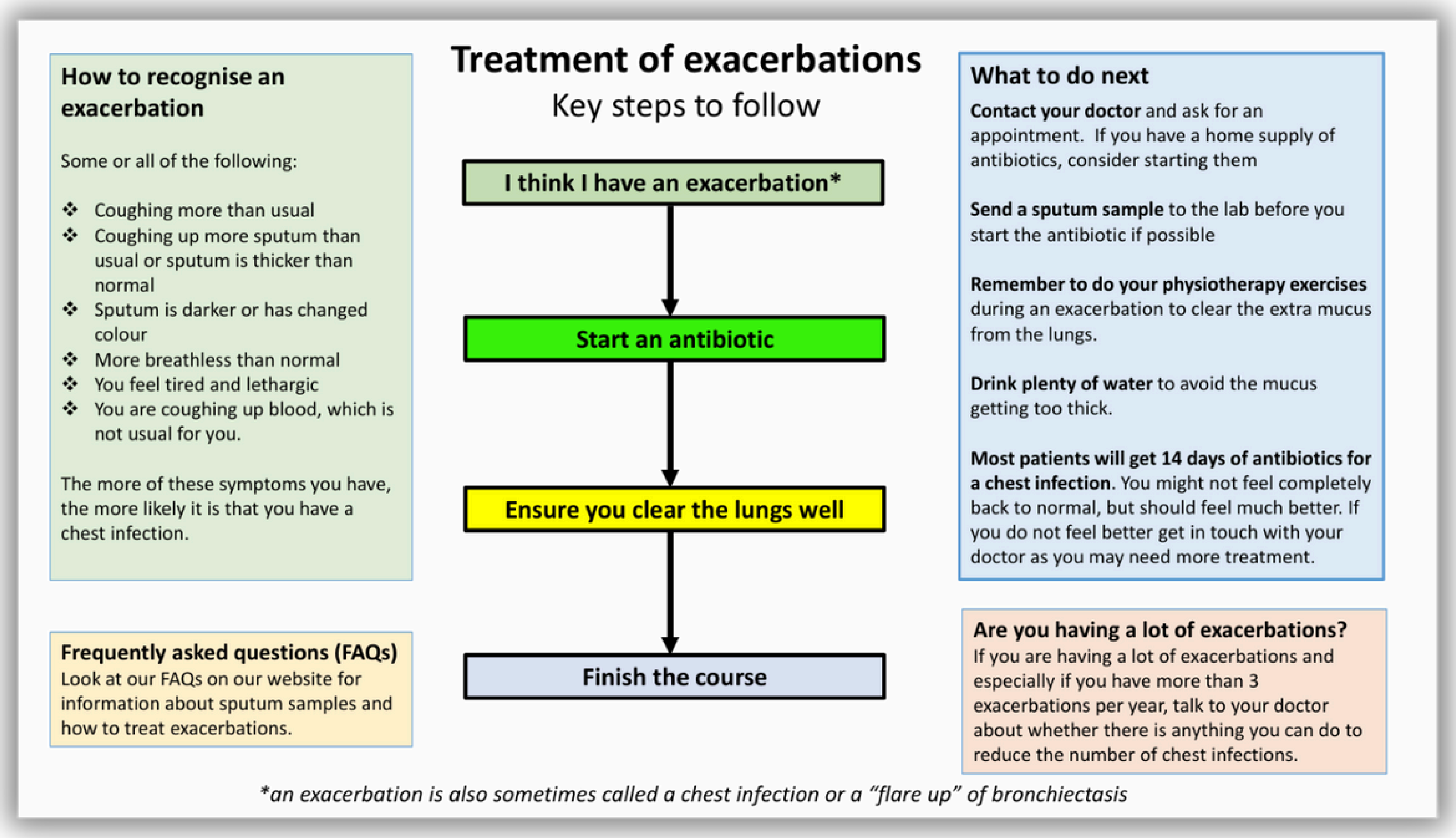
Different healthcare systems have different self-management plan templates.

Alternatively, the British Thoracic Society have a free template available to download.

Exacerbation Management Flowchart

An exacerbation flowchart details what patients should do if they think they are having an exacerbation.

ELF have a downloadable version that you can view **here**.



How to recognise an exacerbation

Some or all of the following:

- Coughing more than usual
- Coughing up more sputum than usual or sputum is thicker than normal
- Sputum is darker or has changed colour
- More breathless than normal
- You feel tired and lethargic
- You are coughing up blood, which is not usual for you.

The more of these symptoms you have, the more likely it is that you have a chest infection.

Frequently asked questions (FAQs)
Look at our FAQs on our website for information about sputum samples and how to treat exacerbations.

Treatment of exacerbations
Key steps to follow

I think I have an exacerbation*
Start an antibiotic
Ensure you clear the lungs well
Finish the course

What to do next

Contact your doctor and ask for an appointment. If you have a home supply of antibiotics, consider starting them

Send a sputum sample to the lab before you start the antibiotic if possible

Remember to do your physiotherapy exercises during an exacerbation to clear the extra mucus from the lungs.

Drink plenty of water to avoid the mucus getting too thick.

Most patients will get 14 days of antibiotics for a chest infection. You might not feel completely back to normal, but should feel much better. If you do not feel better get in touch with your doctor as you may need more treatment.

