

WELCOME TO

NTM LUNG DISEASE 101

- COPD and NTM lung disease
- Epidemiology of NTM
- Pathophysiology
- Clinical Presentation
- Diagnosis
- Treatment and Management of NTMLD
- Risk of Reinfection and Refractory NTMLD
- My Role as a Health Care Provider
- NTM 101 Patient Materials



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|| COPD and || NTM Lung Disease



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COPD and NTM Lung Disease

- COPD affects more than 15 million Americans.¹
- Those with COPD are 16 times more likely to get NTM lung disease (NTMLD).²



Incidence and Prevalence of NTM Lung Disease³

The annual prevalence of NTMLD as of 2015 was 11.7 per 100,000 persons.

The number of NTMLD cases increases by almost 8% each year.^a

The incidence of NTMLD was 4.7 per 100,000 person-years.^b

^aBased on a Medicare population aged ≥ 65 years.

^bIn the year 2015.



|| Epidemiology of || Nontuberculous Mycobacteria



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Epidemiology of Nontuberculous Mycobacteria⁴

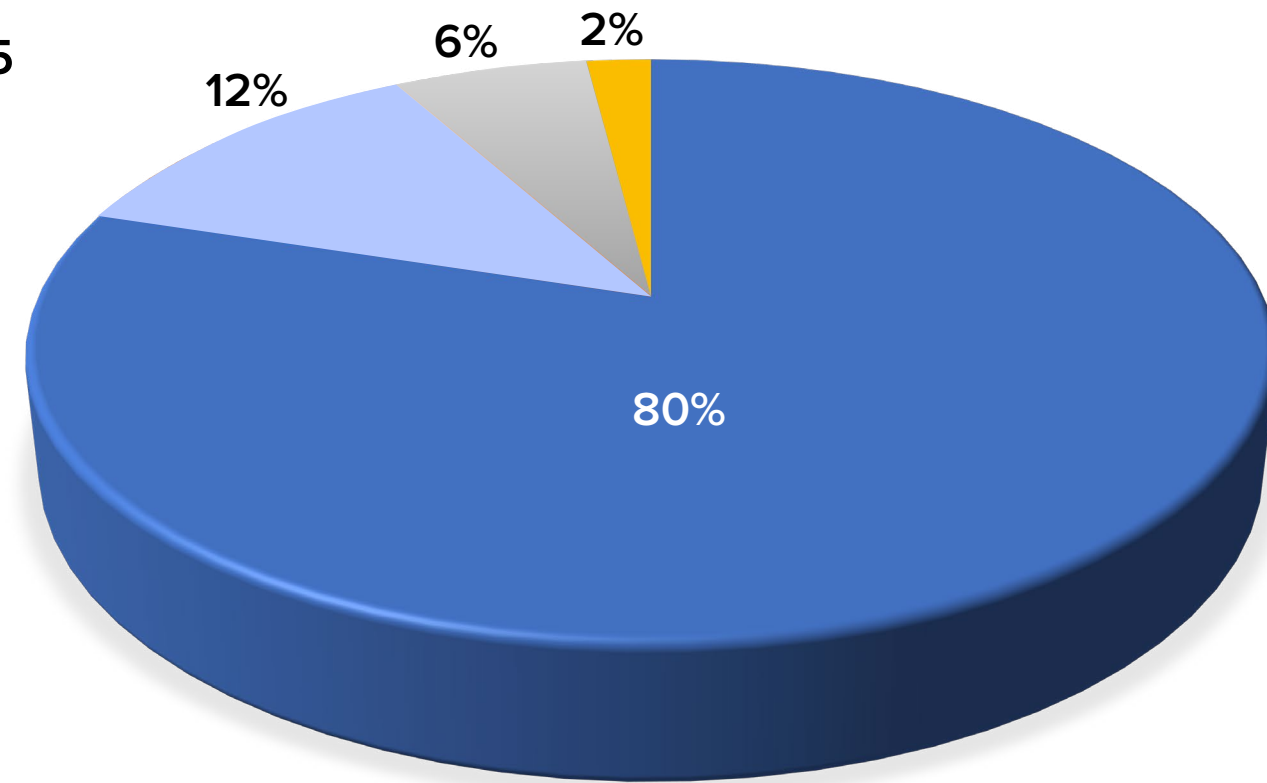
- NTM are commonly found everywhere in the environment, including the soil and water (both treated and untreated sources).
- The source of a patient's infection is often not apparent.
- NTM are not considered contagious.



