INSIGHT





A Patient's Perspective

Bronchiectasis

BE ir
Bronchiectasis
Info & Research

Fern Leitman lived with bronchiectasis for most of her life

It shaped the rhythm of every single day: the time spent on airway clearance each day, the many medications, the exacerbations. It shaped our family's life too, in ways that were profound and in ways that were almost invisible to anyone looking in from the outside.

What we want you to know, as you read this pamphlet, is that Fern was not defined by her disease. She was warm and funny and outgoing. She never met a stranger she didn't befriend. She loved food, really loved it, from stone crabs to a good salad. She loved her family and traveled whenever she could and cared deeply about the people around her. The bronchiectasis was something she carried. It was not who she was.

But she also knew, better than almost anyone, how much the absence of good information costs a patient. She spent years working to make sure that patients and families living with NTM lung disease and bronchiectasis would have access to the knowledge and support she had struggled to find when she began her journey as a patient. She testified before Congress. She spoke at FDA workshops. She founded an organization dedicated to that work and gave herself to it fully, even as her own health declined.

This pamphlet exists because of her, and because of the many patients and families whose experiences have shaped what we know and do. We hope it helps you understand your diagnosis more clearly, advocate for yourself more confidently, and feel a little less alone in whatever you are navigating right now.

— Amy Leitman, *President, NTM Info & Research*

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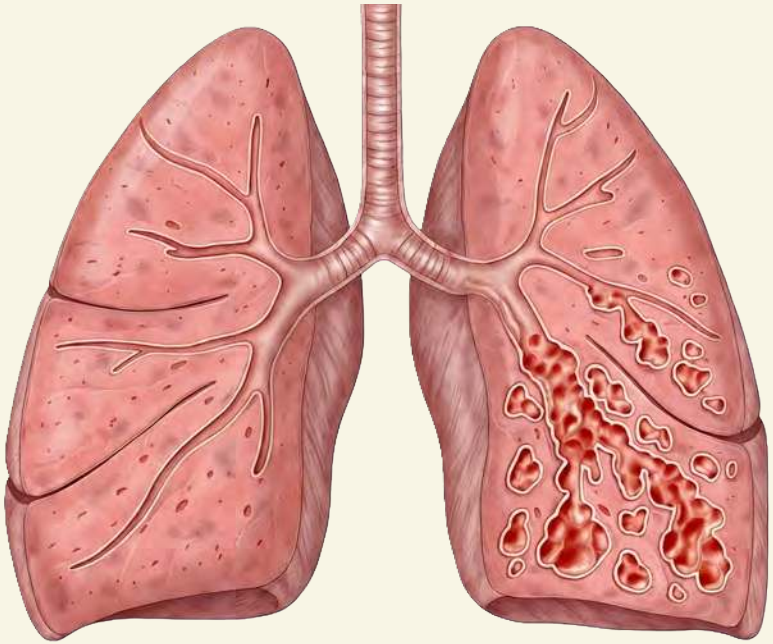
This pamphlet provides an overview of Bronchiectasis (BE), a disease characterized by permanent, physical damage to the airways.

Patients with BE have an increased likelihood of recurrent lung infections. It's important to consider that BE requires consistent care and management. There are effective treatment strategies that can help you live a full, long life. A successful approach to managing BE is achieved through education and actively participating in your care. Currently, there is significant scientific research being conducted on BE. As this research continues, patients can look forward to more treatment options and improved quality of life.

This pamphlet contains condensed versions of the information on our website. For more details, please visit BEinfo.org.

Comparison of a healthy lung with a lung affected by Bronchiectasis.



WHAT IS BRONCHIECTASIS?

Bronchiectasis (BE) is a condition where the airways in your lungs, also called bronchial tubes, become damaged and abnormally widened or dilated. Once BE develops, the physical damage cannot be reversed or cured, but it can be managed.

The abnormal dilation of the bronchial tubes makes them collapsible, or "floppy." This makes it harder to clear naturally occurring mucus out of the lungs. As the mucus stays in the airways, bacteria and environmental organisms such as fungi, mold, and viruses can grow and cause infections, which may result in exacerbations or "flare-ups."

These infections can cause more damage, which leads to more mucus retention. This creates a self-reinforcing pattern, a kind of downward spiral where more mucus leads to more infections, which causes chronic inflammation which can result in more permanent airway damage. Because of this, disease management is the key to reducing the number of flare-ups to keep BE from progressing.

It's important to know that bronchiectasis itself is not contagious. The chronic cough, sputum production, and breathlessness associated with BE are not signs of a contagious illness. You cannot give BE to someone else, and you cannot catch it from another person. It does make you more vulnerable to lung infections, and in some settings, there is an increased risk of passing that infection to another patient who has an underlying vulnerability (such as severe BE, cystic fibrosis, or a significant immune deficiency).

Understanding How Bronchiectasis Progresses

Understanding why BE progresses helps explain why consistent treatment is so important. Many experts now describe the process not as a simple cycle but as a vortex: a complex, multi-directional web of interactions. It works like this: there is an initial insult to the lung (an infection, an environmental trigger, or an underlying predisposition). This damages the airways, impairing the tiny hair-like cilia that normally help propel mucus up and out of the lungs. Without proper mucus clearance, bacteria and other organisms find fertile ground to grow. The immune system responds but in doing so, the inflammatory cells themselves contribute to further airway damage.

This is precisely why daily management is so essential: every intervention that interrupts one part of this process, from airway clearance to remove mucus and antibiotics to treat infection to anti-inflammatory therapies to calm the immune response, can help slow or stop the progression.

WHO GETS BRONCHIECTASIS?

BE affects more than 500,000 people in the United States, though experts believe the actual number is much higher. The disease is more common in older adults, with approximately 75% of those diagnosed aged 65 or older. It also occurs more often in women, who account for roughly 65% of cases.

Over the past 25 years, the number of people diagnosed with BE has increased steadily at approximately 8% per year. Some of this increase is due to greater use of CT scans, which make the disease easier to detect. Patients who previously had lung infections (such as recurrent bronchitis or pneumonia) may develop BE as a result of the damage caused by these infections but the BE was not recognized until it was found later during a CT scan for another issue. Evidence also points to an actual rise in cases as well, highlighting BE as an important and growing public health issue.

HOW DID I GET BRONCHIECTASIS?

Your doctor will use your medical history, imaging pattern, symptoms, family history, and test results to investigate the cause. Finding the underlying cause matters: in some cases, treating the root cause can slow or even halt disease progression. More recent guidelines provide a framework for the testing clinicians should consider when evaluating a new bronchiectasis diagnosis.

No Known Cause (Idiopathic)

For almost half of BE patients, there is no known cause for why they developed BE, even after extensive testing and evaluation. This is called idiopathic bronchiectasis.

Previous Serious Lung Infections (Post-Infectious BE)

Another common reason for developing BE is lung damage caused by an infection such as pneumonia or nontuberculous mycobacteria. These infections can scar and widen the airways, making it harder to clear mucus.

There is a "chicken-or-the-egg" question about post-infectious BE. In some people, an infection causes airway damage that leads to BE. In others, it may have already been developing, for reasons known or unknown, and the infection simply made symptoms noticeable enough for the diagnosis to be made. Because most people don't have lung scans prior to becoming sick, it is often impossible to know which came first.

Asthma or Chronic Obstructive Lung Disease (COPD)

Asthma or COPD and BE can occur together. In some individuals, long-standing asthma or COPD may contribute to airway damage that leads to BE. In others, these conditions simply coexist without one causing the other. When asthma or COPD and BE are present, they must be managed together as part of a comprehensive treatment plan.

It's important to note that while COPD is typically caused by smoking, bronchiectasis is not. Many people are incorrectly diagnosed with COPD for months or years before receiving a proper diagnosis of BE, which can delay appropriate treatment.

Poorly controlled COPD can worsen airway inflammation, increase the risk of infections, and make BE symptoms harder to manage. While smoking does not cause BE, quitting smoking is an essential part of treating both COPD and BE.

