

A COUGH IS ONE THING

COUGHING
OVER & OVER
& **OVER**
— IS ANOTHER —



Coughing, fatigue, shortness of breath—
if you have these symptoms over and over
and already suffer from a lung condition, like
bronchiectasis, COPD, or asthma, it could
be a sign of **NTM lung disease**.

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about**NTM**

WHAT IS **NTM LUNG DISEASE?**

Nontuberculous mycobacterial (NTM) lung disease is a serious infection caused by bacteria that are **common in the environment** and can cause lung damage. They are aerosolized, which means that the bacteria can exist in water and soil particles that are in the air. People can get NTM lung disease when they breathe in the bacteria.

While NTM lung disease is considered rare, cases in the US are rising, growing 8% each year. In 2018, it was estimated that 75,000–105,000 patients were diagnosed with NTM lung disease in the US.

The most common species of NTM in the US is *Mycobacterium avium* complex (MAC).

HOW NTM AFFECTS **YOU AND YOUR LUNGS**

NTM lung disease typically develops in people with preexisting lung conditions. Some of these lung conditions are **bronchiectasis, COPD, and asthma**. People can have NTM for years without knowing it.

NTM can make you sick and cause you to experience symptoms like coughing, fatigue, and shortness of breath. Over time, **your symptoms can worsen**, because NTM lung disease is progressive. That means the infection gets worse over time and can result in severe, permanent lung damage.



For questions about NTM, talk to your doctor.

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YOUR LUNG CONDITION COULD PUT YOU AT RISK

Everyone comes into contact with NTM bacteria during their daily lives. NTM bacteria can be found in places such as tap water, showerheads, steam from hot tubs, and soil from parks and gardens. However, not everyone is at risk of getting NTM lung disease. Most people do not become infected because their lungs are healthy enough to clear NTM bacteria.

People with a history of lung conditions, like **bronchiectasis, COPD, or asthma**, are more likely to develop an infection. You can also get infected if you have had severe or chronic pneumonia.

That's because the damage from these conditions can make it easier for NTM to infect your lungs, and more difficult to get rid of NTM. This puts people with lung conditions at a higher risk for NTM lung disease.

DID YOU KNOW?



APPROXIMATELY

50%

Approximately 50% of people with bronchiectasis may have active NTM lung disease



16x

People with COPD are almost 16 times more likely to get NTM

NTM is **NOT** considered contagious

WHO ELSE IS AT RISK?



NTM lung disease is more common in women. People aged 65 and older, a population that is expected to **nearly double by 2030**, are at an increased risk.

People who have weakened immune systems can also develop NTM infections, including those taking medications which affect immune response.



Some areas of the US have higher rates of NTM lung disease. In fact, 7 out of 10 cases occur along a coastal area.

If this sounds like you, talk to your doctor about whether or not you may be at risk.

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RECOGNIZING THE SYMPTOMS

The symptoms of NTM lung disease are so similar to other lung conditions that NTM is sometimes misdiagnosed or not diagnosed at all.

Many people who have symptoms think they're due to the lung condition they already have. For example, if you have bronchiectasis, you may be coughing a lot. But that cough may not just be from bronchiectasis. It could also be from NTM.

So how can you tell if it's NTM and not just your current lung condition acting up?

Well, the truth is, it's very difficult. But, there are tests your doctor can use to see if it's NTM.

WHAT ARE THE KEY SYMPTOMS?

If you have NTM lung disease, you may experience one or several of these symptoms that just won't go away, or are getting worse:



Coughing

It may be a chronic cough that you can't get rid of like a "coughing fit," or a cough that comes and goes. You may have a cough that is dry, brings up mucus, keeps you up at night, or brings up blood. **If you are coughing up blood, call or visit your doctor right away**



Feeling Tired Often

Being exhausted, making it hard to do daily activities



Weight Loss and/or Lack of Appetite

Sudden, unexplained weight loss and/or when you don't feel like eating



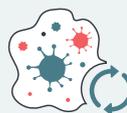
Trouble Breathing/Shortness of Breath

When everyday activities, like walking your dog or climbing stairs, leave you short of breath, with a wheeze, or with tightness in your chest