Common Types of NTM That May Cause Pulmonary Infections in the United States

Types of NTM in the United States⁴

-  M avium complex (MAC)⁴ ~80%⁵
-  M abscessus⁴
-  M kansasii⁴
-  M xenopi⁴



|| Pathophysiology of || NTM lung Disease



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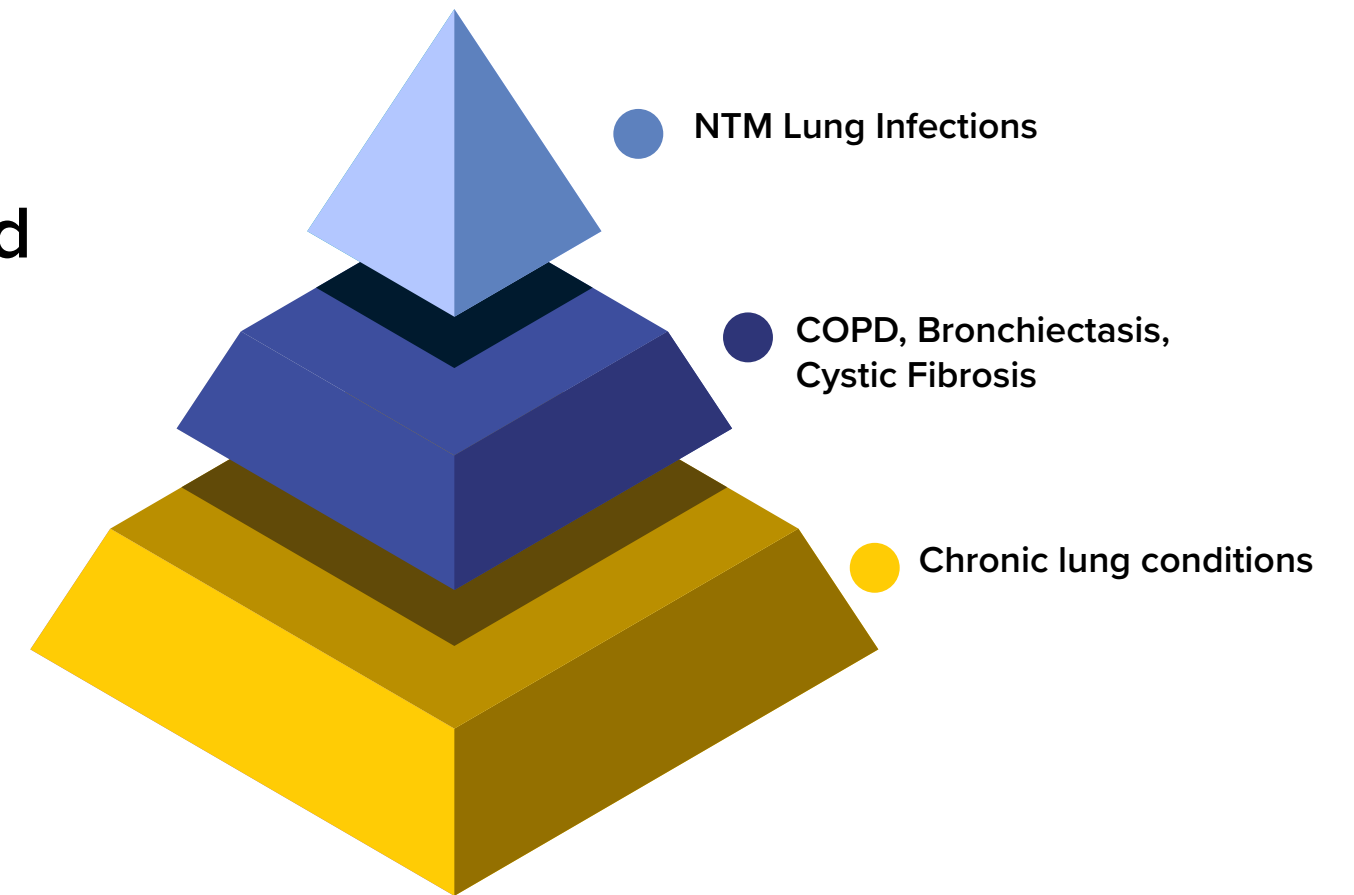


Pathophysiology of NTM Lung Disease⁴

Pulmonary NTM infections are associated with those who have chronic lung conditions or have had significant structural defects.

Examples of these include COPD, bronchiectasis, and cystic fibrosis.

Bronchiectasis and NTMLD often go hand-in-hand.



