

Christa Warden

NONTUBERCULOUS
MYCOBACTERIA



*“We are so much more
than a set of lungs.”*

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I'm Christa Warden, age 69, and I have nontuberculous mycobacteria (NTM). I am a mother of three and a grandmother. I was a military wife, educator, school counselor, and a middle school administrator for 28 years. My professional goal was to retire after 30 years. Disappointingly, my career ended abruptly after a two-year series of repeated and debilitating bouts of pneumonia and worsening asthma.

My recurring respiratory infections fell into a cycle of a new infection every three to four months. I rarely saw my primary care physician, as my pneumonia would begin abruptly. It still does. Urgent care through my medical group was referred to the nurse practitioner or one of the physician assistants. In retrospect, I feel that this lack of continuity of care, and the lack of knowledge of NTM, led to missing the pattern of my infections or exploring their cause.

In 2009, I had a CT scan indicating bronchiectasis. I had no idea what this diagnosis would mean. Few pulmonary physicians were familiar with the impact this would have on my lungs and health. I felt that I had to be my own advocate and find a physician willing to explore the cause of my repeated infections.

My life has been and continues to be highly impacted by NTM. I have life-changing fatigue and limited stamina. I even break into a sweat doing tai chi. I live what I call an “every other day” life. When I undertake a physical activity, social activity, or even the caring of my grandchildren, I must spend the following day recovering.

My forced retirement is not what I dreamed about. I hesitate to make travel plans. My family and friends understand that making social plans too far in advance is based on the fact that I cannot predict how I will feel that day. My experience has been that if I try to “push through” the fatigue and ignore my body, I can become seriously ill requiring hospitalization and IV antibiotics.

One night recently, I was tucking my precocious nine-year-old granddaughter into bed and, she asked if I would be alive in 20 years. I was caught off guard. I reassured her that I

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Nontuberculous Mycobacteria (NTM) are bacteria that are normally present in the environment. NTM comprise more than 160 different species of bacteria that are found naturally in the environment. Inhalation of these bacteria may cause disease in both healthy patients and those with compromised immune systems. NTM disease most often affects the lungs in adults, but it may also affect any body site. NTM pulmonary disease causes symptoms similar to a chronic and non-resolving pneumonia. Common symptoms include:

- cough with sputum production
- tiredness (fatigue)
- fever
- coughing up blood (hemoptysis)—a late sign of illness
- unplanned weight loss

Learn more: ATS Patient Education Series. “What is Nontuberculous Mycobacteria (NTM) Disease?” New York, NY. www.thoracic.org/patients/patient-resources/resources/ntm.pdf

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was doing everything possible to be strong and healthy. Her question went straight to my heart. The truth is, I do worry, “Will the next pneumonia or infection be the end of me?”

The unpredictable nature of my illness fills me with sadness. I have always been an optimistic and social individual. Now I struggle with a big secret, the anxiety and depression surrounding my chronic illness. I fear that even with doing everything suggested, it might not be enough.

I love my family and friends, and I want to do some of the things I said I would do when I retired...I have places to go and people to see! I don't want to wait. There might not be time later.

Regaining some control through action lessens my anxiety. Managing my disease requires time and consistency with medications, inhalers, and general lung hygiene. It also requires getting an hour of strenuous physical activity, building strength, and doing cardio every day. I am currently participating in a great pulmonary rehabilitation program three times a week. I take tai chi on alternate days. Managing NTM is my part-time job.

After a long and bumpy search, I have been extraordinarily fortunate to have found my current physician at Georgetown University Hospital. In addition to the kind and attentive care she provides, she participates in drug trials. When I qualified to enter a trial, I felt hopeful for the first time. I felt the possibility that these trials might directly impact me. Of course, I prayed that I would not get the placebo. It turns out that I received the actual medication, and there was a momentary break in my cycle of flare-ups.

I ask that physicians and researchers please continue their research, and participate in drug trials and education programs to increase knowledge regarding NTM. As a patient, I would encourage them to “be present.” Look for patterns. Look at the whole patient. We are so much more than a set of lungs.

Christa Warden was a patient speaker at the ATS 2017 International Conference in Washington, D.C..