
“insight”



a patient's perspective



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NTM
Nontuberculous Mycobacteria
NTM Info & Research, Inc.



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INSIGHT

This pamphlet provides insight into lung disease caused by nontuberculous mycobacteria (NTM) and empowers the patient to participate in his or her own treatment. NTM is also called atypical tuberculosis (atypical TB), mycobacteria other than tuberculosis (MOTT), MAC (*Mycobacterium avium* complex, which is actually several species or type of NTM), or environmental mycobacteria (EM).

You can find expanded versions of the information contained in this booklet on our website, ntminfo.org.

WHAT ARE NONTUBERCULOUS MYCOBACTERIA?

Nontuberculous mycobacteria (NTM) are naturally occurring environmental organisms found widely in both water and soil. They can cause or worsen significant respiratory damage, such as bronchiectasis. There are more than 180 species of nontuberculous mycobacteria. MAC or *Mycobacterium avium* complex, *M. kansasii*, *M. abscessus*, *M. chelonae*, and *M. fortuitum* are just a few. (M. is used as an abbreviation for mycobacterium.) Some are readily treated with two or three drugs, while other types are resistant to many drugs and more difficult to treat. These require treatment that is often more complex and of a longer duration.

WHO GETS NTM?

NTM lung disease (pulmonary NTM disease) is not as well-known or understood as tuberculosis (TB). We know that there are certain underlying conditions (sometimes referred to as a comorbidity) that make some people more susceptible to NTM infection, such as prior lung infection as well as bronchiectasis, COPD and genetic diseases such as Cystic Fibrosis, Alpha-1 antitrypsin deficiency, and primary ciliary dyskinesia (PCD).

In the past, NTM lung disease in North America was seen predominantly in men and was often misdiagnosed as TB. NTM lung disease then started to be seen more in slender Caucasian post-menopausal women, but we are now seeing it in men, younger women, and children. In other areas of the world including the Netherlands, the patient profile is quite different and is reported to be changing.

Illnesses which feature immune dysregulation, such as autoimmune disorders like Sjogren's disease or rheumatoid arthritis (RA), may also increase someone's risk of infection. We also know now that immunosuppressive medications such as chemotherapy, prednisone, or drugs used to treat conditions such as RA, psoriasis, and Crohn's disease, may increase the risk of NTM infection. This includes extrapulmonary NTM disease, or NTM infection in areas of the body other than the lungs. NTM infections can occur in bone, skin or soft tissue, and outbreaks have been reported that were traced back to nail salons, laser eye surgery centers, dental clinics, and heater-cooler units used in open heart (open-chest) surgery.

Other underlying conditions include pneumonia, prior inhalation of inorganic dust including silica, GERD (gastroesophageal reflux disease, which is spillage of material from the esophagus into the lungs), bronchiectasis, emphysema, or cigarette-induced lung disease.

Current estimates place the number of people with NTM lung disease as high as 180,000 people in the United States at any given time, with that number rising 8 percent each year in people 65 years and older. (Strollo *et al.*, 2015.)

HOW DID I GET IT?

NTM organisms are in the environment, including water (both natural sources and treated tap water) and soil. Doctors and scientists believe that some patients become infected with NTM from inhalation of mycobacteria that become aerosolized by showers, kitchen sink sprayers, indoor pools, hot tubs, or from refrigerator ice makers. If you have an underlying condition that might make you susceptible to NTM infection, you may wish to speak to your doctor about the advisability of bathing in a tub rather than showering.

Some patients may become infected with NTM from inhalation of mycobacteria naturally existing in potting soil, through activities like gardening. Many doctors and scientists believe NTM lung infection is not just due to exposure to the bacteria in the environment but also because of host vulnerability – some people are more predisposed to infection.

AM I CONTAGIOUS?

No. NTM are not considered to be communicable person to person. However, patients with certain comorbidities such as Cystic Fibrosis may be vulnerable to passing certain infections among each other, and it is uncertain whether NTM is one of them. For this reason, CF patients should take extra precautions when in close settings with one another.

WHY HAVEN'T I HEARD OF NTM LUNG DISEASE BEFORE?

You've probably heard of other mycobacterial diseases. The two best known are different than NTM lung illness. They are *Mycobacterium tuberculosis* (TB) and *Mycobacterium leprae* (leprosy), both of which have caused great human suffering and are contagious.

Nontuberculous mycobacteria (NTM) should not be confused with TB or leprosy.

HOW IS NTM DIAGNOSED?

NTM infection is often misdiagnosed. Unfortunately, this may delay initial diagnosis until after the patient has had recurrent infections and suffered more lung damage as a result. This may make treatment more difficult because prior use of a single drug may have created some drug resistance. Recurrent infections and associated inflammation may have resulted in additional damage to the respiratory system. The patient profile has changed through the years, making it important to evaluate the implications of all and varying symptoms, and consider testing for NTM.