Aspiration and Gastroesophageal Reflux Disease (GERD)

Aspiration and GERD (also called acid reflux) are associated with BE because they involve stomach contents entering the airways and lungs. Aspiration occurs when food, liquid, saliva, or stomach contents accidentally go into the lungs while swallowing or breathing. GERD is a digestive condition in which stomach contents repeatedly flow backward into the esophagus and throat, especially when lying down or asleep.

When stomach contents reach the airways, they can irritate and injure the airway lining and introduce bacteria. Over time, this repeated exposure can lead to chronic inflammation, recurrent infections, and permanent airway damage.

Aspiration and GERD are common in people with BE. Though they commonly coexist with BE, they may not be a primary risk factor for everyone. In some individuals, reflux or aspiration may contribute to the development of BE. In others, BE may already be present, and reflux increases symptoms or the risk of infection. Ongoing management of your GERD may help mitigate this risk.

Autoimmune or Inflammatory Conditions

Certain autoimmune diseases, such as rheumatoid arthritis (RA), Sjögren's disease, Crohn's disease, and ulcerative colitis, can cause inflammation throughout the body, including the airways. Over time, this inflammation can cause damage and lead to BE. While these causes are less common, identifying and treating the underlying autoimmune condition may help reduce further progression of BE.

Immune System Problems

Some people have immune system disorders that make them more likely to develop frequent or severe lung infections. One example is hypogammaglobulinemia, a condition where the body does not produce enough immunoglobulins, which are antibodies that help fight infections. Repeated infections over many years can gradually damage the airways and result in BE. If you have an immune system disorder, it is important to treat it to reduce the risk of BE progression. Your provider may check your immunoglobulin levels as part of the diagnostic workup.

Genetic Conditions

Some inherited conditions can lead to BE, with cystic fibrosis (CF) being one of the most well-known. This condition is the result of mutations in the CFTR gene. Although CF is commonly thought of as a severe childhood disease, some adults are now being diagnosed with CFTR gene mutations that cause milder disease. This condition is called CFTR-related BE. Identifying harmful mutations in the CFTR gene as the underlying cause of BE is important because it can help guide treatment and provide information about disease risk for family members, and ensure care is tailored to your specific cause of BE.

Another inherited condition that can lead to BE is primary ciliary dyskinesia (PCD), where the tiny hair-like cilia in the lungs do not work properly. Cilia normally help move mucus out of the airways; when they do not function properly, mucus builds up and repeated infections can occur, eventually leading to BE.

Alpha-1 antitrypsin (A1A) deficiency is an inherited genetic disorder causing low levels of a protective protein (AAT) in the blood, leading to early-onset lung disease (COPD/emphysema, BE) and liver damage. Research is currently being conducted to better understand the role of A1A deficiency in the development of BE.

BE in the Context of Other Conditions

In addition to being caused by other conditions or infections, BE often occurs alongside other medical conditions. Recognizing these associations is crucial for comprehensive treatment.

Chronic or recurring sinus disease (chronic rhinosinusitis) is another common co-existing condition. The sinuses and lungs are part of the same airway system, and inflammation or infection in one area can affect the other. At the same time, BE makes it harder to clear mucus, which can increase the risk of chronic sinus infections. Managing sinus disease is therefore an important part of bronchiectasis care. Swallowing problems, other airway diseases, and gastrointestinal issues also warrant attention as part of a holistic care approach.

Regardless of the cause, BE should be monitored and you should follow up regularly with your recommended care team.

BRONCHIECTASIS SYMPTOMS

The most common symptom of BE is a chronic (persistent) cough. Some people with BE produce only a little mucus, while others may cough up large amounts.

In some patients, there may be little or no cough and minimal or no sputum production. This is sometimes called "dry bronchiectasis." Inflammation of the airways is still present in dry BE. It can still progress and cause airway damage and is sometimes associated with nontuberculous mycobacterial infection. Not producing sputum does not mean you do not have BE! A chronic cough is often the first sign of BE and may continue for years before a patient is diagnosed with BE.

In addition to coughing up mucus, some patients also cough up blood. This is known as hemoptysis. Some patients rarely experience hemoptysis, whereas for others it may be more common. It can also be a signal that an active infection is present in the lungs. *For more information on hemoptysis, see the section on "Hemoptysis: What You Need to Know" on page 28.*

Shortness of breath (dyspnea) is another common symptom of BE, which may occur even when lung function tests appear normal. It may feel like a heaviness in the chest or the inability to take a full, deep breath. This happens when mucus plugs, which are thick clumps of mucus, block the airways, making it harder to breathe.

Patients with BE may also experience wheezing as well as fatigue, which can result from the extra effort of breathing and from repeated lung infections.

These symptoms are not unique to BE, which can lead to delayed diagnosis. Some treatments used to manage other airway diseases may not be appropriate for BE, so an accurate and timely diagnosis is important.

Symptoms can be different for every person and may change over time. Always tell your healthcare provider if your symptoms get worse or change.

Sputum (Mucus) and What It Can Tell You

One of the most practical things you can do to monitor your lung health is to pay attention to the color of your sputum (the mucus you cough up from your lungs). Sputum color is a simple, non-invasive indicator of what may be happening in your airways.

In general, the greener or darker the sputum, the more inflammation and infection is present. A validated four-category sputum color chart (the Murray Sputum Color Chart) is used by clinicians and researchers to assess disease severity:

Murray Sputum Color Chart

Category	Appearance	What It May Indicate	Suggested Action
Mucoid	Clear or white	Low bacterial load; minimal inflammation	Routine monitoring; continue airway clearance
Mucopurulent	Pale yellow or pale green	Moderate inflammation; possible bacterial colonization	Notify provider if this is a new change; sputum culture may be warranted
Purulent	Yellow or green	Higher bacterial load; active infection likely	Contact your care team; sputum culture and possible antibiotic treatment needed
Severely Purulent	Dark green, dark yellow, or tan	High-level inflammation and infection; associated with worse outcomes	Promptly contact your care team; contact your care team promptly for urgent evaluation

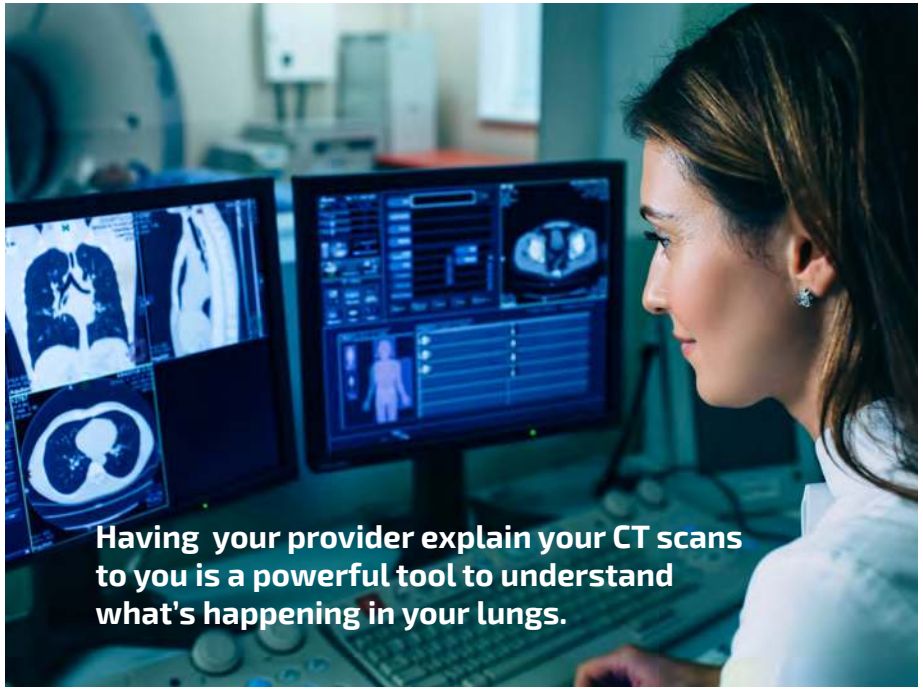
The green color associated with more purulent sputum results from the accumulation of myeloperoxidase, an enzyme released by neutrophils (immune cells) as they fight bacteria. More purulent sputum therefore reflects a higher degree of neutrophilic inflammation. Research has shown that sputum color reliably predicts bacterial colonization and the level of airway inflammation, and confirmed that sputum color is a meaningful marker of disease severity and future risk of exacerbations, hospitalization, and mortality.

