

Debbie Breslawksy

NONTUBERCULOUS
MYCOBACTERIA (NTM)



“The feeling of isolation is devastating. You look to speak with people in the same situation, but where do you find them? A support group would be nice, but none exist. After years of chatting up everyone you know, you find enough people to start your own group.”



You're sailing along in life. You've launched the kids, are about to have some serious fun with your husband, travel, go on adventures, then bam! Cough, cough, cough. Fatigue sets in. And after many attempts at getting a correct diagnosis from far too many doctors you come to grips with having a disease you've never heard of, and people, including most of your doctors, haven't either. The diagnosis: non tuberculous mycobacteria (NTM), a highly resistant mycobacterial infection in the lungs that will stay with you for the rest of your life.

You look OK. Your friends don't understand why you're acting like a wimp. Exhaustion overcomes you. You don't have the energy to do the things you love.

You go to the pharmacy to fill a barrage of prescriptions, an antibiotic cocktail (wish it were another kind of cocktail) and you start coughing. And with that cough, you're able to clear an entire section of Costco. You explain you're not contagious, but people don't believe you. You hide your face in shame.

You used to sing. You used to run. You used to ski. Now you stay home most of the time because you are on three or more strong oral antibiotics, and sometimes inhaled and IV antibiotics, two infusions per day for months at a time. Your gut is majorly annoyed, and so are you. Dining out isn't fun anymore. Your appetite is gone.

So many little things we take for granted! Attending a concert or big party? I don't think so. You now avoid crowds for fear that your weakened immune system is susceptible to catching cold, or even worse, pneumonia. Who doesn't like a hot, steamy shower? A relaxing Jacuzzi? A visit to Miami or Hawaii? All vacations to humid climates are out! Not a good idea to be sitting under a mister at an outdoor café in summertime or hanging out in the produce section of your favorite supermarket because the spray from the misters are filled with NTM. And the NTM-infused aerosolized mist is looking for a place to park, most likely in your lungs.

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- NTM infection causes the bronchial tubes to fill with mucus and, over time, may lead to dilation and scarring of the tubes.
- Types of Nontuberculous Mycobacteria include: mycobacterium avium complex, mycobacterium kansasii, mycobacterium abscessus, mycobacterium chelonae, mycobacterium intracellulare, mycobacterium fortuitum.
- Common symptoms of NTM include coughing, night sweats and fever, loss of weight, loss of appetite, and lack of energy.

Learn more: American Thoracic Society. Breathing in America: Diseases, Progress, and Hope. New York, NY. 2010. thoracic.org/education/breathing-in-america.

To help clear the lungs, you have an array of machines and gadgets which can take up several hours to administer each day: the lung shaker, aka the “vest,” bronco- dilator. These are your new best friends. They are to be used every day for the rest of your life for airway clearance.

You exercise when you can to keep your lungs operating as well as possible. Is all this working? Sometimes you think you are doing a whole lot of huffing and puffing for nothing.

After a few years, you might catch a break for a few months. Yippee, a drug holiday! And if you are lucky enough to get a negative culture, the celebration is short-lived because it will soon be positive. Your lungs are so compromised.

The feeling of isolation is devastating. You look to speak with people in the same situation, but where do you find them? A support group would be nice, but none exist. After years of chatting up everyone you know, you find enough people to start your own group in New York City. The support is invaluable, so you start another group in the dry climate of California where you have moved part time to escape the humidity and to breathe better. Then another group in Connecticut. Patients find you online. Networking helps you find doctors who specialize in NTM, discover treatment options, receive feedback from others in the same boat. You speak from experience about CT scans, spirometries, PFTs, and on and on and on.

Together, you make the best of a bad situation. You put on your game faces when you are feeling sick and keep pushing yourselves.

Some of us can look forward to a lobe or two of our lungs having to be removed. Scary. Yes, the procedure has become more simplified using a video-assisted surgery. However, there’s nothing simple about it if you’re the patient.

We have lost too many friends to this dreaded disease, and many of us fear the same fate for ourselves. More than anything, we need to raise the level of provider education, in medical schools and beyond. We need research to determine genetic predisposition, effective treatments with fewer side effects. Even better—a CURE—or prevention.

Susceptibility to NTM is inherited. If not for ourselves, we must succeed for our future generations.