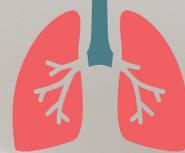


# VOICES OF



# NTM LUNG DISEASE

July 2020



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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 focuses on the management of NTM lung disease, and how patients can best work with their healthcare professional care team and support system to adjust to lifestyle changes.



### **Partnering with My NTM Lung Disease Care Team**

Beth M., an NTM lung disease patient, highlights the different doctors who helped her learn to manage her disease and adjust to her new reality.\*



### **Supporting a Loved One's NTM Lung Disease Management Plan**

Beth's partner, Paul K. discusses how he supports her through the management of her NTM lung disease, and provides tips for other caregivers and loved ones.



### **How a Collaborative Care Team and Support System Can Help You Navigate NTM Lung Disease**

Dr. Patrick Flume, Pulmonologist and Director of the Adult Cystic Fibrosis Center at the Medical University of South Carolina, explains the importance of a care team and how you can work with different members to help manage your disease.\*



### **Advocacy Spotlight: The American Lung Association – A Partner During Your NTM Lung Disease Journey**

Discover ways that the American Lung Association provides support and resources for NTM lung disease patients, as well as other chronic lung disease patients who may be at risk for NTM lung disease.

\*Authors were compensated for their content and time.

## A Letter to the NTM Lung Disease Community from AboutNTM

**W**e remain committed to helping the NTM lung disease community navigate today's environment, providing support and resources.

No matter where you may be in your NTM lung disease journey, it's important to stay in touch with your care team along the way. Today, healthcare services can be conducted virtually through the internet and telephone – also known as telehealth. These online platforms can make it possible for you to communicate with your doctor without stepping foot in a waiting room or office. Certain appointments may still need to occur in person, so you should talk to your doctors to determine your options. To help guide conversations with your care team and make the most of your discussion whether it's in person or virtually, there are discussion guides available for both newly diagnosed patients and those who think they may have NTM lung disease. Click the links below to download the discussion guides.

**Diagnosed Patient Doctor  
Discussion Guide**

**Undiagnosed Patient Doctor  
Discussion Guide**

Additionally, you may find it helpful during this time to stay connected with the online community. Check out our [Support and Resources](#) for more information.

We hope you and your families are staying safe and healthy.

# Partnering with My NTM Lung Disease Care Team

By Beth M., NTM Lung Disease Patient



**A**t the height of my career in public relations, I came down with a case of bronchitis. I was always healthy and active, hiking through the Colorado mountains, playing tennis, running and serving as a volunteer firefighter in my community, but the cough and tiredness started hindering my energy and impacting my ability to do the things I loved.

My primary care doctor treated it with an antibiotic, which cleared up the infection, but the cough and fatigue lingered. They also affected my work as I couldn't make a speech or lead a meeting without coughing. I kept thinking it would get better, but it only got worse.

At a work event, a nurse heard me coughing and urged me to see one of their doctors. His diagnosis was asthma; however, ongoing symptoms meant it would take even more time to find an accurate diagnosis. Finally after about a year, I went to a respiratory specialist who, through a chest X-ray, CT scan and bronchoscopy, found that I had nontuberculous mycobacterial (NTM) lung disease.

This was upsetting news, and I felt alone and afraid. A tenderhearted stranger – another NTM lung disease patient – came over and sat with me, explaining that this disease could be managed. Her caring words made all the difference that day, and later on, I realized I was so relieved to finally know what was going on with my health.

## Care Team Communication Is Essential

Following my diagnosis, I started treatment and engaged different members of my care team as I adjusted to my new reality. My respiratory specialist prescribed an 18-month treatment regimen of three antibiotics, and I had to work with a dietician to ensure my food intake complemented the medicines. I was also instructed to perform a lung hygiene exercise twice a day. To help manage these lifestyle changes, I joined a support group like those mentioned on AboutNTM.com.

As my cough started going away, and my energy returned, I felt hopeful. An important part of my disease management was follow-up with my care team, so I continued sending in sputum samples to monitor my progress on treatment and saw the respiratory specialist every few months. Each time, I learned that the number of NTM bacteria colonies in my lungs was diminishing.