Fever

A slight fever that may also include night sweats and chills



Recurring Infection

If you keep getting a lung infection or pneumonia



Symptoms Don't Get Better With Medicine

You may have taken medications for other lung conditions over a long period of time. But despite taking medicine, you keep getting sick

IF YOU HAVE:



Bronchiectasis + NTM

Your symptoms, like a cough, may get worse and you could find yourself using airway clearance devices more often



COPD or ASTHMA + NTM

You may experience more flare-ups, difficulty breathing, and you may have a harder time catching your breath

For questions about NTM symptoms, talk to your doctor.

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GETTING TESTED

It's important to get tested for NTM as soon as possible because NTM lung disease is progressive. This means that it gets worse over time, causing more damage to your lungs. Your symptoms can get worse too.

Since the symptoms of NTM lung disease are similar to other lung conditions, diagnosis can be delayed. Many people who have it may not know it for months or sometimes years. In fact, 2 out of 3 people with NTM have **moderate to severe lung disease** by the time they're finally diagnosed.

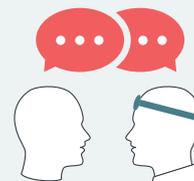


To help determine if you have NTM lung disease, your doctor may:

- Perform a **physical exam**
- Review your **medical history**
- Collect a **sputum culture**, which involves you coughing up mucus for your doctor to analyze
- Do a **chest CT scan**, where a specialized machine takes a picture of your body that shows any damage in your lungs

WHAT IF YOU'RE DIAGNOSED?

There are treatment options available for NTM lung disease. You and your doctor should work together to determine if you need treatment. You may be prescribed a treatment regimen or you may be referred to a specialist who has more experience treating people with NTM lung disease.



If you do start treatment, sticking to your treatment regimen is extremely important. That's because when you stay on treatment, there is a greater chance you could test negative for NTM.

UPDATED 2020 NTM TREATMENT GUIDELINES*

The NTM treatment guidelines were created by leading scientific communities to provide doctors with recommendations for the treatment of NTM lung disease.



Review the guidelines and speak to your doctor to find out if these guidelines could impact your treatment plan.

Learn more at

AboutNTM.com/Guidelines

SUPPORT AND RESOURCES

Useful tools that can help you throughout your journey are available at [AboutNTM.com](https://www.aboutntm.com).

Connect with people living with NTM

You might have a lot of questions, but there are NTM communities for people to support one another

- NTM Info & Research support groups
- Bronch and NTM 360 Social online community
- The American Lung Association online community

Watch real NTM stories

You are not alone. People with NTM have shared their stories in hopes of spreading more awareness of this rare disease.

Get to know them and learn from their experiences at

[AboutNTM.com/Stories](https://www.aboutntm.com/stories)

Read *Voices of NTM Lung Disease* eMagazine

Discover helpful insights for all who come in contact with the condition. Stories and tips from patients, caregivers, physicians, and advocacy groups round out a community of support.

Download the eMagazine at

[AboutNTM.com/eMag](https://www.aboutntm.com/emag)

Join *AboutNTM Support*

If you think you could have NTM lung disease or have already been diagnosed, sign up for the *AboutNTM Support* program. There, you will receive helpful information, support, and resources to help you along the way.

Sign up for more information and resources at

[AboutNTM.com/Support](https://www.aboutntm.com/support)

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TALK TO **YOUR DOCTOR**

If you have been diagnosed or think you may have NTM lung disease, there is something you can do. **Talk to your doctor or a specialist**, like a Pulmonologist or Infectious Disease Specialist — someone who has experience treating people with NTM. Ask if getting tested or starting treatment for NTM may be right for you. The enclosed **Doctor Discussion Guides** can help you prepare which questions to ask.



For more information, visit AboutNTM.com/More or talk to your doctor

about**NTM**

*Guidelines developed by ATS/ERS/ESCMID/IDSA. ATS=American Thoracic Society; ERS=European Respiratory Society; ESCMID=European Society of Clinical Microbiology and Infectious Diseases; IDSA=Infectious Diseases Society of America.