The diagnosis of NTM involves the following:

I. Sputum smear and culture – Acid fast bacilli (AFB) smear and culture, are the basic tests to identify mycobacteria. For accurate identification of the strain of NTM and drug sensitivities, testing should be done at a specialized laboratory, which can tell your doctor which drugs are most likely to work. If you have trouble coughing up sputum (also called mucus or phlegm), your doctor may decide to perform a bronchoscopy to obtain the needed sample.

II. Chest CT (Computed Tomography) – A CT (CAT) scan is a three-dimensional image generated from a large series of two-dimensional x-ray images. Chest x-rays alone provide rudimentary identification of lung ailments. A CT scan provides the doctor with a detailed look at the extent and location of disease and is an important diagnostic tool. NTM diagnosis and follow-up generally requires a high-resolution CT scan **without contrast**.

III. Medical History – Knowing what illnesses you and your blood relatives have had, including childhood illnesses, may provide your doctor with additional understanding of why certain underlying lung conditions exist. For more information on diagnostics and tips on gathering a family health history, visit ntminfo.org.

CYSTIC FIBROSIS

Cystic Fibrosis (CF) is a genetically inherited, chronic, and potentially life-shortening disease. A defective gene results in an unusually thick, sticky mucus that clogs the airways.

If you've been diagnosed with CF, you have at least two mutated genes, inheriting one from each parent. In some cases, additional tests such as the Sweat Test, which measures the amount of chloride in the patient's sweat, may be useful. Testing should be done through an accredited CF care center.

Occasionally, a patient with one CF gene mutation but a mildly elevated sweat test result may not have completely normal lung function, may exhibit other symptoms, or might get sick later in life. In this case, the patient should be followed by a physician or institution with expertise in CF to see if symptoms develop. If you have been diagnosed with CF, your care should be coordinated through an accredited CF center.

CF is a significant comorbidity for NTM lung disease. Some NTM patients are now being diagnosed with a form of CF as adults.

For more information on Cystic Fibrosis as well as available treatments, guidelines, and locations of accredited treatment centers, visit cff.org or ntminfo.org.

BRONCHIECTASIS

Bronchiectasis is a structural change of the airways (bronchial tubes) in your lungs. NTM infection causes your airways to produce or retain extra mucus and over time, it may lead to their dilation (widening) and scarring. Changes like this, which damage muscle or elastic tissue of the bronchial tubes is called bronchiectasis. These dilated bronchial tubes can trap mucus. If you are unable to clear the mucus normally because it is trapped in the damaged airways, the mucus stays there and this can allow infection to grow. As the damage progresses, infections recur.

The problems that lead to bronchiectasis often begin early in life, but you might not be diagnosed for many months or even many years, often until you've had repeated lung infections and have more difficulty breathing. Bronchiectasis is the most common comorbidity of NTM lung disease.

For more information, visit bronchiectasisandntminitiative.org or ntminfo.org

COMMON SYMPTOMS OF NTM

Patients with NTM infections often experience a variety or even all of the following:

- 1. Cough** – You may or may not cough out sputum. NTM lung disease may cause you to cough up blood (this is called hemoptysis). If you cough up blood, you should contact your doctor or seek emergency help immediately. Any time you cough up blood, it is essential that you remain calm and still to help minimize the amount of blood you cough.
- 2. Night Sweats, Fever** – You may experience some low-grade fever. The sensation of feverishness and sweating is often more prominent at night.
- 3. Loss of Weight and Loss of Appetite** – It is not uncommon to lose weight, which is why it is important to be aware of weight changes. Please consult with your doctor and/or a nutritionist to determine how to modify and augment your diet. You can also find a nutrition guide with suggestions for increasing caloric intake, as well as a printable food diary, at ntminfo.org.

4. Lack of Energy – Many patients note a variable but often profound sense of fatigue.

5. Feeling short of breath

6. Wheezing

7. Chest pain around the lung area

YOUR TREATMENT: THE EMPHASIS ON YOU!

Living with a mycobacterial infection requires a skilled and experienced medical team to design and implement a treatment protocol. The success of your treatment relies on YOU, your medical professionals, and your medicines.

Fortunately, you can play an active role in the progress of your treatment. You should be fully committed to wellness and seek the support of family and friends. Your lifestyle and routines may have to change. The changes you make are to improve your health and lengthen your life, and with a positive attitude these can be rewarding rather than burdensome.

Once you have fully discussed your condition and treatment plan with your doctor, you have the responsibility to implement your treatment and follow through with full commitment.

1. Taking Medicines – You will likely need to take multiple medications. Take all medicines every day for as long as needed. Do not stop when you begin to feel better. The doctor will tell you when the bacteria have been controlled long enough to stop taking your medicines.

