Living Well With NTM
Nontuberculous Mycobacteria
PATIENT EDUCATION GUIDE

Materials for this patient education guide contributed by NTM Info & Research.
Supported by an educational grant from Insmed Incorporated.
NTM are found in nature’s water and soil. There are more than 180 species of NTM. Most do not cause disease except in people with a weak immune system. People at risk breathe in the organisms from misty water (for example, in a shower or hot tub) or from soil. If not treated, many people may get a worsening lung infection.

Key Facts

- People at any age can get NTM. It occurs more frequently in older adults and people with other lung diseases, like bronchiectasis and COPD.
- If it is not treated, many NTM infections may cause damage to lung tissue.
- NTM is not contagious. It cannot be passed from human to human.
- Treatment for NTM lung infections generally requires long-term use of antibiotics, often for 1 to 2 years.
About 50,000 to 90,000 people with NTM in the US have NTM lung disease. It’s more common in older adults. NTM can affect any age group. NTM lung infections can become chronic and require ongoing treatment. Severe NTM lung disease can effect a person’s quality of life. Death directly related to NTM lung disease is uncommon.

Get the Facts

- About 50,000 to 90,000 people in the US have NTM lung disease.
- Every year 12,000 to 18,000 people in the US are diagnosed with NTM lung infection.
- NTM cases are increasing by 8% every year in older persons.
- Most people who get NTM also have chronic lung infection.
How Does NTM Affect Your Body?

NTM can enter the lungs from the environment. In most people, NTM are cleared from the lungs naturally and do not cause infection. In some people, NTM infects the airways and lung tissue. This causes an infection. Without treatment, many people will develop a progressive lung infection. Cough, shortness of breath, fatigue, and often weight loss are symptoms.

Causes of NTM Lung Infection

NTM lung infections are caused by mycobacteria that are found in soil and water. Doctors do not know why only some people develop NTM lung disease. Most people do not become sick. The people who do get sick from NTM usually have another lung disease or a weak immune system.

Common Symptoms

People with NTM generally have some or all of these symptoms:

- cough
- fatigue
- night sweats
- fever
- weight loss and loss of appetite
- shortness of breath
- coughing up blood
- excessive mucus production
- wheezing
- chest pain
- recurring respiratory infections
Risk Factors for NTM Lung Infection

NTM has a higher rate among people with certain risk factors, including:

- **Age.** It’s more common in older people.
- **Lung Disease.** Many people have another underlying lung problem, such as:
  - bronchiectasis
  - COPD
- **Genetic Diseases.** Genetic diseases, including cystic fibrosis, alpha-1 antitrypsin deficiency, and primary ciliary dyskinesia, increase the risk of NTM.
- **Weak Immune System.** Illnesses that affect the immune system, such as Sjogren’s disease and rheumatoid arthritis, may increase the risk. Certain drugs can weaken the immune system, such as prednisone and other steroids.
- **Medications.** Some drugs used to treat rheumatoid arthritis or Crohn’s disease increases the risk of NTM.
- **Esophageal (stomach) Disorders.** Acid reflux (GERD) and other disorders of the esophagus can increase the risk due to spillage of stomach contents into the lungs.
- **Postmenopausal Caucasian (White) Women.** Some women may have an increased risk for NTM. These women share certain physical features that include:
  - being tall and slender
  - having a curved spine
  - breastbone abnormalities
  - mitral valve prolapse
- **Environment.** High-risk sources include showers, indoor hot tubs and pools, and soil.

When to See Your Doctor

Go to your doctor right away if you have a cough that won’t go away, with fatigue, night sweats, shortness of breath, or weight loss. If your cough doesn’t improve with treatment, you might need to see a lung specialist.
How NTM Lung Disease is Diagnosed

A typical evaluation by your doctor will include:

- **Detailed Medical History.** If your doctors know your medical history, it may help them discover other lung conditions.
- **Physical Examination.**
- **Sputum Culture.** A sputum sample (also known as mucus or phlegm) is sent to a lab to test for NTM and identify the species. This helps with a targeted treatment. You can cough up the mucus. When you can't produce mucus, a bronchoscopy may be performed to get a specimen.
- **Chest X-Ray and CT Scan.**
  
  A chest X-ray may provide the first hint that NTM are present. A CT scan shows more detail that can help confirm NTM. The CT scan can show the presence of small nodules. These are sometimes referred to as “tree-in-bud” because they look branch-like. The CT scan can also identify cavities, or holes in the lung, which represent a more destructive form of infection.

Diagnosing NTM

Diagnosis is often delayed. Symptoms are similar to other lung diseases, such as:

- COPD
- bronchitis
- bronchiectasis

When NTM infection is suspected, diagnosis is not difficult. A lab test can easily identify NTM. It can also identify which species is causing the disease. The species will affect the type of treatment.

What to Expect

If diagnosed with NTM lung disease, you may never have symptoms. It may take many years to see symptoms. Once they appear, treatment may not completely relieve all of them. Early diagnosis and treatment are essential for good outcomes.
Your Treatment Depends on You

NTM lung disease and its treatment are specific to you. That means you play a vital role in your treatment. You are the center of a team helping you heal your NTM. You have to stick to your treatment plan and take your medications as prescribed. You have to see your doctor for regular tests. You should report on how you feel, especially if you are having side effects of medications.