Sputum color alone cannot identify which specific organism is present in your lungs, but it can provide clues about the level of inflammation. A formal sputum culture is needed to identify bacteria and guide treatment decisions. Track changes in your sputum color over time and report them to your care team. A shift from clear to yellow-green, especially alongside increased cough, fatigue, or shortness of breath, may signal an exacerbation.

Some colors are not captured on the standard chart and deserve special mention. Brown or rust-colored sputum can reflect old dried blood in the airways. Pink or frothy sputum can occasionally be seen in people with heart-related fluid accumulation. Black sputum may rarely be seen in heavy smokers or those with certain fungal infections. Any of these unusual colors should be reported to your provider.

HOW IS BRONCHIECTASIS DIAGNOSED?

Most cases of BE are diagnosed using a non-invasive, high-resolution chest CT scan without contrast. While a standard chest X-ray may show some lung abnormalities, CT scans offer greater precision in identifying BE. The CT scan shows exactly which parts of the lungs are affected and how significantly the disease has progressed, both of which help determine the best treatments. T scans also reveal distinctive patterns or appearances of BE, such as “tree-in-bud,” which describes the appearance of a small airway surrounded by tiny bud-like nodules resembling a tree branch. This pattern reflects inflammation in the small airways, usually due to infection and mucus impaction, and highlights the need for airway clearance – both to test for a bacterial infection and to remove the stagnant secretions.



Nodular bronchiectasis, characterized by small, clustered airway nodules, and cavitary bronchiectasis, marked by thick-walled air-filled spaces, are more commonly associated with recurrent respiratory infections, particularly those caused by nontuberculous mycobacteria (NTM).

Other descriptions of BE on a CT scan include the shape, often referred to as morphology:

1. **Cylindrical:** milder form of BE where the bronchus is the correct shape but does not taper properly

2. **Varicoid:** widened segments of the bronchus bulge in some areas, narrow in others, causing an irregular shape. This form of BE tends to have a higher secretion burden, meaning heavier mucus buildup in the airways.

3. **Cystic:** a severe form of BE where the airway is very dilated into a cyst-like form. Patients with cystic BE tend to have high secretion burden.

A CT scan report may also refer to the extent or distribution of the BE:

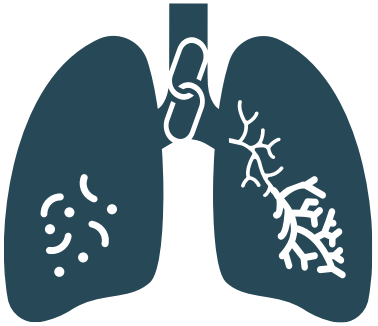
1. **Diffuse:** BE affects most or all lobes of the lung
2. **Localized:** BE affects one or two lobes, or is localized to one lung
3. **Focal:** common in post-infectious BE, the bronchiectasis affects only one or two smaller areas of a lobe

Your provider will also order respiratory cultures, pulmonary function tests, and a basic panel of blood tests aimed at finding the cause of your bronchiectasis. At a minimum, the workup should include:

- **Immunoglobulin levels** (to look for immune deficiency)
- **IgE and ABPA testing** (to look for allergic-related bronchiectasis caused by Aspergillus)
- **Sweat chloride test and/or genetic testing** for cystic fibrosis
- **Testing for alpha-1 antitrypsin deficiency**
- **Consideration of genetic testing** for primary ciliary dyskinesia (PCD)
- **Autoimmune blood tests** (for rheumatoid arthritis, scleroderma, and other systemic diseases)
- **Sputum cultures** to identify organisms

The frequency of CT scans depends on your disease severity and the recommendations of your provider. For some people with BE, a scan every three to five years may be sufficient. For others with more active disease, a CT scan every one to two years – or in some cases, every six months – may be needed. Your care team will help you determine how often they are needed. Consider asking your provider to show you your CT scans and explain them to you; understanding what is visually happening in your lungs is a powerful tool.

ARE NTM AND BRONCHIECTASIS LINKED?



Yes! Nontuberculous mycobacteria (NTM) are a type of naturally occurring bacterial organism widely found in water and soil. While many people are exposed to NTM without becoming sick, these bacteria can cause lung infections in some individuals, particularly those with underlying lung disease such as BE. There are more than 200 species of NTM; among the most common are *Mycobacterium avium complex (MAC), Mycobacterium abscessus complex, Mycobacterium kansasii, Mycobacterium chelonae, and Mycobacterium fortuitum*.

NTM and BE have a closely linked, two-way relationship. NTM infections can cause BE by leading to inflammation and permanent airway damage. At the same time, BE increases the risk of developing NTM infection many fold. The abnormal, widened airways seen in BE make it harder to clear mucus, allowing NTM bacteria to grow and remain in the lungs. Once present, NTM infection can worsen existing BE by causing additional inflammation and further lung damage.

Because of this cycle, it is not always clear whether NTM came first or developed as a result of BE. Even when the sequence is uncertain, what matters more is whether NTM is actively affecting the lungs.

If NTM is causing lung damage or disease progression, treatment may be recommended. However, in other cases, if NTM is present but not causing active disease, no treatment may be needed and careful monitoring over time will help determine whether treatment is necessary.

*To learn more about NTM, please visit **NTMinfo.org**.*

BRONCHIECTASIS INFECTIONS AND TESTING

People with BE are more susceptible to lung infections because damaged airways allow mucus to build up, creating an environment that promotes infection. While bacteria are the most common cause, viruses and fungi can also infect the lungs and contribute to flare-ups. The specific infections can vary from person to person, but some are more common in people with BE.

Routine sputum tests that include culture and antibiotic sensitivity – looking for infections and determining which drugs may work on those infections – are a cornerstone of monitoring BE. One such test is an acid fast bacilli (AFB) test to identify nontuberculous mycobacteria. Other tests would look for fungal infection which may also need to be treated.

Some types of fungi, including Aspergillus, can infect the lungs or trigger allergic reactions. Common aspergillus-related diseases affecting patients with BE include allergic Bronchopulmonary Aspergillosis (ABPA), chronic pulmonary aspergillosis (CPA), and aspergilloma.

Viral infections (such as flu, common cold, or RSV) can also trigger exacerbations.

Bacterial Infections and Treatments

The following chart covers some of the more common bacterial infections, but there are other germs that you may encounter and other treatments that may be used for you.

The treatments here are examples of some of the drugs that can be used to treat these infections, but there are other options available that your care team may recommend, based on your specific infection and lab results.

Gram-positive bugs are indicated with (+) and gram-negative with (-). Bacteria are classified as either gram-positive or gram-negative based on a lab technique called the Gram stain, in which bacteria are treated with a series of dyes. Those with a thick outer cell wall retain a purple color (gram-positive), while those with a thinner wall and an extra outer membrane wash out to pink (gram-negative). This distinction helps doctors identify the type of bacteria causing an infection.

Note: "MSSA" stands for "methicillin-susceptible staphylococcus aureus." "MRSA" stands for "methicillin-resistant staphylococcus aureus." Where the Genus and species names are used, after its first appearance, the genus name will be abbreviated throughout the rest of this document.