Your medications may have some side effects. Call your doctor to discuss any side effects and determine whether your medicines should be changed, or the dosage altered. If you are having a severe reaction, call your doctor or pharmacist immediately, however, unless your reaction is life-threatening, do not stop taking any of your medicines because doing so can make your NTM drug-resistant.

The American Thoracic Society (ATS) and Infectious Disease Society of America (IDSA), and the British Thoracic Society (BTS) recommend a standard treatment for pulmonary NTM disease consisting of three or four medications.

Certain combinations of antibiotics work better together because they attack the bacteria in more than one way. Drug combinations are often prescribed to effectively treat a specific strain of NTM. For this reason, it is very important that your sputum samples be sent to a qualified, specialized mycobacteriology lab for precise identification of the species and sensitivity testing.

Occasionally the standard therapy will fail, or another combination of drugs will be recommended depending on the strain of NTM. In these cases, medications may be added or changed.

For more information on these and other medications, please see the “Types of Antibiotics” chart on pages 14 – 17 of this pamphlet. You can also find links to other resources and full ATS/IDSA treatment guidelines at ntminfo.org.

2. Types of Medicines

A. Oral – Pills or liquid medicines taken by mouth, as directed by your doctor. Make sure you understand what time of day to take the medicines and whether they should be taken before, after, or with meals.

You may have trouble swallowing pills. When taking them, don't tilt your head back. Instead, put your chin down to your chest and swallow the pills. You can also use soft food like applesauce; combine the pill with it and swallow.

B. Intravenous (IV) - IV medicines are infused via a port or “picc” line and may be done in a hospital or at home. In some cases, IV treatments are relatively short in nature (a matter of weeks), but in other cases, may be of much longer duration. Be sure you know how often you are supposed to take these medicines. It is also very important that you know how to care for any central catheter (port) or picc line to avoid introducing any other infections.

C. Inhaled - Some medicines may be inhaled directly into your lungs or nose, potentially minimizing side effects or complications. These drugs include antibiotics or anti-inflammatory agents such as steroids, or bronchodilators. It is important that you learn how to care for the nebulizer to maintain sterile

conditions to avoid introducing other bacteria or infections into your lungs. Run the unit to clear and dry the tubing and sterilize the nebulizer mouthpiece regularly. Visit ntminfo.org for more information on sterilizing medical equipment.

Certain inhaled medicines may also be taken by metered dose inhalers, which are easier to maintain than nebulizers. It is very important that your doctor or respiratory therapist show you the proper way to use these inhalers so that you get the benefit of the full amount of medicine into your lungs or sinuses.

3. Hearing, Vision and Other Testing – Some of the antibiotics your doctor may prescribe can affect your hearing or vision. By the time you notice a problem, it may be too late, so regular checkups are recommended because you might not notice the damage until it has progressed. Ask your doctor about getting baseline tests on your hearing and vision when beginning treatment for NTM lung disease.

Patients with certain heart conditions may be at risk of developing a dangerous irregular heart rhythm when taking certain types of antibiotics. Speak with your doctor about getting evaluated for these conditions and having regular EKGs if taking one of these medications.

4. Clear Your Lungs and Sinuses (Airway Clearance) - You and your doctor or respiratory therapist may have selected one or more ways to clear the mucus from your lungs. It could be chest physical therapy (chest PT) with postural drainage, use of an airway clearance device, or inhaled saline solution. Whatever methods of mucus clearance you use, remember that every time you cough out infected mucus, there is that much less in your lungs to do damage and that much less for the antibiotics to overcome.

Your doctor may have instructed you to do a sinus wash once or twice a day. If so, be sure that you know the correct procedure and how to sterilize the water used and equipment. Visit ntminfo.org for sinus wash guidelines established by the U.S. Centers for Disease Control.

5. Stay Well Hydrated – Patients with NTM disease need adequate fluids. Fluid is essential for thinning mucus secretions, which in turn helps you clear mucus from your airways. It also helps your kidneys and liver process

medications. Try to minimize drinks such as alcohol and coffee, tea or any other drink that acts as a diuretic and actually results in dehydration.

6. Exercise – Exercise is important to help maintain and improve endurance overall. Some patients report that the hard breathing associated with exercise helps them clear their lungs. Weight training can also help muscles become more efficient at extracting oxygen from your blood. Exercise is a recommended part of most treatment plans, but you must discuss the extent and type with your doctor before starting an exercise regimen.

CAREGIVERS & FAMILIES

As the caregiver, your role is an important one on the NTM patient's journey, and while the illness takes a great toll on patients, the caregivers and family members also live with the stress of a chronic illness.