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**My respiratory specialist provided routine updates to my primary care doctor on my progress, ensuring a holistic approach to my care.**

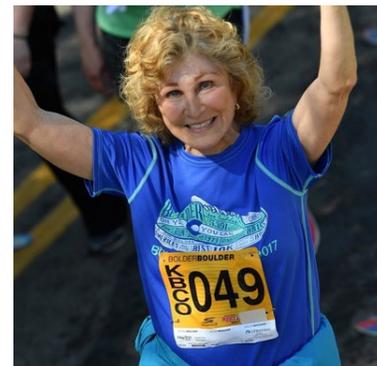
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Throughout my journey, I found it important to have ongoing conversations with my doctors about my management plan and progress. I also appreciated the collaboration between my doctors. Both doctors encouraged me to keep exercising and eating healthy meals prescribed by the dietician. They both regularly asked about my emotional health and discussed my depression, which had been building for some time.

## A Support Network Is Critical to Fighting NTM Lung Disease

I am now good friends with the woman who helped me the day I was diagnosed, and we keep each other updated on our condition and progress. My friendships with her and several other patients have been my rock over the years. We share advice and tips from our care teams that make our lives easier.

As part of my support system, I also frequently connect with family and friends and give talks about what it's like to have NTM lung disease, encouraging other patients to join a support group. One of the most important parts of my support system, however, is my relationship with my partner, Paul, whose loving care and sincere interest in my health have made all the difference. He is there to support me any way he can, exercising with me and helping me prepare healthy meals. If I could give every person with NTM lung disease a partner like Paul, I would.



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# Supporting a Loved One's NTM Lung Disease Management Plan

By Paul K., Partner of NTM Lung Disease Patient

As an amateur bird-watcher, one of my favorite things to do is go hiking on Colorado trails where I can identify a number of birds, listen to their songs and watch them in their natural habitat. When I met my partner Beth and learned that she loved it too, I knew we were meant for each other.

I quickly realized that Beth had traits that connected us in many ways. She was energetic, positive, and most importantly, someone I could talk to about anything.

Yet as Beth and I began building our life together, she was diagnosed with nontuberculous mycobacterial (NTM) lung disease, a condition that turned her world upside down.

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**It was hard to watch her suffer, but Beth was determined to fight the disease and keep doing the things she loved. I wanted to learn more about NTM lung disease so I could support her in any way I could.**

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## Support Takes Many Forms

I began by accompanying Beth on visits to her respiratory specialist to understand how I could support her disease management plan. The doctor told me I would play an important role in Beth's health and gave me some helpful suggestions. I also attended seminars and developed relationships with the spouses of other NTM lung disease patients to educate myself on how I could be there for Beth.

Through these relationships and open communication with Beth about her condition, I learned how to help with her disease management efforts. For example, when Beth performs her lung hygiene exercises in the morning, I follow up by applying a flat vibrating mechanism to her back to loosen any bacteria-filled sputum in her lungs and make it easier for her to cough up. At first she was embarrassed by the sound of her coughing, but I assured her it did not bother me.

I also work with Beth on planning menus each week, focusing on healthy staples like rice, vegetables, fish, chicken, and salads. We enjoy preparing and eating these meals together. At the recommendation of her doctor, we usually have an early dinner, allowing at least two hours before bed, to prevent any acid reflux issues that may exacerbate her NTM lung disease.

In addition to encouraging a healthy diet, we began working out with a weight trainer at a local gym, which was another recommendation from Beth's doctor. This type of exercise has greatly improved our strength, balance, and stamina. Last year, we trained for and completed a bicycle trip on the Danube River in Austria, Slovakia and Hungary.

We continue to do virtual workouts with our trainer, using weights, bands and a stationary bike in our basement. This trainer is tough, but empowering, and keeps Beth and me in good shape.