Class	Medication Name (Brand Names)	Form	Notes	Common Side Effects	Can Be Used to Treat
Aminoglycoside	Amikacin (Amikin)	Inhaled, IV	Patients on aminoglycosides should have a baseline hearing test before or at start of treatment. Hearing as well as BUN, creatinine, and electrolytes should be monitored at routine intervals while on therapy.	Hearing loss, tinnitus (ringing in the ears); nausea; muscle weakness; rash; poor balance; kidney problems; risk of increased respiratory adverse reactions (inhaled)	*Pseudomonas aeruginosa* (-)
	Tobramycin (TOBI)	Inhaled, IV	Patients on aminoglycosides should have a baseline hearing test before or at start of treatment. Hearing as well as BUN, creatinine, and electrolytes should be monitored at routine intervals while on therapy.	Hearing loss, tinnitus (ringing in the ears); nausea; muscle weakness; rash; poor balance; kidney problems; risk of increased respiratory adverse reactions (inhaled)	*P. aeruginosa* (-)
Carbapenem	Imipenem-cilastin (Primaxin)	Injection, IV		Itching; rash; loss of appetite; gastric upset	*Acinetobacter baumanii* (-)
	Meropenem (Merrem)	Injection, IV	Avoid driving and other tasks if you feel motor function impacted by the medication. Have regular bloodwork as instructed by your doctor.	Itching, rash, loss of appetite, gastric upset	*Achromobacter* (-) *Enterobacter cloacae* (-) *P. aeruginosa* (-)

Class	Medication Name (Brand Names)	Form	Notes	Common Side Effects	Can Be Used to Treat
Beta-lactam	Aztreonam (Cayston, Azactam)	IV, inhaled		Itching, rash, loss of appetite	*Klebsiella pneumoniae* (-) *P. aeruginosa* (-)
Cephalosporin	Cefepime (Maxipime)	IV	Have routine bloodwork as instructed by your doctor.	Rash; diarrhea; nausea	*E. cloacae* (-) *K. pneumoniae* (-) *P. aeruginosa* (-)
	Ceftazidime (Fortaz)	IV	Avoid driving and other tasks if you feel motor function impacted by the medication. Have regular bloodwork as instructed by your doctor.	Itching, rash; red or irritated eyes; sores in the mouth, throat, nose, or eyes; abnormal kidney function; fever, chills, or sore throat; fatigue; weakness	*P. aeruginosa* (-)
	Ceftriaxone (Rocephin)	IV, intra-muscular injection	Have regular bloodwork as instructed by your doctor. Monitor carefully if you take anticoagulants.	Diarrhea; nausea; vomiting; rash; injection site pain or swelling; headache; elevated liver enzymes; abnormal blood count; anemia; blood clotting abnormalities	*Streptococcus pneumoniae* (+) *K. pneumoniae* (-)
	Cefuroxime (Ceftin)	Pill	Have routine bloodwork as instructed by your doctor.	Diarrhea, rash, abnormal kidney function; fever, chills, sore throat; fatigue	*Haemophilus influenzae* (-)
	Cephalexin (Keflex)	Oral capsule, liquid suspension	Monitor for adverse skin reactions. Have regular bloodwork as instructed by your doctor.	Reddening of skin; stomach pain; diarrhea; urinary or kidney abnormalities; fatigue	*MRSA* (+) *MSSA* (+) *Moraxella catarrhalis* (-)

Class	Medication Name (Brand Names)	Form	Notes	Common Side Effects	Can Be Used to Treat
Cycline	Doxycycline (Vibramycin)	Pill	Avoid prolonged sun exposure and have regular bloodwork as instructed by your doctor.	Sun sensitivity; nausea; diarrhea; dizziness; rash; elevated liver enzymes; blood count abnormality; pancreatitis	*MRSA* (+) *MSSA* (+)
	Minocycline (Minocin)	Pill	Avoid prolonged sun exposure and have regular bloodwork as instructed by your doctor.	Sun sensitivity; nausea; diarrhea; dizziness; rash; elevated liver enzymes; blood count abnormality; pancreatitis	*Stenotrophomonas maltophilia* (-)
Glycopeptide	Dalbavancin (Dalvance)	IV	Have regular bloodwork as instructed by your doctor.	Fatigue, anxiety, dizziness, diarrhea, nausea, fever	*MRSA* (+) *MSSA* (+)
	Vancomycin (Vancocin, Firvanq)	Pill, IV	Have regular bloodwork as instructed by your doctor. Have your hearing checked.	Fever; chills; sore throat; pain while urinating; flushing or rash on skin; abdominal pain; nausea; hearing changes; abnormal kidney function	*MRSA* (+) *MSSA* (+) *S. pneumoniae* (+)
Oxazolidinone	Linezolid (Zyvox)	Pill	Have regular bloodwork as instructed by your doctor. Have your eyesight checked. Monitor your blood glucose levels on this medication.	Rash; abnormal blood count; headache; upset stomach; nausea; diarrhea; vomiting; dizziness; numbness in hands and feet; vision changes	*MRSA* (+) *MSSA* (+) *S. pneumoniae* (+)

Class	Medication Name (Brand Names)	Form	Notes	Common Side Effects	Can Be Used to Treat
Penicillin	Amoxicillin (Augmentin)	Pill	Have routine bloodwork as instructed by your doctor.	Nausea, rash, diarrhea	*MSSA* (+) *S. pneumoniae* (+) *H. influenzae* (-) *K. pneumoniae* (-) *M. catarrhalis* (-)
	Dicloxacillin (Dynapen, Pathocil)	Oral capsules, liquid suspension	May interact with warfarin and increase bleeding risk; monitor anticoagulation levels.	Nausea; vomiting; diarrhea; rash; headache	*MSSA* (+)
	Oxacillin (Bactosil, Prostaphlin)	Pill		Fatigue; anxiety; dizziness; diarrhea; nausea; fever	MSSA (+)
Penicillin/beta-lactam combo	Ampicillin/ sulbactam (Unasyn)	IV (oral form available outside the US)		Nausea; rash; diarrhea	*A. baumanii* (-)
	Piperacillin/ tazobactam (Zosyn)	IV	Have regular bloodwork as instructed by your doctor.	Diarrhea; nausea; headache	*Achromobacter* (-) *E. cloacae (-)* *P. aeruginosa* (-)
Polymyxin	Colistin/Polymyxin E (Coly-Mycin M, Colobreathe)	IV, inhaled, intra-muscular injection	BUN, creatinine, and electrolytes should be monitored at routine intervals while on therapy.	Abnormal kidney function; nausea; rash; diarrhea; risk of increased respiratory adverse reactions (inhaled)	*P. aeruginosa* (-)
	Polymyxin B	IV	Have regular bloodwork as instructed by your doctor.	Abnormal kidney function	*A. baumanii* (-)

Class	Medication Name (Brand Names)	Form	Notes	Common Side Effects	Can Be Used to Treat
Quinolone	Ciprofloxacin (Cipro)	Pill	At-risk patients should check EKG for QTc interval prior to therapy and after treatment has started	Upset stomach; rash; diarrhea; headache; loss of appetite; EKG abnormality; dizziness; may cause tendon abnormalities or tears, low blood sugar, or adverse psychiatric reactions including depression	*A. baumanii* (-) *E. cloacae (-)* *H. influenzae* (-) *K. pneumoniae* (-) *P. aeruginosa* (-)
	Levofloxacin (Levaquin)	Pill	At-risk patients should check EKG for QTc interval prior to therapy and after treatment has started.	Upset stomach; rash; diarrhea; headache; loss of appetite; EKG abnormality; dizziness; may cause tendon abnormalities or tears, low blood sugar, or adverse psychiatric reactions including depression	*S. pneumoniae* (+) *A. baumanii* (-) E. cloacae (-) H. influenzae (-) K. pneumoniae (-) S. maltophilia (-) P. aeruginosa (-)
	Moxifloxacin (Avelox)	Pill	At-risk patients should check EKG for QTc interval prior to therapy and after treatment has started.	Upset stomach; rash; diarrhea; headache; loss of appetite; EKG abnormality; dizziness; may cause tendon abnormalities or tears, low blood sugar, or adverse psychiatric reactions including depression	*S. pneumoniae* (+) *E. cloacae* (-) *H. influenzae* (-)
Sulfonamide	Trimethoprim-sulfameth-axazole (Bactrim, Septra)	Pill, IV, liquid suspension		Itching; loss of appetite; diarrhe a; abdominal pain; dry mouth and skin; orange or brown skin discoloration	*MRSA* (+) *MSSA* (+) *Achromobacter* (-) *A. baumanii* (-) *E. cloacae* (-) *K. pneumoniae* (-) *M. catarrhalis* (-)

For more information on nontuberculous mycobacteria (NTM) and medications used to treat them, visit **ntminfo.org.**

Fungal Infections and Treatments

People with bronchiectasis are also more vulnerable to lung infections caused by fungal pathogens such as *Aspergillus fumigatus, Exophiala* spp., *Trichosporon* spp., and *Scedosporium* spp. Below are some of the anti-fungal treatments used to treat them.