|| Clinical Presentation of NTMLD

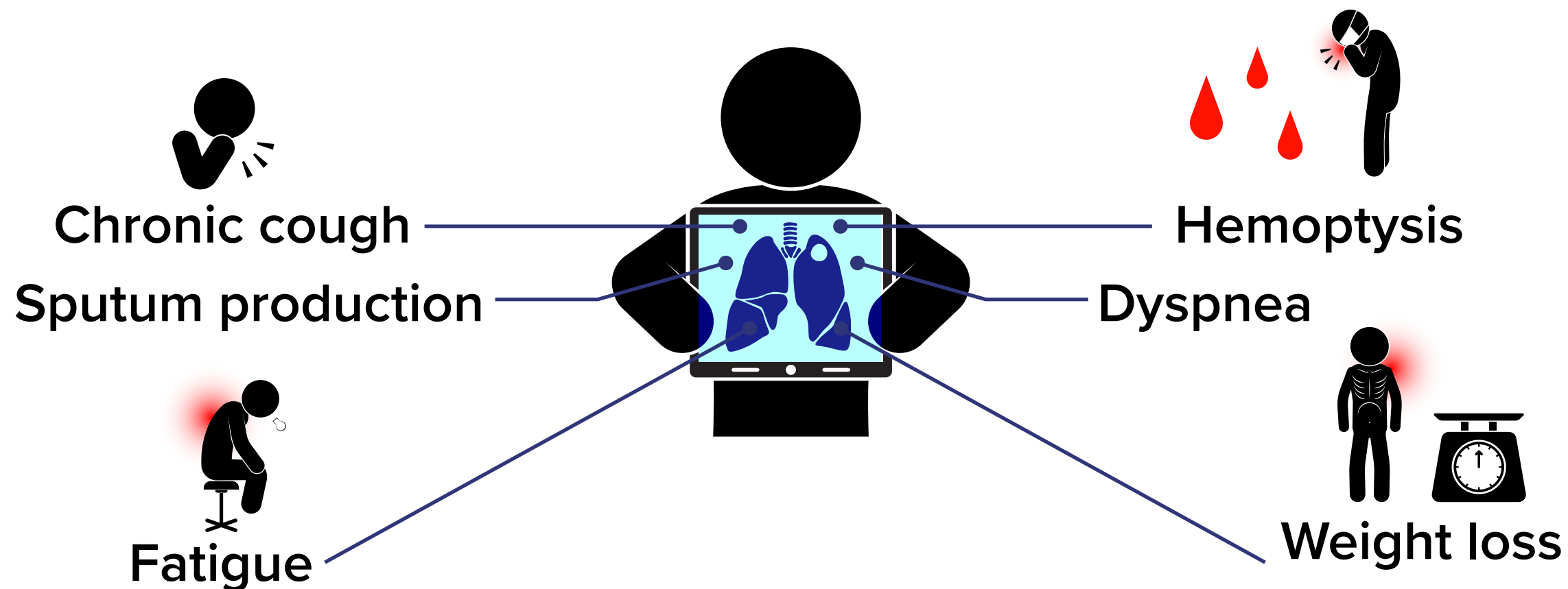


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Clinical Presentation of NTMLD⁴

- Symptoms can vary from patient to patient and may often be associated with other pulmonary conditions.
- Symptoms most common of an NTM infection



Clinical Presentation of NTMLD⁴

- NTM lung disease can progress to chronic lung damage.

- A study found that **OVER**

60%

of patients with MAC showed progressive symptoms within 3 years if left untreated.⁶



Clinical Presentation of NTMLD⁴

NTMLD has the ability to⁷:



Seriously impair a patient's strength and capacity to perform daily activities



Place a serious financial burden on patients and caregivers



Increase a patient's risk of mortality.



II Diagnosis of NTMLD



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Diagnosis of NTMLD⁴

Three areas are required for an accurate diagnosis



- Characteristic radiographic findings
- Microbiologic data
- Clinical presentation of symptoms consistent with disease process



Diagnosis of NTMLD: Radiographic Findings⁴

- Chest HRCT imaging is often completed to show specific characteristics and abnormalities of nodular disease.
- Radiographic findings may reveal fibrocavitary disease and characteristics of nodular bronchiectasis.



Diagnosis of NTMLD: Microbiologic Data⁴

- Clinical and radiographic finds are not adequate to diagnose and initiate therapy.
- Two or more sputum cultures (acid-fast bacilli) should be evaluated to properly diagnose NTMLD.
- Bronchial wash may suffice.



Who should be tested?⁴

- People with chronic lung conditions such as COPD, bronchiectasis, alpha-1 antitrypsin, and cystic fibrosis that are showing classic symptoms.
- Patients with chronic or recurring cough and other variable symptoms.



Treatment and Management of NTMLD



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2020 NTMLD Clinical Practice Guidelines⁸

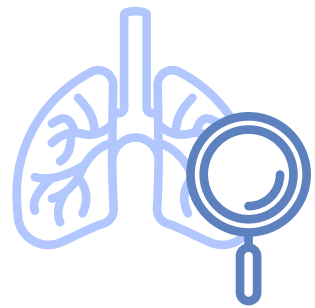
What The Guidelines Include

- Diagnostic Criteria
- Laboratory diagnosis of NTMLD
- Recommendations for the Treatment of NTMLD



Multidisciplinary Approach⁹

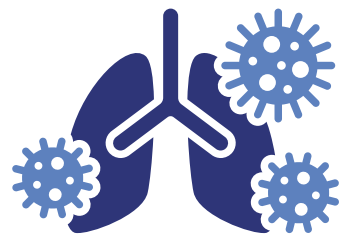
A teamed approach could benefit the treatment and management of the NTMLD patient



Pulmonologist



Dietitian or Nutrition Counselor



Infectious Disease Specialist



Pharmacist



Respiratory Therapist



Pharmacologic Treatment Options⁸

For patients who meet the diagnostic criteria for NTM pulmonary disease it is recommended to start treatment with multiple antibiotics, particularly if the patient has positive acid-fast bacilli sputum smears and/or cavitory lung disease.

NTM Species	Treatment Recommendation
MAC	Susceptibility-based treatment for macrolides and amikacin
<i>M abscessus</i>	Susceptibility-based treatment for macrolides and amikacin
<i>M kansasii</i>	Susceptibility-based treatment for rifampicin



Pharmacologic Treatment Expectations⁸

- Pharmacologic treatment of NTMLD should continue for at least **12 months AFTER culture conversion.**
- Providers should set expectations with clear communication for all patients for the treatment for NTMLD.
- Routinely observe sputum cultures.



