

# VOICES OF



# NTM LUNG DISEASE

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## VOICES OF NTM LUNG DISEASE

### **About *Voices of NTM Lung Disease***

The *Voices of NTM Lung Disease* eMagazine shares different perspectives from those familiar with this chronic condition to support readers throughout their own journeys. This issue discusses what to expect after an NTM lung disease diagnosis, with tips to help reduce exposure to NTM bacteria and for talking to your doctor about ways to manage the condition.



### **How My Life Has Changed Since My NTM Lung Disease Diagnosis**

Barbara H. shares the impact of NTM lung disease on her life since being diagnosed 5 years ago, including changes that she's made to help reduce her exposure to NTM bacteria.\*



### **Supporting a Loved One With NTM Lung Disease**

Mary S. discusses how she supports her longtime friend, Barbara, and provides advice for other friends or loved ones of NTM lung disease patients.



### **How to Work with Your Doctor to Better Understand the Complexities of NTM Lung Disease**

Dr. Colin Swenson, Pulmonologist and Director of the NTM & Bronchiectasis Clinic at Emory University School of Medicine, provides his perspective on ways you can work with your doctor to better understand the disease, including important questions to ask.\*



### **Advocacy Spotlight: How NTM Info & Research (NTMir) Helps Navigate the Road After Diagnosis**

Read more about how NTMir is helping guide patients through the many questions and challenges they'll face following diagnosis and throughout their NTM lung disease journey.

\*Authors were compensated for their content and time.

# How My Life Has Changed Since My NTM Lung Disease Diagnosis

By Barbara H., NTM Lung Disease Patient



**W**hen I was diagnosed with NTM lung disease in 2014, I felt overwhelmed and scared, but also relieved to have an explanation for how I was feeling. I quickly learned, however, that diagnosis was just the beginning of a long road that would change how I spent my days.

After diagnosis, I set out to learn everything I could about NTM lung disease, reading every article and watching every video to understand why I was at risk for this condition and how to manage my symptoms.

I have found that there are ways to limit my exposure to this potentially harmful bacteria that can be found everywhere in the environment. The following are steps I take to reduce my contact with the bacteria every day, no matter where I happen to be.

## Rethinking Daily Activities to Reduce Exposure

After being diagnosed, I talked to my doctor about steps that I could take in my daily life to reduce my exposure to NTM bacteria. For example, I learned NTM bacteria can be found in water from sinks and refrigerators, so I try to drink spring water. I also installed medical grade water filters within my faucets and showerheads where NTM bacteria can be found, and keep my hot water temperature at least 130°F.

In the bathroom, I found that increasing the exhaust rate and disinfecting showerheads also helped limit my exposure to the bacteria.

I don't garden or keep plants in my home anymore, but if that's a hobby of yours, I've heard others say they wear a mask and use wet soil to limit their contact with dirt particles.

## Avoiding NTM Bacteria on the Go

It can be more challenging to protect yourself away from home, but it's often just a matter of planning ahead. If I'm traveling or on vacation, I limit my time in hot tubs, spas, and indoor swimming pools that send water vapor into the air. If a restaurant doesn't have bottled water, I'll just ask them if I can use my own.

I find that exercising daily helps me physically and emotionally, so I've started walking with my friend Mary, who has been a great source of support to me. We love walking and hiking, but avoid swampy areas, ponds, creeks and rivers since these areas can have NTM bacteria.

While these avoidances may seem inconvenient, taking these steps have helped reduce my potential exposure to NTM bacteria.

## Surround Yourself with Support

When I was first diagnosed with NTM lung disease, I saw a video posted by another patient talking about hope. I felt inspired and decided to reach out. She became the first of many people living with NTM lung disease I would connect with on my journey.

Over the years, a group of us became acquainted through email. We gradually created a network of NTM lung disease patients who were able to understand and empathize with each other's experiences. Many of us have even met in person, getting to know each other beyond our NTM lung disease diagnoses.

These relationships have reassured me that I'm never alone on my NTM lung disease journey, no matter how scared or overwhelmed I may feel at times.

## Know if You're at Risk

My test results showed that I have not one, but two lung conditions. In addition to NTM lung disease, I have bronchiectasis, or damaged airways. At the time I didn't know that living with this lung condition, or others like asthma or chronic obstructive pulmonary disease (COPD), increased my risk for developing NTM lung disease.