Medication Name (Brand Names)	Form	Notes	Common Side Effects
Amphotericin B (AmBisome)	IV	Have regular bloodwork as instructed by your doctor.	Fever; chills; nausea; vomiting; headache; low blood pressure; abnormal kidney function; low potassium or magnesium
Isavuconazole (Cresemba)	Oral capsules, IV	Monitor liver function during treatment. Contraindicated in patients with short QT syndrome.	Nausea; vomiting; diarrhea; constipation; stomach pain; headache; rash; elevated liver enzymes
Itraconazole (Sporanox, Onmel)	Oral capsules, liquid suspension, IV	Have regular bloodwork and monitor cardiac function regularly as instructed by your provider.	Nausea; vomiting; diarrhea; stomach pain; headache; rash; dizziness; elevated liver enzymes
Posaconazole (Noxafil, Posanol)	Tablet, liquid suspension, IV	Have regular bloodwork and monitor cardiac function regularly as instructed by your provider.	Nausea; vomiting; diarrhea; stomach pain; headache; rash; dizziness; elevated liver enzymes
Voriconazole (Vfend)	Tablet, liquid suspension, IV	Have EKG for QTc interval prior to therapy and after treatment has started. Have regular bloodwork as instructed by your provider.	Nausea; vomiting; diarrhea; headache; EKG abnormalities; vision changes; elevated liver enzymes; skin reactions

Colonization vs. Infection

Not every organism found in the airways causes an active infection. If someone is "colonized," this means the infectious organism is somewhere in or on the body but is not causing symptoms. Some people with bronchiectasis carry bacteria or other organisms in their lungs long-term without feeling sick. This is called "asymptomatic infection." Symptomatic infection, or disease, begins when the infectious organism enters the body and begins to replicate and cause symptoms. While colonizing organisms may not require treatment right away, identifying and monitoring them is important because they may turn into a symptomatic infection later on.

Testing for Infections

To properly treat an infection, your providers need to know which organism is causing it. This begins with testing your sputum. Routine sputum testing is one of the most important aspects of managing bronchiectasis since organisms in the lungs can change over time. This testing should be repeated at regular intervals or when your symptoms change.

Sputum Collection

Before testing can be done, a sputum sample needs to be collected. The preferred method is to cough up sputum and collect it in a sterile container. If you are unable to produce sputum on your own, there are several techniques that can help, including huff coughing, nebulized hypertonic saline treatments, and devices such as positive expiratory pressure (PEP) or high frequency chest wall oscillation devices. Once collected, the sample can be refrigerated overnight before being taken to the lab for testing.

Another intervention to collect a sputum sample is bronchoscopy, where a thin, flexible tube with a tiny camera and light on the end is gently guided through your nose or mouth, down your throat, past your vocal cords, and into your airways. A saline rinse loosens mucus that is then suctioned out as your sample. You will be given a sedative and a numbing spray beforehand. The procedure typically takes 30–60 minutes, after which your throat may feel temporarily sore or numb.

Lab Testing and Culturing

After the sputum sample reaches the lab, it is tested using a process called a culture. This process allows laboratory professionals to identify any bacteria, fungi, or other organisms already present in the sample. If organisms are identified, the results help providers choose the most effective treatment and avoid unnecessary antibiotics.

TREATMENT AND MANAGEMENT: THE EMPHASIS IS ON YOU!

When it comes to BE treatment and management, there is no one-size-fits-all approach. What works well for one person may not work for another. That's why your care plan should be tailored to your individual symptoms, test results, and lifestyle.

Staying informed about treatment options, communicating openly with your healthcare team, keeping regular medical appointments, and taking an active role in your care all play an important role in managing BE. While BE treatment should be highly individualized, nearly everyone benefits from regular airway clearance.

Airway Clearance

Airway clearance is another cornerstone of BE treatment and management. It helps clear the trapped mucus that leads to a cycle of infection, inflammation, damage, and further mucus retention. Most people with BE benefit from daily airway clearance to achieve disease stability and prevent progression. The key to successful airway clearance is finding what works best for you. Many people find that combining multiple techniques works better than relying on one single method.

There are several techniques for clearing mucus, including:

- **Positive Expiratory Pressure Devices (PEP)** – This is a handheld tool that causes resistance and vibration when you exhale into it, which causes the mucus to loosen so it is easier to cough out.

- **Nebulized saline treatments** – This type of nebulizer treatment is frequently used to stimulate mucus production. It is often used successfully in conjunction with other airway clearance devices such as a positive expiratory pressure (PEP) device.

- **High-frequency chest wall oscillation vests** – This is a wearable device that helps "shake" the chest to loosen thick mucus, making it easier to cough up.

- **Postural drainage** – This method involves positioning your body in specific ways to use gravity to help drain mucus from parts of the lungs. Respiratory therapists can help identify which positions may work best for specific lung regions.

- **Deep breathing exercises and huff coughing** – These techniques work together to loosen mucus from smaller airways to larger airways, and then help cough it out using controlled, forceful breathing.

- **Regular physical activity** – Aerobic activity, including walking, biking, yoga, or swimming, can promote deeper breathing and help mucus movement.

Antibiotics

Antibiotics can play an important role in managing bronchiectasis, but they must be used carefully since they can cause side effects and contribute to antibiotic resistance.

In people with BE, the total number of germs in the airways does not always increase as the disease progresses. Instead, the balance of organisms often changes where one or two can begin to dominate, driving inflammation and infection.

Before starting antibiotics, your doctor should test your sputum to see which bacteria and/or fungi are present in your lungs. This testing ensures the most effective antibiotic is prescribed and avoids unnecessary or ineffective treatments.

For patients who develop frequent bacterial infections despite consistent airway clearance, chronic antibiotic therapy may be recommended. This often involves using a nebulizer to inhale the antibiotics on a regular rotating schedule. The type of antibiotic and specific schedule depends on the bacteria being treated and you and your provider's preferences.

Other Medications

In addition to antibiotic use, some people with BE may benefit from the use of other medications to help manage symptoms and support lung health.

- **DPP-1 inhibitors** - This new class of medication inhibits the dipeptidyl peptidase 1 (DPP-1) enzyme, which reduces inflammation in the lungs, thereby reducing the number of exacerbations. This medication works locally in the lungs, rather than throughout the body, helping to preserve overall immune system function.

- **Bronchodilators** - These medications open the airways and can help make breathing easier. This type of medication can help loosen mucus and make airway clearance treatments more comfortable and effective. Bronchodilators are also used when BE occurs alongside asthma or COPD, helping address those additional lung conditions.

- **Corticosteroids** - This type of medication may be used in BE if there are coexisting conditions such as asthma, COPD, or inflammatory bowel disease-associated BE that require steroid treatment. For people with bronchiectasis alone, steroids are usually avoided because they do not provide benefits, can cause side effects, and may make you more vulnerable to infections.

- **Mucoactive agents** (such as hypertonic saline): These agents help thin and loosen mucus. Some patients respond well to them, though results in research studies have been mixed. They may be appropriate for some patients.

Surgery

Surgery for BE is usually only used in cases where there is more extensive damage in one specific area of the lung which hasn't responded to other treatments. When surgery is used, typically only the affected portion of the lung is removed. Antibiotics are usually started before surgery to help prevent further spread of infection. While surgery is less common and reserved for very specific situations, it can be an appropriate option for some patients.

MANAGING SIDE EFFECTS

BE treatment plays an essential role in slowing disease progression, but like all therapies, there can be side effects. The good news is that many of these can be managed with small adjustments. If you experience unwanted side effects, work with your care team to help resolve them and don't make any treatment adjustments on your own.

Airway Clearance Techniques

Some people may experience chest or muscle soreness, fatigue, lightheadedness or shortness of breath, and cough-related throat irritation after airway clearance sessions. However, moving out retained mucus helps minimize infections and makes it a little easier for medications to do their work.

Helpful tips:

- Start slowly and build up intensity over time
- Use proper positioning and techniques (a respiratory therapist can help)
- Stay well hydrated to keep mucus easier to clear
- Let your provider know if pain or dizziness occurs or persists

Bronchodilators

Bronchodilators play an important role in helping open the airways. Sometimes, they may cause tremors or shakiness, rapid heartbeat, nervousness, problems sleeping, and headaches.