Having to care for a loved one with a serious illness like NTM lung disease can cause great disruption to your life, as you help your loved one with treatments and the challenges of a changed lifestyle. This is a chronic illness, and there is often a feeling of loss of control, or that it is a huge burden or undertaking. These feelings are normal and should not be pushed aside. It helps for both you and the patient to know as much as possible about the illness and treatments, so you can make decisions together.

It's important to address the emotional and physical issues you face, because each patient needs a strong support system, and as the caregiver, so do you, to be a strong support to the patient.

Some helpful tips for caregivers:

- Get an annual flu shot and if warranted, pneumonia vaccination as well
- Wash your hands well and avoid close contact with people who are ill
- Develop a personal support system for yourself
- Ask for help from friends and family
- Be realistic about how much of your time and yourself you can give, and communicate those limits clearly
- Join a support group for caregivers – it helps to know you're not alone

- Schedule some social time for yourself

From specialists to primary care physicians to pharmacists and therapists, health care providers are often a valuable source of information needed to help with the ongoing long-term regimen needed to treat NTM lung disease. Listen to your instincts and to your loved one as well. Listen and observe for anything out of the ordinary in case it needs to be reported to the doctor.

Online resources for caregivers include the National Alliance for Caregiving (www.caregiving.org), the Family Caregiver Alliance (caregiver.org) and the National Family Caregiver Support Program (www.aoa.acl.gov). Links to these and other resources, as well as more information and helpful tips for caregivers and families can be found on ntminfo.org.

TREATMENTS & SIDE EFFECTS*

Medications with FDA approval for treatment of NTM lung disease are indicated in the chart.

CLASS	MEDICATION NAMES (BRAND NAMES)	FORM	NOTES	COMMON SIDE EFFECTS
Rifamycin	Rifampin (Rifadin®, Rimactane®)	Capsule, Injection	Generally used to treat MAC, along with ethambutol plus macrolide.	Red, brown or orange saliva, sweat, tears or feces; diarrhea/upset stomach; fever, chills, flu-like symptoms; flushing; itching; rash; elevated liver enzymes; abnormal blood count
	Rifabutin (Mycobutin®)	Capsule	Rifamycins may permanently stain contact lenses orange. Consider disposable contact lenses. Can interact with other drugs, especially anti-fungal and newer CF drugs.	
Ethambutol	(Myambutol®)	Pill	Patients on ethambutol should have regular vision checks.	Vision changes; numbness, tingling in hands and feet; rash
Macrolide	Clarithromycin (Biaxin®)	Pill	Do not take a macrolide alone or with a quinolone as this can cause drug resistance.	Irregular heart rhythm; hearing changes; nausea; muscle weakness; kidney problems; metallic taste; diarrhea; abdominal pain; rash
	Azithromycin (Zithromax®)	Pill	Patients on azithromycin should have an EKG and regular hearing checks.	

CLASS	MEDICATION NAMES (BRAND NAMES)	FORM	NOTES	COMMON SIDE EFFECTS
Aminoglycoside	Amikacin	Intravenous (IV), Inhaled	Patients on aminoglycosides should have a baseline hearing test before or at start of treatment. Hearing as well as BUN, creatinine, and electrolytes should be monitored at routine intervals while on therapy.	Hearing loss; tinnitus (ringing in the ears); nausea; muscle weakness; rash; poor balance; kidney problems; risk of increased respiratory adverse reactions (inhaled)
	(ARIKAYCE®)+ <i>FDA-approved to treat MAC lung disease</i>	Inhaled		
	Tobramycin (TOBI®)#	Inhaled, IV		
	Streptomycin	Injection, IM		
Fluoroquinolones (“Quinolone”)	Ciprofloxacin (Cipro®)	Pill	Do not take alone or only with a macrolide as this can cause drug resistance.	Upset stomach; rash; diarrhea; headache; loss of appetite; abnormal EKG in at-risk patients or in combination with other medications; dizziness; tendon abnormalities; low blood sugar; adverse psychiatric reactions including depression
	Levofloxacin (Levaquin®)	Pill		
	Moxifloxacin (Avelox®)	Pill		

+ FDA-approved for treatment of *Mycobacterium avium* complex (MAC) lung disease as part of a combination antibacterial drug regimen for adult patients who have limited or no alternative treatment options.