MAC Pharmacologic Treatment Expectations⁸

- It is strongly recommended that a 3-drug regimen be used that **INCLUDES** a macrolide.
- Azithromycin is preferred over clarithromycin due to better patient tolerance.
- Frequency of dosing depends on the presence of cavitory disease.
- If after 6 months patients remain culture positive, alternative treatment options should be considered.



Pharmacologic Treatment Considerations⁸

The ultimate decision to start therapy for those with NTMLD should be personalized base on:

- Clinical presentation of the patient
- The type of NTM found in the lung
- The patient's willingness to start treatment



Pharmacologic Treatment Considerations⁸

Providers should discuss:

- Potential side effects of drug regimen
- Expectations of treatment
 - Frequent follow-ups
 - Monitoring
 - Reassessment at 6 months
- Anticipated results



Nonpharmacologic Treatment⁹

- Avoiding exposure to further mycobacteria in the environment
- Nutrition evaluation (especially in patients with low BMI)
- A personal exercise plan
- Airway clearance therapy
- Management of comorbidities



Avoiding Further NTM Exposure⁹

Careful evaluation of environmental exposures

Recreational

Gardening



Camping



Horse-riding



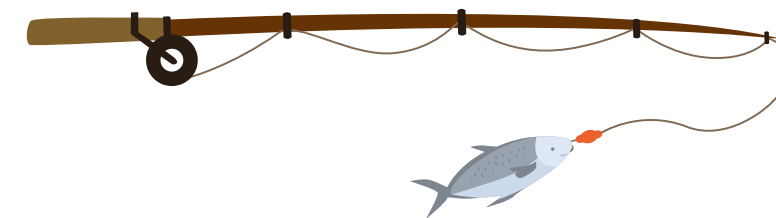
Swimming



Hot Tubs

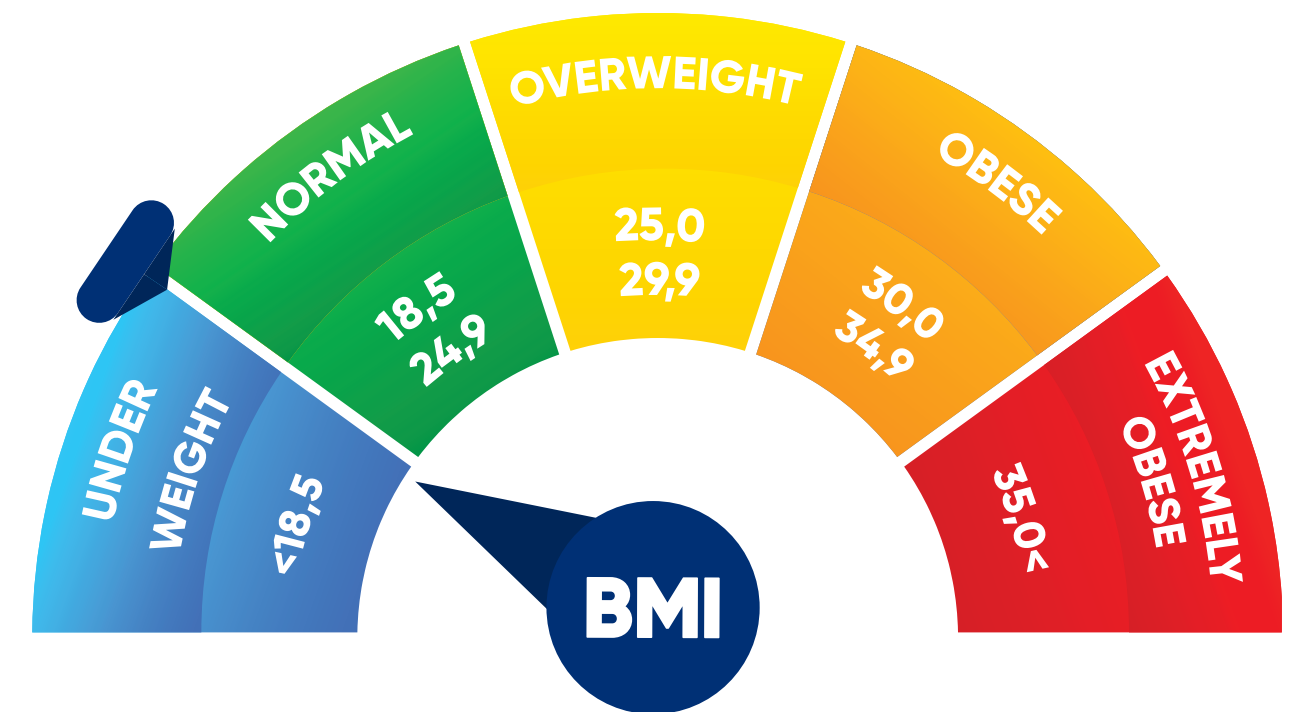


Fishing



Nutritional Evaluation

- Those with NTMLD often (not always) exhibit low BMI.¹⁰
- Low BMI and/or weight loss are associated with worsening outcomes.¹⁰
- Although the role and benefits of probiotics and supplements remain largely untested for those being treated for NTMLD, physicians may sometimes recommend their use to improve symptoms.¹¹