Helpful tips:

- Wait and see how your body adjusts as effects often lessen over time
- Don't take the medication close to bedtime
- Time your dosages so they are not taken too close together or right before strenuous activity
- Use as directed before airway clearance to improve effectiveness
- Report persistent or bothersome symptoms

Corticosteroids

Inhaled and oral steroids are used to reduce inflammation. They may cause some effects, especially when used long-term. Inhaled steroids may cause oral thrush, which can be treated with medication or with medicated mouthwash, and hoarseness. Oral steroids may cause bone thinning (when used long-term), weight changes, and mood changes.

Helpful tips:

- Always rinse and spit after using inhaled steroids
- Use a spacer, if recommended, for inhaled steroids
- Have bone health, weight, and mood monitored regularly if oral steroids are used long term

DPP-1 Inhibitors

This new class of medication is used to reduce inflammation but can cause upper respiratory tract infections, headaches, rashes and dry skin, dental problems, and high blood pressure.

Helpful tips:

- Report any fever or worsening cough to your care team
- Use gentle skincare and monitor for new rashes; visit a dermatologist if needed
- Get regular dental checkups and cleanings and brush your teeth as recommended by your dentist
- Monitor blood pressure regularly

Oral Antibiotics

Oral antibiotics, whether used to treat an active infection or to reduce inflammation, can cause possible side effects, including upset stomach, diarrhea, yeast infections, changes in taste, and increased risk of antibiotic resistance over time.

Helpful tips:

- Take medications exactly as prescribed
- Report ongoing stomach issues or new symptoms
- Ask about taking a probiotic supplement and how to time it when taking oral antibiotics

Inhaled Antibiotics

Inhaled antibiotics behave differently than oral antibiotics because they go straight into the lungs. As a result, they can cause localized side effects including coughing or throat irritation, hoarseness or voice changes, and chest tightness or bronchospasms.

Helpful tips:

- Use a bronchodilator before inhaled antibiotics if prescribed
- Always rinse your mouth and throat after treatments
- Use proper nebulizer technique and follow all guidelines for equipment cleaning
- Tell your provider if symptoms worsen or don't improve

Nebulized Treatments

Nebulized treatments deliver medication directly to the lungs. Some people notice mild throat irritation, coughing during or after treatment, throat or mouth dryness, hoarseness, dry eyes or irritation, and blurry vision during or shortly after treatment.

Helpful tips:

- Rinse your mouth after treatments if recommended
- Stay well hydrated
- Make sure the nebulizer mist is directed properly through the mouth piece or a well-fitted mask
- Keep your eyes gently closed during treatments or wear goggles
- Let your care team know if symptoms persist or worsen

EXACERBATIONS (FLARE-UPS)

An exacerbation (sometimes called a flare-up) is a worsening of your usual symptoms. During an exacerbation, you may notice a worsening cough, increased mucus, changes in sputum color or thickness, greater shortness of breath, increased fatigue, coughing up blood, a fever or night sweats.

Exacerbations are sometimes described as sentinel events in BE: tipping points of worsening inflammation, usually triggered by infection, that result in significantly worse symptoms, and can cause additional airway damage and accelerate disease progression.

Patients who frequently exacerbate may represent a more severe phenotype of bronchiectasis, and this pattern can help guide treatment decisions including consideration of anti-inflammatory therapies.

Exacerbations can be triggered by bacterial or viral infections, or inflammation and irritation from inhaled particles such as pollen or pollution.

People who experience frequent exacerbations – more than two or three per year – are at higher risk of hospitalization, more severe infections, and the need for IV antibiotics.

If your exacerbation symptoms last for more than 48 hours, contact your healthcare provider. Your care team will work to determine the cause of your exacerbation and recommend the best treatment, which may include antibiotics, airway clearance, or other supportive care. It may be necessary to drop off a sample of your sputum for culture.

Regular daily management, such as airway clearance and consistent use of prescribed medications, plays an important role in reducing the frequency and severity of exacerbations.

HEMOPTYSIS: WHAT YOU NEED TO KNOW

Coughing up blood — called hemoptysis (hem-OP-tih-sis, from the Greek words for "blood" and "spitting") — can be alarming. While it does occur in BE, it is less common than many people fear: roughly 1 in 5 patients with bronchiectasis will experience it over their lifetime. That said, when it does happen, the amount matters and knowing how to respond can make all the difference.

Hemoptysis happens because the chronically inflamed, damaged airways of bronchiectasis can weaken the blood vessels lining the lungs, making them more prone to bleeding, especially during infections or exacerbations. Not all blood that appears to come from the airway actually originates in the lungs. Nosebleeds, heart conditions, blood clots in the lungs, and other causes can all produce a bloody cough, which is why your provider will want to investigate the source carefully.

Certain medications may increase the risk for hemoptysis occurring. Non-steroidal anti-inflammatory drugs (Aspirin, Ibuprofen, Naproxen, etc) and blood thinners (Xarelto, Eliquis, warfarin, Plavix) should be taken into account when investigating hemoptysis.

How Much Blood? Why It Matters

The single most important factor in evaluating hemoptysis is how much blood is involved. Providers often use a practical benchmark: think in terms of a standard coffee mug, which holds about 250 milliliters (mL) or roughly one cup. Coughing up 500 mL — about two full mugs — over 24 hours is considered a significant amount, though any episode that concerns you deserves attention.

It can be very helpful to take a photo of what you coughed up and share it with your care team. This gives your provider a much clearer picture than a verbal description alone.

Hemoptysis is generally thought of in three levels of severity:

Mild (streaking or small flecks of blood) Blood appears as streaks mixed into mucus, or as very small flecks. The bleeding is self-limited, meaning it stops on its own, and you otherwise feel okay.

Moderate (more than streaking, or anything that worries you)
If the amount of blood concerns you — or concerns your provider when you describe or show it — treat it as moderate. This category also includes bleeding that is ongoing or comes and goes repeatedly.

Severe / Massive (large amounts, not stopping) Coughing up large amounts of blood that is not stopping is a medical emergency. Do not wait to see if it resolves.

What To Do

For mild hemoptysis:

- Call your provider or care team to report what happened and share a photo if possible.
- You may be able to **continue airway clearance cautiously**, but check with your provider first. If you are very anxious or unsure, it is reasonable to hold airway clearance for 24 hours and then resume once things have settled.
- Watch for other signs of a flare-up: increased cough, more sputum, change in sputum color, increased shortness of breath, or loss of appetite. If these accompany the bleeding, your provider may want to treat you with antibiotics. A single self-limited episode of hemoptysis in a patient who otherwise feels fine does not automatically require antibiotics.

For moderate hemoptysis:

- **Stop airway clearance** and contact your care team promptly. Your provider will likely want to evaluate you in person.
- **Make sure you let your doctor know about NSAID or blood thinner use.**
- Do not resume airway clearance until you have been bleeding-free for at least 24 hours and your provider has given the go-ahead.

For severe / massive hemoptysis:

- Call 911 or go to the emergency room immediately. This is not a situation for a message to your doctor — get emergency help right away!
- If someone is with you, ask them to stay close and help guide you.
- If you have a sense of which side of your chest the bleeding is coming from, try lying with that side *down* to help protect the other lung.
- Emergency care may include IV fluids and medications, imaging, and in some cases placement on a ventilator to protect the airway.

Other Warning Signs: When To Call 911

Go to the emergency room or call 911 immediately if you experience any of the following, regardless of how much blood you see:

- Severe shortness of breath or chest pain
- Feeling faint or dizzy
- A bluish tint to your lips or fingertips
- A rapid or pounding heartbeat

These can indicate that bleeding is affecting your ability to breathe, which is the most serious risk.

How Hemoptysis Is Treated

Once you are in the care of a medical team, the approach depends on the severity of bleeding and what is causing it.

Reversing contributing factors. If you are on blood thinners or antiplatelet medications, your team will carefully weigh whether to pause them or even reverse their blood-thinning effects with special medicines. Infections will be treated with antibiotics. Any problems with blood clotting will be addressed.