CLASS	MEDICATION NAMES (BRAND NAMES)	FORM	NOTES	COMMON SIDE EFFECTS
Cyclines	Minocycline (Minocin®)	Pill, Injection		Sun sensitivity; nausea; diarrhea; dizziness; rash; elevated liver enzymes; abnormal blood count
	Doxycycline (Vibramycin®, Monodox®)	Pill		
	Tigecycline (Tygacil®)	IV		
Cephalosporin (Beta-lactam)	Cefoxitin (Mefoxin®)	IV		Rash; elevated liver enzymes
Penicillin (also Beta-lactam)	Amoxicillin (Augmentin®)	Pill		Nausea; rash; diarrhea
	Ampicillin-sulbactam (Unasyn®)	IV (oral form available outside the US)		
	Piperacillin-tazobactam (Zosyn®)	IV		
Other Beta-lactams	Aztreonam# (Azactam®, Cayston®)#	IV, inhaled		Itching; loss of appetite; rash;
	Imipenem (Primaxin®)	Injection, IV		
	Meropenem (Merrem®)	Injection, IV		

CLASS	MEDICATION NAMES (BRAND NAMES)	FORM	NOTES	COMMON SIDE EFFECTS
Sulfa Drugs	Trimethoprim/Sulfamethoxazole (Bactrim®, Septra®)	Pill		Itching; loss of appetite; diarrhea; abdominal pain; dry mouth and skin; orange or brown skin discoloration
Riminophenazine	Clofazimine (Lamprène®)	Pill	Sometimes used for patients when standard therapy has failed. Requires FDA or Novartis approval for use on a case-by-case basis.	Loss of appetite; diarrhea; abdominal pain; dry mouth and skin; orange or brown skin discoloration
Oxazolidinone	Linezolid (Zyvox®)	Pill		Rash; abnormal blood count; headache; upset stomach; numbness in hands and feet; vision changes
	Tedizolid (Sivextro®)	Oral, IV		Headache; upset stomach; nausea; diarrhea; vomiting; dizziness

Tobramycin and aztreonam are FDA-approved for the treatment of serious bacterial infections caused by susceptible gram-negative microorganisms. Cayston® and TOBI® are FDA-approved for use in cystic fibrosis (CF) patients with *Pseudomonas aeruginosa* lung infections.

* Medications may not be available in every country and some medications may only be available through specialty pharmacies. Refer to ntminfo.org for the latest information on drugs that become approved or are under investigation, and for clinical trial updates. You can also sign up for email updates via the website.

MANAGING SIDE EFFECTS

Though the medications used to treat NTM lung disease can be difficult to tolerate, here are some tips which may help reduce the severity of some of the side effects. You can find more information on ntminfo.org. Remember to always talk to your doctor about any side effects and any remedies you plan to try for them, or about adjusting your medication dosages.

Weight Loss

You may find it difficult to keep weight on; this can be a side effect of both the disease and the treatment. In addition to proper nutritional intake, there are medications which can induce appetite.

Fatigue

Fatigue is a common side effect of both the illness and the treatments for it. While there are no medications that can restore your full energy, there are ways to help fight the fatigue. Proper nutrition, good hydration, and exercise can all help. For more information, visit ntminfo.org.

Dry Mouth / Unpleasant Taste

Many patients experience dry mouth or an unpleasant taste, particularly with inhaled antibiotics. There are ways to reduce this side effect, such as special mouth rinses for dry mouth. You may also want to try sucking on hard candies like lemon drops or using new flavors and spices in your food to challenge your taste buds.

Upset Stomach

Gastrointestinal distress is one of the more common side effects of antibiotics. It can range from bloating and mild discomfort to nausea or severe diarrhea, which can lead to extreme dehydration. This upset stomach may be the result of the antibiotics killing off the good bacteria which normally reside in your gastrointestinal tract. You can help replace these good bacteria by taking a probiotic supplement. For nausea, ginger in some form such as ginger ale or ginger chews may help. If the nausea is severe, your doctor may prescribe an anti-nausea medication.

Yeast: A Candid Look at Candida

One of the most common side effects of any antibiotic treatment is candidiasis, or a yeast infection. These infections are the result of an overgrowth of a fungus, usually *Candida albicans*. The most common type of infection is a vaginal yeast infection, though it can also occur inside the mouth (this is called thrush).

Symptoms of a vaginal yeast infection include an abnormal discharge, painful urination, redness and swelling of surrounding skin, itching and burning. Oral thrush appears as whitish, velvety sores in the mouth and on the tongue, with inflamed tissue underneath which may bleed easily. Either one should be diagnosed by a physician and promptly treated.

Treatments for yeast infections range from over-the-counter medications or rinses to prescription creams or suppositories. (Suppositories may be easier to use if they have been refrigerated for a short while.) Severe or repeat infections may require oral antifungal medications. There are also things you can do to help your body replace and rebalance the bacteria. These include probiotics or food such as yogurt with live cultures.

Thrush can be treated and held at bay by rinsing and brushing your mouth with a soft toothbrush several times a day, using a diluted 3% hydrogen peroxide solution. Your doctor may also prescribe antifungal mouthwash, lozenges or oral medication.

For more information, visit ntminfo.org.

A Note on Probiotics

The most common live culture in probiotic supplements, which are sold over-the-counter and in live culture foods, is *Lactobacillus acidophilus*, and most contain others as well. There are many brands, and your doctor may have a preferred brand to recommend for you, or you may try several until you find one you like.