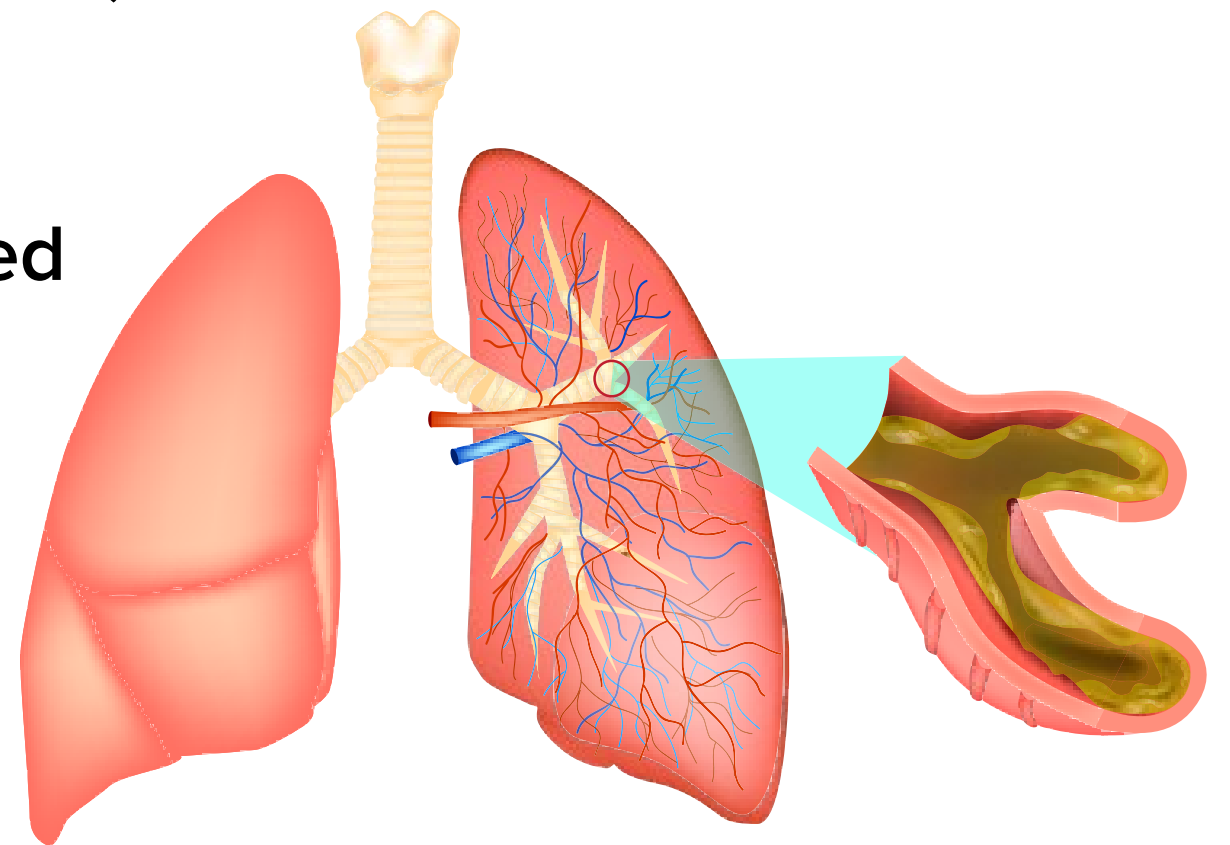
Implementation of a Personal Exercise Plan⁹

- Consider pulmonary rehab for comprehensive, patient-tailored therapy (including exercise training).
- Routine exercise training can improve exercise capacity, dyspnea, fatigue, and number of exacerbations over 12 months.



Airway Clearance Therapy

- Increase mucus production in patient with NTMLD can lead to reduced lung function, worsening disease, and poor quality of life.¹²
- Airway Clearance Therapy can be accomplished in a variety of ways:
 - Airway Clearance Devices
 - Manual Airway Clearing Techniques
 - Medications for Airway Clearance



Management of Comorbidities

- Other lung diseases and conditions (as well as immune disorders) should be suspected in those with NTMLD.⁹
- Conditions such as diabetes, GERD, and anxiety/depression should be appropriately managed so not to cause further complications during treatment.⁹
- Patients with NTMLD have a higher prevalence of GERD than those without.¹³



“Watchful Waiting”⁸

- Just because a patient meets NTMLD diagnostic criteria does not mean that treatment with antibiotics is required.
- Sometimes HCPs may choose to “watch and wait”.



CAUTION:

A careful assessment of the NTM species should be completed and the patient should be aware of risks (e.g., the potential for continued damage to the lung) and benefits before watchful waiting is considered.



|| Risk of Reinfection and Refractory NTM



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Risk of Reinfection

- Re-infection is common in NTM lung disease, even in those successfully treated.¹⁴
- Patients with a history of NTMLD should avoid exposure to potentially contaminated environments.⁹



Refractory NTM Lung Disease⁸

Refractory NTMLD is a term which describes patients with NTM who have failed to culture convert after 6 months of antimicrobial therapy.

If a patient with NTMLD fails to obtain clear cultures after 6 months, a change in treatment should be considered.



|| My Role as a Health Care Provider



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|| Patient Follow-up and Communication Expectations

Navigate your patient's feelings of fear and uncertainty. Suggest resources for them to learn more about NTMLD.