## Tips for Caregivers

While taking on the role of caregiver can seem daunting in the beginning, I have tips I like to share with others who want to know how they can help support a loved one with a chronic condition like NTM lung disease. First and foremost, actively

listen to your loved one describe his or her condition, treatment, feelings and concerns. Secondly, be patient and willing to change your schedule or routine to accommodate his or her needs, if you can.

Third, be an involved partner in his or her disease management. This could include encouraging ongoing discussions with their doctor, accompanying them to medical appointments, exercising or meditating together, supporting a faith practice or strengthening family relationships in a way that supports them. Finally, keep a sense of humor because that could help reduce your level of stress.



Just like Beth's ongoing treatment, learning how to be a caregiver can be a lifelong journey. As her needs change and evolve, I continue learning new ways to adapt and support her management plan. I'm happy that Beth knows I am there for her and that she isn't alone in navigating life with NTM lung disease. If you're a caring and dedicated partner, you already have what it takes to be an excellent caregiver.

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# How a Collaborative Care Team and Support System Can Help You Navigate NTM Lung Disease

By Dr. Patrick Flume, Pulmonologist and Director of the Adult Cystic Fibrosis Center at the Medical University of South Carolina



After learning that you have a chronic disease, you may have concerns about how this condition may affect your life. When the patients I see learn that they have nontuberculous mycobacterial (NTM) lung disease, they often have many questions about the journey ahead. I remind them that they are not alone and ensure they are working with a dedicated and expert care team and support system to manage their new reality effectively.

## Care Team Members

Because a condition like NTM lung disease can cause damage to the lungs in addition to other problems if left untreated over time, being mindful about working with your care team is not only recommended, but can truly help you better manage your symptoms. The following list includes professionals that may be involved in your care team and how they can work together:

- 1 NTM Lung Disease Specialists:** Pulmonary and infectious disease specialists often collaborate on treating an NTM lung disease patient. If you have been diagnosed with NTM lung disease, or are at risk and experiencing signs and symptoms, your doctor may refer you to one of these specialists who may have more experience in the diagnosis and treatment of the disease. These specialists may include physicians, nurse practitioners and physician assistants.
- 2 Program Coordinator:** Often led by a specialized nurse, program coordinators help manage patients' needs and implement therapy plans. They work directly with patients to navigate their treatment journey and help organize support provided by care team members.
- 3 Pharmacist:** The treatment of NTM lung disease typically involves multiple antibiotics over a long period of time. Discussions about drug interactions, dosing adjustments and more can run through the pharmacy. A pharmacist's expertise and counseling can make a huge difference in managing patient expectations and helping to address insurance hurdles.
- 4 Respiratory Therapist:** NTM lung disease can make your body create excess mucus in your airways. Airway clearance techniques, performed as breathing exercises or using specific devices and even aerosol medications, can help clear the mucus from the lungs. This can also help reduce infection and inflammation. Respiratory therapists provide necessary education on the standard airway clearance techniques and inhaled therapies for NTM lung disease, helping patients with this aspect of disease management.
- 5 Psychologist:** NTM lung disease diagnosis and treatment can be stressful for some patients. Underlying mental health issues may also contribute to challenges with the management of the disease. A psychologist can help you navigate feelings of depression and anxiety through your journey.
- 6 Microbiologist:** Physicians stay in close contact with the laboratory, as culture results provide insight into a patient's progress, determining if there is treatment success or when there is a need to make changes in the therapy plan. While patients may not have direct contact with this member of their care team, microbiologists can help inform disease management decisions.

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### Navigating New Routines Together

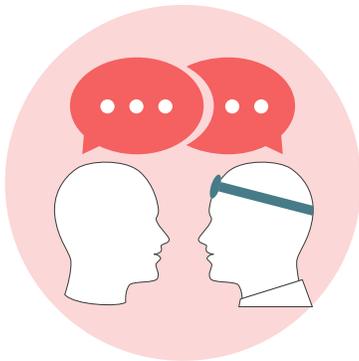
Of course, you also play a significant role in managing your care, which is why it's important to have open conversations with your doctor and other members of your care team. At my practice, we let patients know how they can get in touch with each member of their care team, which facilitates a steady flow of communication.