Some lifestyle changes may be necessary. You should focus on good nutrition, exercise, and stress relief. Treatment of NTM lung disease can take a long time. It requires antibiotics for one to two years. Treatment should continue until sputum culture results have been negative for at least 12 months.
Your Treatment Team

Your treatment team wants to help you live with and treat your NTM lung disease. The team may include these medical professionals:

- Pulmonologist – a lung doctor
- Internal Medicine/Primary Care Physician
- Infectious Disease Specialist
- Pharmacist
- Respiratory Therapist
- Dietician/Nutritionist
- Mental Health Professional
- Exercise Physiologist
- Pulmonary Surgeon

Treating NTM Pulmonary Disease

NTM are relatively resistant to antibiotics. They can become more resistant if only one antibiotic is used. Effective treatment requires two to three drugs. The exact drugs and combination of drugs depend on the:

- NTM species
- how bad the infection is
- results of drug susceptibility testing

Remember to take all medications as prescribed by your doctor. Things to consider are:

- the best time to take your medications
- should the medication be taken on an empty stomach

Let your doctors know if side effects develop. Many times, you can lessen the symptoms by changing the type or amount of medication you take.
Types of Medications

There are three kinds of drugs to treat NTM lung disease:

- **Oral Medications.** These include pills taken by mouth.
- **Intravenous (IV) Medications.**
  These enter the body through a vein. Some IV treatments can be completed at home. Other IV treatment must be given in a hospital or clinic.
- **Inhaled Medications.** These enter the body with a nebulizer.

Side effects of drugs are common. Most people can finish the prescribed treatment.

Treatment Protocols

Different NTM species require different treatments:

- **M. avium complex (MAC) and M. kansasii,** the most common causes of pulmonary NTM disease, require three drugs given either 3 days a week or daily. The timing depends on the severity of disease.
- **M. abscessus** treatment is more complicated and has poorer outcomes compared to MAC and M. kansasii. Many people need several months of treatment with one or two IV drugs, and oral and sometimes inhaled antibiotics.

Remember, treatment should continue until sputum culture results have been negative for at least 12 months.
Testing

You may need to get regular blood tests. Blood tests ensure your body is handling the drugs well. You may also need vision and hearing tests before and during treatment. Your sight or hearing could be affected by the treatment. In some people, blood tests can ensure that you are receiving the right doses of drugs.

Your doctor may conduct tests in your lungs to check treatment progress. These tests measure:

- How well you get oxygen into your lungs.
- How well oxygen passes through the airways to get into the blood.
- How well air flows out of your lungs.

These tests may include:

- chest x-ray
- CT Scan
- pulmonary function tests like spirometry
- oxymetry

Surgery

Surgery may be needed to remove the most damaged areas of the lung. Make sure you meet with experts in NTM and surgery first. In most cases, surgery can be performed using VATS (video-assisted thoracic surgery).
Managing NTM Lung Disease

Treatment takes a long time. There are many changing variables that affect how you feel. Living with NTM can be hard. You may have chronic coughing, feel tired, or have other side effects from treatment. Many patients also feel isolated, anxious, or depressed. A complete cure can be expected with some NTM species and not with others. Re-infection is common so you may need to make some lifestyle changes.

What can you do to help manage your NTM?

- **Focus on other lung conditions you may have.** Many patients with NTM have another lung disease, such as bronchiectasis, COPD or prior tuberculosis. Treatment of these diseases may help improve some of the symptoms of NTM disease, such as cough and shortness of breath.
- **Prevent fatigue.** Feeling tired is a common symptom. It is important to maintain your weight through proper nutrition. Use nutritional supplements if necessary. Exercise is also important. It may improve your fatigue level.
- **Keep your airways clear.** Your doctor or respiratory therapist can teach you ways to reduce mucus in your lungs and keep your airways clear. This is very important for people with bronchiectasis.
- **Prevent infections.** Get a flu shot each year. Get pneumonia shots when recommended. Wash your hands often to avoid germs that can lead to other lung infections.
- **Improve air and water quality at home.** Keep bathrooms, showers, and steam rooms ventilated. Clean your showerheads regularly. Don't use humidifiers.
- **Avoid contact with soil.** Wear a dust mask to prevent breathing in dirt when gardening and avoid soil.
Questions to Ask Your Doctor

It is helpful to make notes before your appointment. Taking a family member or friend can help. Questions include:

- Which strain of NTM do I have?
- Where in my lungs is the infection?
- What will happen if I don't get treated?
- What drugs will I take? How much? For how long?
- Will I need IV drugs?
- Are there side effects of the treatment? What can I do about them?
- Should some side effects be reported to you right away?
- Are there other treatments I can take besides the antibiotics?
- How will you observe me? Will there be tests?
- When do I need to see you?
- Can I still take my other prescriptions? (Bring a list of all medications you are taking)
- Can I take over-the-counter drugs or supplements?
- Do I need to make lifestyle changes? What can I do to improve my general health and nutrition?
- Should I change how I exercise?
- Should I have surgery to remove the infected part of my lung?
- What is my chance of being cured?
Additional Resources

www.NTMInfo.org
www.lung.org
www.sciencedirect.com
www.youtube.com/watch?v=NUjXGmHfo7s

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