If you or a loved one who has one of these lung conditions and is also experiencing NTM lung disease symptoms, like chronic coughing, feeling tired often and shortness of breath, learning about the potential risk factors may help encourage earlier discussions with doctors.

Risk factors include:

- **History of Lung Conditions:** People with lung conditions, like bronchiectasis, COPD or asthma are more likely to develop NTM lung disease because the damage from these conditions can make it easier for NTM bacteria to infect their lungs.
- **Weakened Immune Systems:** People with weakened immune systems may be more at risk, including those taking medications that affect immune response.
- **Age:** The people most at risk for NTM lung disease are those aged 65 and older.
- **Gender:** NTM lung disease is more common in women than in men.
- **Location:** The 10 states that have the highest prevalence rates of NTM lung disease are Florida, New York, Texas, California, Pennsylvania, Ohio, New Jersey, Georgia, Illinois and Arizona.



# Supporting a Loved One With NTM Lung Disease

By Mary S., Friend of NTM Lung Disease Patient

Having a friend or loved one with a chronic and progressive condition teaches you many things: patience, understanding and adapting to lifestyle changes after diagnosis. But for me, it taught me the importance of listening and being there for my friend, Barbara, along her journey.

Barbara and I met eight years ago when I sat next to her in a yoga class. We somehow ended up talking about our families, current events and our shared love of reading, and decided to keep the conversation going by taking weekly walks together. It was on these walks that I noticed Barbara started having coughing fits and got tired quickly.

One day Barbara told me she was living with a progressive and chronic condition called nontuberculous mycobacterial (NTM) lung disease. As her friend, I was upset that she had to face this health issue and wanted to know how I could help. I realized the best way I could show Barbara my support was to “walk with her” and let her know she wasn’t alone.

From speaking with Barbara, I understand that people who are living with NTM lung disease may be frightened about their diagnosis and the road ahead. This is my advice for helping a friend or loved one who may be facing a similar journey.

## Listen and Understand Their Experience

Barbara’s diagnosis made our friendship stronger because she knew she could confide in me and receive the support and reassurance she needed – even if that just meant listening. We often talked about her diagnosis, tests and treatment. I always encouraged her to tell me how she was feeling.

After her diagnosis, I was also there to support her through some of the lifestyle changes that she was making to help manage her condition – whether it was hearing about the adjustments she made when traveling or changes she made to limit her exposure to NTM bacteria.

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**While everyone’s experience with NTM lung disease is different, sometimes knowing there is someone willing to listen to what you’re going through can make a world of difference.**

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## Provide Encouragement

After a diagnosis, patients may have a hard time coping with the impact the disease can have on their lifestyle. Emotional support from family and friends plays an important role in navigating these new challenges.

For Barbara, keeping up our weekly walks helped her physically and emotionally. We stuck to our routine and made adjustments whenever necessary. In the beginning, after her diagnosis, we walked slowly and for short distances. As time went on, we were able to increase our pace and go farther. If Barbara felt that we needed to slow down our pace, we did. It meant a lot to Barbara that I was there for her, being by her side on her NTM lung disease journey, and it meant a lot to me too.

## Stay Informed

When Barbara first told me about her diagnosis, I didn’t know anything about it. I let her be my teacher and learned a lot about the condition through her experience. Today, I’m more informed and can be a better source of guidance and support.

I encourage you to be proactive. Having open conversations and visiting online resources like AboutNTM.com are great ways to learn about the symptoms, treatment and lifestyle changes your friend or loved one may be facing. The more you know about NTM lung disease, the more you’ll be able to help as they adjust to life after their diagnosis.



# How to Work with Your Doctor to Better Understand the Complexities of NTM Lung Disease

By Dr. Colin Swenson, Pulmonologist and Director of the NTM & Bronchiectasis Clinic at Emory University School of Medicine



**T**hrough my experience treating nontuberculous mycobacterial (NTM) lung disease, I've learned that diagnosis is just the first step in a patient's journey. As patients prepare for the road ahead, my goal is to help them understand the disease and work together to create a plan that will help them manage their condition.

Maintaining an open dialogue with a doctor is crucial for patients with NTM lung disease, whether they've been diagnosed recently or living with the condition for years. As NTM lung disease can be progressive – meaning that it can worsen over time – speaking with your doctor about your symptoms and testing can help lead to a timely diagnosis as well as track your progress during treatment.