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**We know that many patients experience ‘information overload’ following their diagnosis, so we make time during visits to help them digest key takeaways.**

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For patients who are beginning a long treatment journey that may involve multiple medications, having the resources of a full team of experts can be helpful and comforting.



Managing NTM lung disease takes time and effort, especially when new medical routines, like airway clearances must become part of your day. A collaborative care team can work with you to integrate these practices into your lifestyle. It's also important to talk to your team about how to adapt their model to suit your needs. While emerging trends like telehealth may present new opportunities for patients to communicate with their care team remotely, certain activities, like specific testing and imaging, will need to occur in person. It's important to work with your care team to determine what options will work best for you.

Whether your appointment is held in person or virtually, there are discussion guides available on [AboutNTM.com](https://www.aboutntm.com) to help support conversations with your care team if you have been [newly diagnosed](#) or [think you may have NTM lung disease](#).

### Expanding Your Support System

Beyond your care team, you may benefit from a support system to help manage your condition. This can include any family members, friends or loved ones who are willing to help with any of the following activities:

- 1 **Transportation to or from doctor appointments**
- 2 **Researching the disease and taking notes during appointments**
- 3 **Picking up, and helping administer treatments, as appropriate**
- 4 **Providing moral support during emotionally difficult periods**



While finding out you have a chronic condition like NTM lung disease may feel overwhelming at first, it's important to remember that you aren't alone on your journey. Engage your family and loved ones to provide much needed emotional support as you get through treatment and adapt to new lifestyle changes, and work with the members of your care team to stay active and informed in managing your care.

If you're unsure of where to begin, you may find it helpful to stay connected with the online community and check out our [Support and Resources](#).

# Advocacy Spotlight: The American Lung Association – A Partner During Your NTM Lung Disease Journey



Lung disease overall can be a life-changing diagnosis that can appear challenging for many patients to navigate. With research to learn about various treatment options and decisions to make about their care, it's often hard for patients with lung disease to know where to begin. That's why having access to a partner like the American Lung Association can be a valuable resource for patients from the initial diagnosis to ongoing management.

The American Lung Association promotes education, advocacy and research to improve the quality of life of nearly 37 million Americans living with chronic lung disease and their families. The organization provides support for people with conditions like chronic obstructive pulmonary disease (COPD) and asthma; and because having one of these conditions can increase a person's risk for NTM lung disease, the American Lung Association provides information about NTM lung disease as well.

## Understanding and Managing NTM Lung Disease

The American Lung Association shares information on how to build and work with the most effective care team as well as exploring various lifestyle changes to improve your health, which can be helpful if you are at risk or have been diagnosed with NTM lung disease.

The organization's [website](#) educates readers on NTM lung disease, including signs and symptoms, diagnosis, treatment and management of the condition. Lung health researcher Emily Henkle, PhD, MPH, also authored an [Each Breath Blog post](#) that speaks to the power of patient-centered research.

Whether you are at risk for NTM lung disease or currently navigating the journey associated with this disease, you will likely have questions. The American Lung Association has a free Lung HelpLine staffed by registered nurses and respiratory therapists to answer patients questions one-on-one. Available at 1-800-LUNGUSA, individuals can also access the service via [online chat](#).

The organization also understands that living with a chronic condition like NTM lung disease goes beyond diagnosis and treatment. A patient's care team extends beyond healthcare providers and can effectively be rounded out with a strong support network of family, friends and individuals with similar experiences. Support groups like the [Better Breathers Club](#) or their [online support community](#), provide a space where patients can discuss what it's like to be living with their disease, with people who understand their experience and can provide insight into how their life is being affected.

## Embarking on the NTM Lung Disease Journey Together

People who are living with NTM lung disease do not have to go through their journey alone. By engaging a full care team, including physicians, family, caregivers and more, they can find support to help navigate life with this chronic condition. They also have resources available from organizations – like the American Lung Association – who are available to help along the way.

*Insmed Incorporated provides financial support to the American Lung Association through corporate sponsorships and charitable contributions.*



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**Interested in sharing a topic  
or being a part of our next issue?**

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