Because they are live cultures, probiotics should never be taken at the same time as antibiotics. You should allow a three to four-hour window between an antibiotic dose and a probiotic dose. Otherwise, the antibiotics will simply kill off the live cultures. Many probiotics are meant to be refrigerated, so read the instructions on the packaging carefully.

Probiotic supplements come in varying doses (the number of live microorganisms in each capsule), which means some may be much stronger than others. You may choose to start with smaller doses and work up to larger doses.

PULMONARY FUNCTION TESTS (PFT)

What are they and why do I need them?

Chest x-rays and CT scans show if there are any abnormalities affecting your lungs. Pulmonary function tests (PFTs) are a group of tests that measure how well your lungs are functioning. PFTs are usually performed to follow the progression of lung disease and are also used to determine if surgery is safe.

Some of the most common Pulmonary Function Tests are:

- A. Spirometry:** the patient breathes in deeply and exhales as fully and forcibly as possible to assess airflow into and out of your lungs.
- B. Plethysmography:** measures the gas volume of the lung, using changes of pressure that occur during breathing.
- C. Diffusing capacity:** the patient breathes in a small amount of carbon monoxide and the test measures how much of this gas gets into the blood. This indicates the ability of the lung to allow oxygen into the blood.
- D. Arterial blood gas measurements:** a small amount of blood is extracted from one of the small arteries in the body (usually in the wrist) to analyze the amount of oxygen and carbon dioxide in the blood.
- E. Oxymetry:** also provides a measurement of the oxygen level in the blood using a pulse oximeter placed on the patient's finger for a minute or two.

SURGERY

Your lungs are made up of three lobes on the right and two lobes on the left, although each lung is about the same size. Sometimes lung damage associated with an NTM infection may be isolated or most severe in one lobe or one area of your lung. Surgical removal of that lobe or area (“lobectomy” or “segmentectomy”) combined with other treatments such as antibiotics may be recommended.

Although surgery doesn't usually replace the need for antibiotics, it may improve the chance the infection is eventually eradicated. You might be considered a candidate for surgery if the infection is more localized in one area of the lung, and if standard antibiotic therapy has failed or isn't well tolerated. Many times, surgery is performed using a minimally invasive technique known as VATS (video-assisted thoracic surgery), which is considerably less painful and has a shorter recovery period. The open surgical method, which requires the use of a rib spreader, is used when there is more extensive damage and more lung tissue needs to be removed.

Prior to surgery, you will be on an intensified antibiotic treatment for two to three months to reduce the infection in your lungs as much as possible, as this can help minimize complications. Getting moderate exercise prior to surgery may also aid in your recovery.

After the procedure, you will probably stay in hospital two to four days, and you'll be prescribed oral medications for pain management at discharge. Typical recovery length is 3 to 6 weeks.

The remaining lung generally should be relatively free of disease, and calculated pulmonary function after surgery should be in the range of acceptable to relatively normal or reasonable. For more detailed information on this type of surgery, visit ntminfo.org.

PREVENTION & REDUCING EXPOSURE

Influenza can be serious for a patient with an NTM infection. For patients with chronic lung disease, an annual flu shot and a periodic vaccine against pneumonia is generally advisable.

Try to avoid contact with people who have colds or the flu, or with items they've touched or used. Wash your hands thoroughly with soap and water frequently, and carry hand sanitizer with you.

Other measures may help reduce (though not completely eliminate) your exposure to NTM, including:

- Properly ventilating bathrooms or other shower/steam areas.
- Cleaning your showerheads and kitchen faucet sprayers regularly to remove the biofilm, which acts as a breeding ground for mycobacteria. After cleaning it, you can also soak it in vinegar to remove calcium buildup. For more information on how to remove biofilms, visit ntminfo.org.
- Using a water filter to reduce exposure to waterborne pathogens including mycobacteria, and to serve as an immediate barrier against gram-negative bacteria, fungi, and parasites.
- Raising the temperature of your household water heater to 55° C (131° F) to kill the mycobacteria in the hot water
- Using humidifiers with caution. Avoid ultrasonic humidifiers if possible and clean your humidifier's reservoir frequently. Soak it in undiluted bleach for 30 minutes and rinse it thoroughly. Use sterilized water in the humidifier.
- Wearing an inexpensive dust mask to prevent inhalation of dirt particles while working with potting soil or in the garden *and* wetting down the soil to reduce the number of particles released into the air.
- Taking steps to reduce GERD (gastroesophageal reflux disease).

For more detailed information on these and other measures to reduce exposure, log on to ntminfo.org.

ALLERGIES

Substances that irritate your lungs may create additional inflammation and result in increased sputum production, making airway clearance more difficult. Be aware of irritants that you sense you may be allergic to.

Some possible irritants to be aware of are: perfumes and colognes, cigarette smoke, pollens from trees, grasses, and flowers, dust, air pollution, and aerosol sprays.