Talk with your patient about clear expectations of timelines regarding the treatment of NTMLD.

Make recommendations for avoiding NTM in their environment in order to avoid further exposure.

Let your patient know when and how to contact their health care provider. Be sure they have access and know how to use their electronic medical record.

Develop a treatment and management plan including scheduling future sputum testing.



Patient Follow-up and Communication Expectations

- This tool is designed to facilitate communication between HCPs and patients.
- Designed to be reviewed every 6 months, patients are to fill out the top section before seeing their physician and bring the tool with them to each visit.

<https://copdf.co/NTMmanagement>

NTM LUNG DISEASE MANAGEMENT TOOL

Patient please fill out this section prior to the office visit.

My Name: _____ **Date:** _____
My Doctor's Name: _____
Best contact (e.g., phone, email, portal): _____
Date of last sputum culture: _____ I am currently being treated for: MAC ___ M. Abscessus ___ Other: _____

CURRENT HEALTH CONDITION:
Right now (on MOST DAYS) I feel: better worse about the same
My symptoms impact my day-to-day activities (e.g., trouble sleeping, missing/changing plans with friends, unable to do activities I once did, missing work). yes no

Current Symptoms	Better	Worse	About the Same
Cough			
Sputum Production			
Breathing			
Fatigue			
Appetite			
Weight			

My sputum color is _____ My other symptoms include: _____

MY GOALS FOR MANAGEMENT (Please number your top three goals from 1-3)
___ Improve my health ___ Increase my activity level ___ Make changes to my lifestyle ___ Gain or Lose Weight
___ Get rid of the NTM ___ Make changes to my environment ___ Other _____
I would like to feel: _____ I want to do these activities more easily _____
Lifestyle/Environmental changes I plan to make: _____

QUESTIONS TO ASK YOUR HEALTH CARE PROVIDER
 When and how should I take each of my medicines?
 Do my medicines have common side effects? Which side effects should I report right away?
 What airway clearance techniques or devices do you recommend?
 What kinds of exercises should I do?
 What measures can I take to protect myself? Are there any activities I should avoid?
 How can I obtain a copy of my imaging and clinical notes?
 Other: _____

MY CURRENT TREATMENT PLAN (Providers check all that apply.)
 Take all medicines/supplements as prescribed. Avoid smoking and inhaling irritants.
 Perform airway clearance _____ times a day. Get adequate sleep and/or rest.
 Be active for _____ minutes a day. Drink _____ ounces of water/fluids a day (avoiding caffeine).
 Eat regularly, focusing on nutritious foods. Date of next sputum culture: _____
 Other: _____

NOTIFY YOUR HEALTH CARE PROVIDER IF:
• You have increased cough and/or congestion.
• Your sputum has changed color, amount, or thickness.
• You are losing weight without trying.
• You notice increased breathlessness with exertion.

SEEK EMERGENT CARE OR CALL 911 IF:
• You have extreme shortness of breath.
• You have chest pain.
• You are coughing up bright red blood.

Details of your next visit
Date and time: _____ Testing needed before visit: _____

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NTMLD 101
Patient Information



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How did I get NTM lung disease?¹⁶

- NTM are bacteria commonly found in soil and water (including natural like streams and lakes, as well as domestic like household faucets and showerheads).
- This bacteria can be breathed in and can infect the lung causing NTM lung disease (NTMLD).
- People with healthy lungs can typically fight the bacteria. However, if a person has another lung condition (e.g., COPD or bronchiectasis) or has an impaired immune system (e.g., HIV or lung transplant), they may be more likely to develop NTMLD.