Tranexamic acid (TXA). This medication — pronounced tran-EX-am-ik AS-id — is a "clot stabilizer." It works by preventing the body from breaking down clots too quickly, which helps stop or slow bleeding. For patients hospitalized with significant but non-massive bleeding, inhaled TXA has become an increasingly common and generally well-tolerated treatment.
An oral form is also available by prescription for outpatients with recurrent low-grade bleeding. Side effects are uncommon but can include vision changes or allergic reaction.

Bronchial artery embolization (BAE). For significant or recurrent hemoptysis, the first-line procedure is bronchial artery embolization.
A radiologist threads a thin catheter into the blood vessel that is bleeding and uses coils or other agents to seal it off. Because the lungs have abundant redundant circulation, blocking one vessel is generally safe and can stop bleeding effectively. As with any procedure, there are small risks which radiologists are specifically trained to watch for.

Surgery. In rare cases where embolization cannot control the bleeding, surgical removal of the affected portion of the lung may be necessary.
This is considered a last resort for life-threatening situations, but it can be lifesaving when other options have been exhausted.

Vitamin K and Blood Clotting

Vitamin K is essential for blood clotting. It is directly responsible for producing and activating specific clotting factors in the liver. Without sufficient vitamin K, these coagulation proteins cannot bind calcium, resulting in impaired blood clotting, excessive bleeding, and bruising. If blood clotting is abnormal, your provider may administer vitamin K to help restore proper clotting function, particularly in patients who are not on blood thinners but may have vitamin K deficiency due to liver disease or poor nutrition.

Rifampin and Vitamin K — An Important Interaction for NTM Patients

Patients being treated for NTM with rifampin should be aware of an important interaction: rifampin can lower vitamin K levels, which may cause a rare but serious vitamin K deficiency leading to a bleeding disorder. If you are on rifampin and experience unusual bruising, prolonged bleeding, or hemoptysis, alert your care team promptly so your clotting function can be checked.

Make a Plan Before It Happens

The most important step you can take is to talk with your provider now, before any bleeding episode occurs, so that you have a personal action plan ready. Know who to call, when to go to the emergency room, and what to do about your airway clearance routine. Having that plan in place and sharing it with a family member or caregiver means you will not have to make difficult decisions in a stressful moment.

PULMONARY FUNCTION TESTS

Pulmonary function tests (PFTs) are a group of breathing tests, each measuring different aspects of lung function, which are routinely used to assess lung health in people with bronchiectasis. If you are newly diagnosed, PFTs can help establish a baseline that shows how much the disease has affected your breathing. Over time, these tests track disease progression and evaluate how well treatments are working. Typically, patients undergo PFTs annually.

Common PFTs include:

- **Spirometry** — Measures airflow and how quickly air can be exhaled.
- **Plethysmography** — Measures how much air the lungs can hold.
- **Diffusion capacity** — Measures how well oxygen passes into the blood.
- **Arterial or venous blood gas measurements** — Measures the amount of oxygen and carbon dioxide levels in the blood.
- **Oximetry** — Measures the oxygen level in the blood.
- **Six-minute walk test** — Measures how your lungs and heart handle activity.

FOLLOWING UP WITH YOUR CARE TEAM

With ongoing care, BE can be effectively managed. An important part of management is maintaining a strong partnership with your care team, including keeping regularly scheduled appointments.

Tips for staying on top of your care:

1. Schedule your next follow-up visit before leaving the doctor's office.
2. Contact your provider when something changes or you experience an exacerbation of your symptoms.
3. Maintain a log of your symptoms, reactions to medications, and changes to your health.
4. Keep a list of questions in between appointments.
5. Take your symptom log and question list to your appointments and talk to your care team about them.

IMPORTANT QUESTIONS TO ASK YOUR DOCTOR

If you are newly diagnosed with BE, you likely have many questions. Below is a starting list. You will probably find it helpful to bring someone with you to your appointment to ensure you don't miss important information. Bring a notebook and pen or use your phone to take notes.

1. ***How severe is my bronchiectasis?***
2. ***What parts of my lungs are most affected, and how does that affect my symptoms or treatment?***
3. ***How can I reduce fatigue and shortness of breath during daily activities?***
4. ***What tests do I need and how often will I need them?***
5. ***Based on my test results, what does my baseline show as far as how mild or severe my BE is?***
6. ***What airway clearance techniques or devices will work best for me?***
7. ***What medications should I take, and when?***
8. ***What should I do during an exacerbation?***

9. What should I do if I cough up blood (have hemoptysis)?

10. What type of exercise should I do, and how often?

11. Are there dietary or lifestyle changes that could help my lungs?

12. How could some of my other health conditions impact my BE or make it worse?

REFERRALS AND BUILDING YOUR CARE TEAM

Many people are misdiagnosed for years before finally receiving a proper BE diagnosis, highlighting the importance of putting together the right care team. Once you have the correct diagnosis, you may want to start asking for referrals. These specialists could include pulmonary, internal medicine, infectious disease, respiratory therapy specialists, dieticians, nutritionists, and mental health professionals.

As you are putting together your care team, ask questions to find the right mix of medical professionals who have experience and knowledge in treating BE and are willing to work together to create a comprehensive treatment plan.

CAREGIVERS AND FAMILIES

BE affects more than just the patient. It can impact the daily routines and emotional well-being of families and caregivers. Since caregiving can be demanding, it's important to maintain your own health and well-being by taking breaks, asking for help when needed, staying physically active, managing stress, and seeking support.

NTM Info & Research and Bronchiectasis Info & Research maintain an extensive support group network and hosts a secure online discussion platform, NTM/BE Connect, for patients and caregivers.

You can find information at **bronchiectasisinfo.org** and **ntminfo.org**. Other online resources for caregivers include the National Alliance for Caregiving (caregiving.org) and the Family Caregiver Alliance (caregiver.org).

Helpful tips for caregivers:

- Maintain up-to-date flu, pneumonia, RSV, and COVID, and other recommended vaccinations.
- Wash your hands with soap and water for 20 seconds; use hand sanitizer if soap and water are not available.
- Avoid close contact with people who have symptoms of illness.
- Develop a support system for yourself with family and friends.
- Join a support group to be reminded you are not alone in providing care.
- Schedule time for yourself.

LIVING WELL WITH BRONCHIECTASIS

Overall Health and Wellness

The key to overall health and wellness is rooted in the basics such as getting adequate sleep, eating healthy foods, maintaining regular physician visits, limiting your alcohol intake, not using (or quitting) tobacco products, and maintaining up-to-date vaccinations, especially vaccines that protect against respiratory infections.

Nutrition and Hydration

Good nutrition helps support your overall health and your ability to fight infections. It also helps you maintain a healthy weight, which is important as being underweight can make it difficult to fight infections, while being overweight can make breathing more difficult. Drinking plenty of water is also important because it helps keep respiratory secretions thinner and easier to clear from your airways. **If you are underweight, with a BMI less than 18.5, consider making an appointment with a dietician to help develop a weight gain plan.**

*For more information on eating and living well with BE, visit **ntminfo.org** or **beinfo.org**.*

Exercise and Physical Activity

Physical activity is crucial for overall health and wellness. Even simple exercise such as neighborhood walks or yoga stretching can help with airway clearance and benefit your body and mind.

If you're not sure how to get started, a formal pulmonary rehabilitation program may be helpful. These programs combine supervised exercise with education, breathing techniques, and nutritional counseling and are very effective in improving exercise capacity, reducing symptoms, and enhancing quality of life. Your care team can determine whether you qualify for a pulmonary rehabilitation program and provide you with a referral to a program in your area.

Mental and Emotional Health

When living with BE, some days and weeks may be harder than others, which is why taking care of your mental and emotional health is just as important as managing your lung health.

Support may include talking with a counselor, connecting with a support group, joining the NTM/BE Connect online patient forum, or sharing concerns with a trusted friend or family member. Making time for yourself and doing activities that bring you joy, such as a hobby, can also help reduce stress. If emotional challenges begin to affect your daily life or treatment routine, talk with your healthcare provider.

*Visit **beinfo.org** or **ntminfo.org** for more information*

TRAVEL TIPS

With a little extra planning, you can stay healthy and comfortable while traveling.