Are you having a lot of exacerbations?
If you are having a lot of exacerbations and especially if you have more than 3 exacerbations per year, talk to your doctor about whether there is anything you can do to reduce the number of chest infections.

an exacerbation is also sometimes called a chest infection or a "flare up" of bronchiectasis

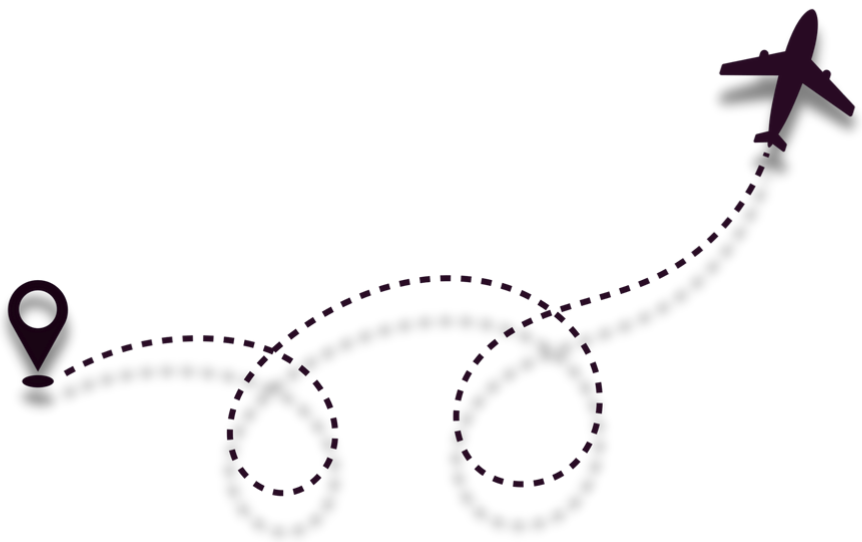
TIP

Knowing your usual symptoms makes it easier to recognise a flare-up early.

Lifestyle and Support

Travel advice

Travel is a common concern for people with bronchiectasis. Until recently, doctors had no clear guidelines to advise patients on travelling safely.



The ELF Bronchiectasis Patient Advisory Group and EMBARC worked together to create travel advice that addresses common worries and questions, such as:

- Is it safe for me to travel with bronchiectasis?
- Are there destinations or conditions I should avoid?
- What kind of travel insurance should I get?
- What medications or devices should I bring?
- How can I maintain my regular treatments while away?
- Should I prepare or carry any medical documentation?
- What activities are safe, and what precautions should I take?
- Are there specific oxygen needs for travel?
- How else can I prepare for my trip?
- Where can I get help if become sick while travelling?

The full recommendations can be found in the ERJ **here**.

ELF have a patient-friendly breakdown of the advice **here**.

EMBARC/ELF Bronchiectasis Patient Conference

Every year, EMBARC and the ELF host a virtual conference for anyone interested in learning more about bronchiectasis and how to manage the condition, including patients, caregivers and healthcare professionals.

During the conference, the audience learns from people living with bronchiectasis and healthcare professionals across a range of topics related to bronchiectasis, including updates on the latest research and findings from clinical trials.

The conference is held in English with automated captions in over 60 languages, making the conference accessible to all. There are also opportunities to have your questions answered through a live chat.

We will start at 10:00 CET

EMBARC ELF

15 MARCH 2025

PATIENT CONFERENCE
BRONCHIECTASIS 2025
Get involved in the discussion **#Bronchiectasis2025**

For translation scan QR code or use link:

https://attend.wordly.ai/join/AORV-2619

This event has been developed with and supported by EMBARC, a pan-European network and the ELF Bronchiectasis Patient Advisory Group.

> ***'The Patient Conference is a concrete case study of a close exchange between healthcare professionals and patients, and is proof that medical and patient languages are complementary and allow everyone to learn from each other.'***
> *- Bronchiectasis Patient Conference attendee, 2025*

Attending the conference empowers both patients and doctors with accessible, evidence-based information.

Recordings of previous editions of the Bronchiectasis Patient Conference are available to watch **here**.

The ELF Bronchiectasis Patient Advisory Group

Patient advisory groups (PAGs) are made up of people who have a particular condition. They share their views and become involved in projects that aim to raise awareness and improve diagnosis, treatment, and care for that condition.

For bronchiectasis, the ELF has its own PAG that has been involved in a variety of projects for patients' benefit. Many of the resources seen here in this Patient Empowerment Pack, including the patient conference, have been produced in collaboration with the ELF's Bronchiectasis PAG!

Are you interested in joining the ELF Bronchiectasis PAG?

You can volunteer as a member of the ELF Bronchiectasis PAG if you:

- are >18 years old
- live in a European country
- can communicate in English (spoken and written)

ELF provides full training, guidance and support for those volunteers who would like to join.

Find out more about becoming a member of the ELF Bronchiectasis PAG **here**.

Other Patient Support

Other charities/organisations

- **Asthma and Lung UK**
- **Chest, Heart and Stroke Scotland**
- **Associazione Italiana Bronchiettasie**

Support Groups

- **Bronchiectasis & NTM 360**
- **BEHappy Bronchiectasis Online Support Group**
- **Bronchiectasis Support HealthUnlocked**

Resources for Healthcare Professionals

EMBARC has developed a set of videos for clinicians who are looking for additional resources.

- **For General Practitioners**
- **For Respiratory Professionals**