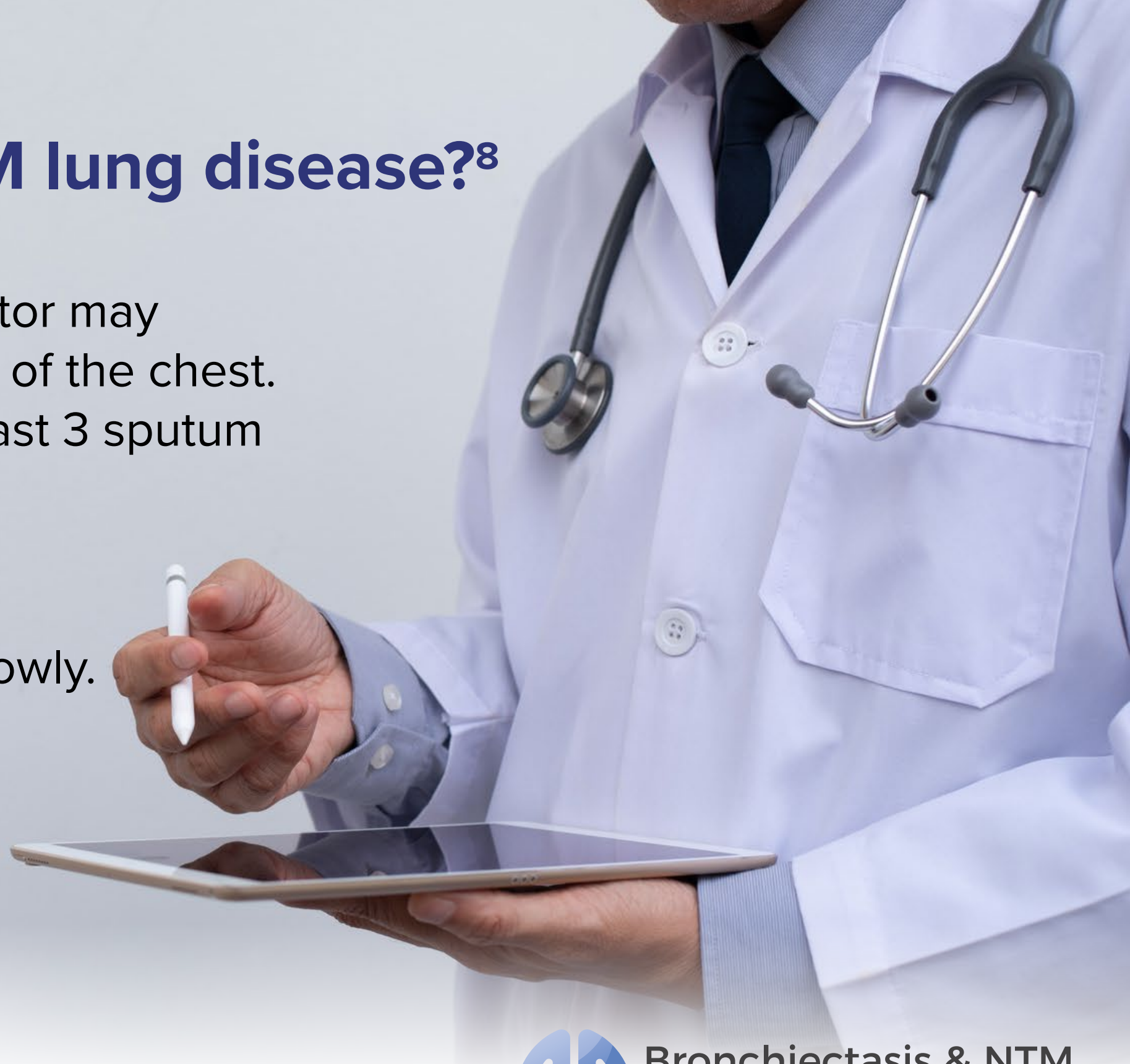
Is NTM lung disease contagious?¹⁶

- NTM is not considered contagious.
- Many people with NTMLD are extremely careful and avoid working with soil. They also avoid spas, jacuzzi tubs, and steam showers.



How do I get tested for NTM lung disease?⁸

- After a complete assessment, your doctor may order a CT (computerized tomography) of the chest. They will also ask that you submit at least 3 sputum samples for testing.
- It may take a while for the lab to return results to your doctor as NTM grows slowly.



I have a diagnosis of NTM lung disease. Now what?⁸

- Once you have been diagnosed with NTMLD your doctor will review options for treatment.
- Treatment with multiple antibiotics at one time is recommended for those with NTMLD.
- Those with NTM who begin treatment with medicines are recommended to stay on those medicines for at least 12 months after their sputum cultures are clear of NTM.



What are somethings I can do to feel my best with NTM lung disease?⁹

Your doctor may recommend other things to improve your health like

- [Airway Clearance](#)
- [Exercise](#)
- [Eating nutritious meals](#)
- Avoiding further exposure to NTM
- Avoiding illness



NTM Lung Disease Information Sheet

Download this 2-sided information sheet to learn more about NTM lung disease and how to manage it.

<https://copdf.co/NTMInfoSheet>

Tell Me More About NTM Lung Disease

How is NTM lung disease treated?
If treatment is recommended, your HCP will prescribe multiple antibiotics over a long period of time to treat the NTM.⁴ Guidelines say that those on multiple medicines should use them for at least one year after test results are clear of NTM.^{3,4}

Sputum cultures should be collected periodically while on treatment. If NTM is still present after 6 months, alternative treatment options may be evaluated.⁴

Your health care provider may also recommend:

- starting an airway clearing routine.
- exercising regularly.
- getting plenty of rest.
- eating a healthy diet.

Do you, or someone you know, have a lung condition such as COPD, bronchiectasis, and/or a history of tuberculosis? If so, they may be at risk for NTM lung disease.¹

Because symptoms of NTM lung disease are similar to other lung conditions, some people may go years without a proper diagnosis.

What is NTM?
NTM is short for nontuberculous mycobacteria. These bacteria are found in soil and both natural and treated water. NTM is typically not passed from person to person.²

Common symptoms are

- cough
- fatigue
- weight loss
- shortness of breath.³

How is NTM lung disease diagnosed?

- Complete health history
- Chest CT (computerized tomography) scan
- Two or more sputum samples (cultures)^{3,4}

Because the bacteria grow slowly, the culture may take up to 6 weeks to get the final result.

Those with COPD are about 16 times more likely to get NTM lung disease.¹

How does NTM lung disease occur?³

NTM is breathed in and enters the airways → NTM finds a home in the lungs and slowly grows → Over time, symptoms can start to develop

It is hard to avoid NTM but wearing a mask while gardening and staying away from saunas and hot tubs can help.