Before You Travel

- Talk with your healthcare provider, especially if you've had recent infections or frequent exacerbations
- Pack enough medications for your entire trip, plus extra in case of delays

Traveling with Airway Clearance Equipment

- Plan how you will bring and clean airway clearance devices while away from home
- Airway clearance devices such as nebulizers, inhaled medications, IV supplies, and oscillation vests are allowed on flights and should be placed in your carry-on bag whenever possible
- Check with your airline in advance for any specific policies regarding medical devices

At Airport Security

- The TSA Medical Device Notification Card may help make the screening process easier
- You can download and print the TSA card from our affiliate NTM organization at ntminfo.org/traveling-tips

While Traveling

- Stay well hydrated
- Allow time for rest
- Continue your daily airway clearance routine

After Travel

- Contact your healthcare provider if you notice worsening symptoms during or after your trip

RESEARCH AND CLINICAL TRIALS

There is exciting momentum for BE research and therapeutic development. Clinical trials and ongoing research projects are showing great advancements around BE causes and newer targeted treatments.

Participating in clinical trials can potentially give you access to new treatments and contribute to breakthroughs that can advance the field and help future patients. You can find information about clinical trial opportunities at **bronchiectasisinfo.org** or by visiting clinicaltrials.gov.

Many larger medical practices and medical centers also participate in research as clinical trial sites. Your physician may be at one of those sites, but even if they are not, you can still be screened for and enroll in a clinical trial at a site close to you.

SUPPORT GROUPS

You don't have to face bronchiectasis alone. Support groups can play an instrumental role in helping you connect with others. We offer online and in-person support groups. To access these resources, please visit **ntminfo.org** or **beinfo.org**. In addition to support group information, you can also find a provider referral list, published research, and more.

Join our secure online patient forum, NTM/BE Connect, where patients from around the world come together to share experiences, exchange helpful information, and support one another on their journey.

ABOUT NTMir AND BEir

NTM Info & Research (NTMir) is a 501(c)(3) nonprofit organization dedicated to supporting patients with bronchiectasis by providing medical education and promoting research. NTM Info & Research, which focuses on NTM lung disease, was established in 2002. Because many NTM patients also have bronchiectasis, Bronchiectasis Info & Research (BEir) was created as an affiliate to address the specific needs of the bronchiectasis community.

Both NTMir and BEir serve patients, healthcare providers, and researchers dealing with bronchiectasis, NTM, and related health concerns. We advocate for early diagnosis, improved treatments, and research, and we bring the concerns of our community to government officials and agencies that guide, regulate, and fund research and therapies for the disease.

Our educational materials are provided free of charge. Please consider supporting our work; you can give online at **beinfo.org**.

GLOSSARY OF TERMS

Allergic Bronchopulmonary Aspergillosis (ABPA): An allergic reaction to a fungal infection caused by Aspergillus that causes wheezing, shortness of breath, cough, and sometimes fever.

Alpha-1 antitrypsin deficiency: An inherited condition in which the body produces insufficient amounts of a protective protein (alpha-1 antitrypsin). Without enough of this protein, the lungs can become damaged over time, increasing the risk of emphysema and bronchiectasis.

Antibodies: Proteins that are made by the immune system to help identify and fight infections.

Antifibrinolytic: A type of medication that prevents the body from breaking down blood clots too quickly, helping to stabilize clots that have formed. Tranexamic acid (TXA) is an example used in the management of hemoptysis.

Aspiration: When food, liquid, saliva, or stomach contents accidentally go into the lungs during swallowing or breathing.

Asthma: A chronic condition where the airways in the lungs become inflamed and narrow, making it hard to breathe.

Autoimmune disease: A condition in which the body's immune system attacks its own healthy tissues instead of protecting them from infection.

Bronchial artery embolization (BAE): A procedure in which a radiologist uses a catheter to locate and seal off a blood vessel in the lung that is causing significant bleeding.

Bronchial tubes: The airways inside the lungs that carry air in and out.

Bronchiectasis (BE): A disease characterized by permanent, physical damage to the airways that causes chronic cough, shortness of breath, and wheezing, as well as an increased likelihood of recurrent infections.

Bronchodilators: A medication that opens the airways and can help make breathing easier.

Bronchoscopy: A procedure in which a thin, flexible tube with a camera is guided into the airways to collect sputum sample or examine the airways.

Chest CT scan: An imaging test that captures two-dimensional images that appear as "slices," providing clearer, more detailed views of the lungs, heart, and surrounding areas.

Chronic Obstructive Pulmonary Disease (COPD): A generalized designation for diseases involving persistent airway obstruction such as emphysema.

Cilia: Tiny hair-like structures that line the airways and work continuously to propel mucus and debris up and out of the lungs.

Colonization: The presence and growth of bacteria or other microorganisms in the body without causing infection or symptoms.

Corticosteroids: A type of steroid that helps reduce inflammation, swelling, and allergic reactions in the body.

Culture: A laboratory test that is used to grow and identify bacteria or other microorganisms from a patient sample (such as blood, urine, sputum, or tissue).

DPP-1 Inhibitors: A new class of drugs that reduces inflammation in the lungs by inhibiting the dipeptidyl peptidase 1 (DPP-1) enzyme, thereby reducing the number of exacerbations.

Dyspnea: Shortness of breath.

Eosinophils: A type of white blood cell that typically rises in response to allergic conditions or certain infections.

Exacerbation: A flare-up of symptoms, often caused by bacterial or viral infections, inflammation, or irritation.

GERD (Gastroesophageal Reflux Disease): A digestive condition in which stomach contents repeatedly flow backward into the esophagus, especially when lying down or asleep. Also called acid reflux.

Gram-negative bacteria: A group of bacteria that can cause respiratory infections

Hemoptysis: Coughing up blood from the airways or lungs.

Hypogammaglobulinemia: A condition where the body does not produce enough immunoglobulins (antibodies), making it harder to fight infections.

Idiopathic: Used to describe a disease or condition that develops for an unknown reason.

Mucus: The slippery substance produced by the airways to trap germs and particles. Also called phlegm.

Mucus plugs: Thick clumps of mucus that block the airways, making it harder for air to move in and out of the lungs.

Nebulizer: A device used to administer medication to people in the form of a mist inhaled into the lungs.

Neutrophils: A type of white blood cell that is a key part of the immune response to bacterial infection.

Nontuberculous mycobacteria (NTM): A type of naturally occurring bacterial organism widely found in water and soil, which can cause lung infections in some individuals, particularly those with bronchiectasis.

Organism: Any living thing, including bacteria, viruses, fungi, and even parasites.

Oscillation vests: A wearable device that helps "shake" the chest to loosen thick mucus, making it easier to cough up.

Phenotype: The observable characteristics or presentation of a disease in an individual patient including symptoms, physical findings, imaging results, lab markers, and how the disease behaves over time.

Positive Expiratory Pressure (PEP) devices: A handheld tool that causes resistance and vibration when you exhale into it, which causes the mucus to loosen so it is easier to cough out.

Primary ciliary dyskinesia (PCD): An inherited condition in which the cilia (tiny hair-like structures in the airways) do not work properly

Pulmonary function tests (PFTs): A group of breathing tests, each measuring different aspects of lung function.

Respiratory secretions: The broad clinical term for fluids produced anywhere in the respiratory tract. This can include mucus, saliva, inflammatory fluid, or infected material.

Rifampin: An antibiotic commonly used as part of treatment regimens for NTM and tuberculosis.

Sputum: Mucus that comes from the lungs and is coughed up, often collected for culturing and laboratory testing.

Tranexamic acid (TXA): An antifibrinolytic medication used to help control bleeding by preventing the body from breaking down blood clots too quickly. Used to treat hemoptysis.

NOTES

ALL THE INFORMATION CONTAINED IN THIS PAMPHLET AND MORE CAN BE FOUND ONLINE AT **BEINFO.ORG**

BE ir Bronchiectasis Info & Research

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> ***"I used to think I was the only one dealing with this. Finding a community of people who truly get it was a turning point for me. The support and education I've found have helped me feel less alone and more in charge of my own health."***
>
> — Carl B., patient

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