Indoor air quality can play a part in increasing or decreasing lung irritation. More information is available at ntminfo.org.

NTM AND OTHER INFECTIONS

Some patients with NTM infections are also vulnerable to other bacterial infections. Some of these infections may also be quite difficult to treat, particularly aspergillus, pseudomonas, or other gram-negative infections.

It is important to have your sputum checked on a regular basis and particularly at any time when your symptoms change. This culture must be requested separately from the test for mycobacteria.

FOLLOW UP – KEEP CONTROL OF YOUR ILLNESS

Your treatment is a partnership between YOU, your doctor and your medicine/ treatments. ***Follow-up is your responsibility.***

Because treatment of NTM requires multiple medicines, it is very important that you schedule regular follow-up visits, preferably at the end of each visit, with your doctor to monitor your condition.

It's important to contact your doctor when something changes. Don't wait for a future or scheduled visit. He or she will be able to decide whether new testing is warranted to determine whether your treatment plan should be modified. This is the most important reason for timely and early follow-up. It allows your doctor to work in partnership with you to keep control of your illness.

Listen to your body and communicate. Keeping a log of your symptoms, reactions to various medicines and anything else that you observe about your condition will help your doctor treat your illness effectively.

Never feel foolish about discussing any aspect of your illness and calling or seeing your doctor. Your observations may be medically significant, so don't keep it a secret - let your doctor decide.

QUESTIONS TO ASK YOUR DOCTOR

Sometimes it is helpful to have a list of questions so you don't forget. It might help to bring someone with you to your appointment if you are especially anxious. These questions were written from a patient's perspective and are not intended as medical advice.

1. What strain(s) of mycobacteria do I have? Where in my lungs is the infection located?
2. Was drug sensitivity testing performed? If so, what were the results? If not, can and should it be done?
3. What drugs will I be taking? What is the dosing level for each medication? Can and should therapeutic drug levels be checked?
4. When and how do I take my medication?
5. How long do you expect me to be on the medications?
6. What side effects will I be likely to have? Which side effects should be reported immediately? Do you have any suggestions for coping with side effects?
7. Will IV drugs be necessary?
8. Will I also need inhalers?
9. How often will I have:
 - a. Follow up appointments with you?
 - b. X-rays/CT scans?
 - c. Lab work? What kind?

- d. Hearing or vision tests? (Try to have hearing and vision tests done before starting your medications so they will have a baseline by which to judge any changes.)
 - e. Sputum cultures?
10. What other monitoring will I need?
 11. Should I use an airway clearance device? How often?
 12. Can I still take over the counter medicines/vitamins/supplements? (Be sure to tell your doctor about ALL nutritional supplements, herbs, or over the counter products that you take. These can interact with your medicines or decrease their effectiveness.)
 13. Would I be a candidate for surgery? Why or why not?
 14. What if I lose my appetite?
 15. What if I feel depressed?
 16. Can I exercise? What kind of exercise?
 17. What precautions should I take? What activities should I avoid?

Several medications used to treat NTM have side effects that can impact vision, hearing, and organ function. Speak with your doctor about what kind of regular monitoring and testing you will need, including lab work. Notify them immediately if you notice any changes. Request and keep copies of all your lab work and radiographic imaging (CT scans, etc.).

For more information on medications and their side effects, see the chart on pages 14-17 of this pamphlet or visit ntminfo.org.

THE ROLE OF REFERRALS

NTM is frequently misdiagnosed and often not tested for.

Your local pulmonary or infectious disease specialist is usually the first step in diagnosing an NTM infection so that you can be treated. If you need to find a local specialist, NTMir has an online Physician Referral List and links to treatment centers at ntminfo.org.

Because of the complexity of developing a treatment plan, you may wish to ask your doctor about the feasibility of a referral to a center that specializes in

treatment of NTM infections. Often the diagnosis and treatment of NTM lung disease involves more than one physician, and there are other medical disciplines that can further support you as a patient. Because treating this disease is so complex, you might want to look for doctors who are willing to work with other medical professionals as part of your “treatment team.”

In addition to pulmonary and infectious disease specialists, other medical professionals who may be valuable additions to your team include internal medicine specialists, respiratory therapists, dietitians or nutritionists, and mental health professionals.

Many patients also like to explore alternative medicine as part of an integrative treatment plan. Although most alternative medicines and treatments are not FDA-approved or scientifically vetted through clinical trials, some patients report therapeutic benefits from integrative medicine added to their treatment.

If you have found something that works for you, that is great! But before you try anything, particularly something that you ingest or inject, please consult your physician. Certain vitamins and minerals (calcium, for example) can interfere with the effectiveness of certain antibiotics as can certain food products, so it is important that your doctors know what you are taking, in case you need to schedule those differently from your prescribed medications. You can also consult with your pharmacist about drug/supplement interactions.