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NTM Lung Disease Management Tool

The NTM Management Tool is designed to help those with NTMLD communicate well with their HCP.

Download the tool and fill out the patient portion. Bring the tool with you to your next lung doctor's visit.

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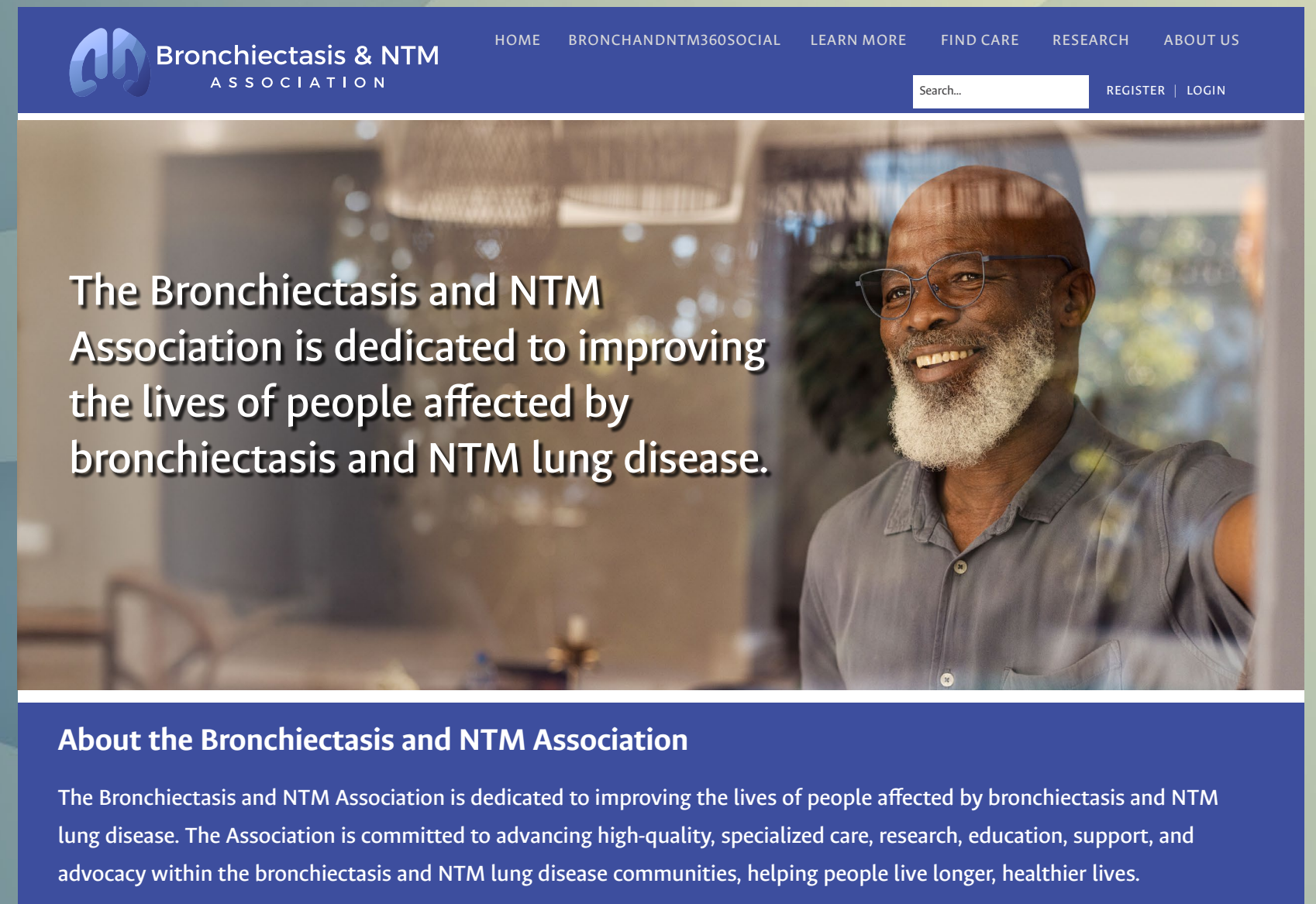
Date and time: _____ Testing needed before visit: _____
Details of your next visit: _____
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Additional Resources

You can learn more about NTM lung disease by visiting BronchandNTM.org.

Join BronchandNTM360social for access to a community of patients, caregivers, and HCPs willing to offer support.



The screenshot shows the website's header with the logo and navigation menu. The main content area features a photograph of a smiling man with a beard and glasses, with text overlaying it. Below the photo is a blue section with the heading 'About the Bronchiectasis and NTM Association' and a paragraph of text.

Bronchiectasis & NTM ASSOCIATION

HOME BRONCHANDNTM360SOCIAL LEARN MORE FIND CARE RESEARCH ABOUT US

Search... REGISTER | LOGIN

The Bronchiectasis and NTM Association is dedicated to improving the lives of people affected by bronchiectasis and NTM lung disease.

About the Bronchiectasis and NTM Association

The Bronchiectasis and NTM Association is dedicated to improving the lives of people affected by bronchiectasis and NTM lung disease. The Association is committed to advancing high-quality, specialized care, research, education, support, and advocacy within the bronchiectasis and NTM lung disease communities, helping people live longer, healthier lives.



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