To make these conversations productive, patients should educate themselves using online resources (like those available on AboutNTM.com) and patient advocacy websites. These resources can help patients find the right doctors and help prepare themselves for what to expect after diagnosis. Heading into a doctor's appointment with a list of questions will ensure patients get the most out of each visit.

Many people don't realize, for example, that having a history of lung conditions, like bronchiectasis, chronic obstructive pulmonary disease (COPD) or asthma, puts them at higher risk for developing NTM lung disease because the damage from these conditions can make it easier for NTM to infect their lungs. If a patient with one of these lung conditions is also experiencing NTM lung disease symptoms, like chronic coughing, feeling tired often and shortness of breath, it's important that they see a doctor. The following questions can help start these discussions:

1. **Could my symptoms be caused by something other than my current lung condition?**
2. **Is there a reason my symptoms haven't gotten better?**
3. **Does my current lung or other health condition put me at a higher risk for other lung diseases, like NTM lung disease?**
4. **Why am I at risk for NTM lung disease if I have another lung condition? Are there other reasons why I'm at risk?**
5. **Is there a test I can take to find out if I have NTM lung disease?**
6. **Should I get tested for NTM lung disease?**
7. **Are there specialists for NTM lung disease?**

This conversation should also continue beyond diagnosis, with patients asking their doctor about various treatment options and lifestyle changes to help manage their condition. These questions can include:

1. **What are my treatment options for NTM lung disease?**
2. **How long will I be taking medicine?**
3. **Do I need to see other specialists to treat my disease?**
4. **How will I know if my treatment is working and I'm getting better?**
5. **How often should I be tested to evaluate my progress?**
6. **Could certain exercises or activities help improve my lung health?**
7. **Can you recommend any dietary changes that would improve my lung health?**
8. **Where can I be exposed to NTM bacteria? How might I reduce my exposure to NTM bacteria in and outside of my house?**

NTM lung disease is complex, and while getting to diagnosis can be a journey in itself, patients should also prepare for what comes next. Treatment may involve a multidisciplinary team of physicians, including their primary care doctor, a pulmonologist and/or infectious disease specialist. Depending on their needs and medical history, nutritionists and other specialists may also become part of the care team.

Support from loved ones is also invaluable when it comes to navigating the challenges and lifestyle changes associated with NTM lung disease. Many patients tell me that before their diagnosis, their family and friends had never heard of NTM lung disease – and that's OK. There are resources available to help keep them informed, and in doing so, become a source of support and guidance along the way. By learning more about NTM, loved ones will be more likely to recognize symptoms and encourage patients to be proactive in managing their care.

# Advocacy Spotlight: How NTM Info & Research (NTMir) Helps Navigate the Road After Diagnosis



NTM Info & Research (NTMir) is an advocacy organization founded by the late Fern Leitman, an NTM lung disease patient, and her husband, Philip. Through firsthand experience and conversations with patients and caregivers around the country, Fern and Philip gained an understanding of the unique struggles associated with the disease, including delayed diagnoses, lack of education and an overall fear of what may lie ahead.

They started NTMir to support other patients through these challenges. Over the past 10 years, the organization has become an essential source of education and guidance for members of the NTM lung disease community.

## Understanding NTM Lung Disease and Impact on Lifestyle

NTM Overview

NTM Prevalence

Common Symptoms of NTM

NTMir guides patients through the many questions and challenges they'll face, offering an array of resources to help navigate the NTM lung disease journey, whether a patient has been newly diagnosed or living with the condition for years.

When a patient receives an NTM lung disease diagnosis, the next steps involve working closely with your doctor to not only find the right treatment, but also to evaluate how your lifestyle may need to change to accommodate this diagnosis. NTMir shares tips for living with NTM lung disease and reducing your potential exposure to NTM bacteria.

Reducing Exposure

## Finding Support

One of the best ways NTM lung disease patients can learn about their condition is to connect with others who are experiencing it too. NTMir provides information about online and [local in-person support groups](#), as well as guidance for patients who are interested in starting their own support groups. NTMir strives to work with patients, doctors and researchers to help raise awareness and educate others about the ongoing challenges associated with this condition, providing support for those impacted.

*Insmed Incorporated provides financial support to NTMir through corporate sponsorships and charitable contributions.*

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or being a part of our next issue?**

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