In addition, you should never start or stop any prescribed medication or treatment without consulting your doctor first.

LIVING WITH NTM

Quality of Life Issues

NTM lung disease is a serious illness that has an impact on your life, and it can have a significant impact on your family’s life as well. You may feel like your relatives and friends don’t understand what you are going through. It is difficult for someone who has never faced such an illness to grasp what it’s like to live with it, particularly when it’s a disease they probably have not heard of before.

You might find that giving them a copy of this pamphlet helps them better understand what you are dealing with. You should not be afraid to speak up about

what your needs are. Communicating your needs clearly might be just what they need in order to help you.

For you and your family, a serious illness can be upsetting and even cause anxiety or depression to set in. Don’t ignore this issue – seek help for it.

Visit **ntminfo.org** for more information and resources to help patients and caregivers.

Travel Tips

Travel, particularly by airplane, can become burdensome for NTM patients who deal with medications through IV or inhalation, or who require supplemental oxygen. Thankfully, there are ways to make this easier.

The TSA has approved a printable card that you as a traveler can use to notify agents of any conditions or devices that would require special attention. You can download and print this card from **ntminfo.org**. It is important to note that the cards do not exempt a passenger from screening.

You may also wish to get a physician’s note/letter, explaining your medical issues and the medications and devices needed for them.

Health Insurance

Health insurance is a key issue facing NTM patients, but understanding or choosing your health insurance is not easy. Whether you are on Medicare or with a private insurance program, it is important to know what your obligations and options are. You will need to advocate for yourself as the patient to ensure the best possible results from your coverage.

For more information on what you should know about your health care coverage, log on to **ntminfo.org**.

Keep Track of Your Treatment

Because treating NTM lung disease requires multiple medications, it can be a daunting task to keep track of your daily medical regimen. You may wish to develop a medication schedule to help you keep track of when you take your medications and in what dosages, and when to reorder your prescriptions. You can also download and print a medication schedule from **ntminfo.org**.

Your doctor might be away sometimes when you need to reach him or her, and you may end up speaking with a doctor on call who is unfamiliar with your medical history. It is important for you to keep careful records of what medications you take, in what doses, how often, and how they are mixed if compounded. Remember to follow up with your doctor as soon as he or she returns to the office.

You can also use modern technology to help you remember when to take and reorder your medications! There are numerous apps available for download to your smart phones and tablets, and most come equipped with calendar features, which you can use to set reminders for yourself. There are also many different sizes of strip pill boxes which separate your oral medications out by day, and can also separate them out by time of day as well. These are usually available at your local pharmacies.

RESEARCH & CLINICAL TRIALS

NTM Info & Research has helped accelerate medical research by funding or co-funding numerous studies related to NTM patient vulnerabilities, infection sources and treatments, and prevalence of the disease in the United States, as well as assisting other organizations and companies in recruiting patients for clinical trials of new medications being developed to treat NTM lung disease.

Information about completed and current studies and other research is available on our R&D Pipeline page at ntminfo.org. To support this research, please contact us at ntmmail@ntminfo.org or 305.667.6461. You can also make a donation through our website.

NTM Patient Registry

To make the process of patient recruitment for clinical trials easier and faster, NTMir funded the creation of the NTM Patient Registry (as part of the COPD Foundation's existing Bronchiectasis Registry). There are several participating centers nationwide which are enrolling patients in the Registry. For more information on registering as a patient or becoming a Registry site, visit the Research section of our website on ntminfo.org.

Dr. Steven Holland, from the National Institutes of Health, authored an article titled *The Importance of Clinical Trials: Hope for the Future*. We encourage you to read the full article, and to find current NTM clinical trials, by logging on to

ntminfo.org. You can also search for clinical trials that are or will be recruiting, at www.clinicaltrials.gov.

LOCAL PATIENT SUPPORT GROUPS

On our website, you can find a list of more than 30 active local support groups across the United States as well as in other countries.

As not all NTM patients live close to a support group that holds regular meetings, we also offer an online forum for all NTM patients as well as their loved ones, physicians and researchers. Registration for this online support group with more than 3,500 members is free, and we do not share your personal information.

If there is no local support group in your area and you would like to start one, please email us at ntmmail@ntminfo.org. We will be happy to provide further guidance on starting your new group.

NTMir is always happy to assist new and existing groups by providing copies of this pamphlet, flyers to put in doctors' offices, stickers with contact information to put on copies of pamphlets left in doctors' offices, and a Support Group Leader training manual.

GLOSSARY OF TERMS

Aerosolized – Dispersed as an aerosol, which is a suspension of tiny particles in gas. Mist and steam are types of aerosols.

AFB Smear – Mycobacteria like NTMs are in a group called acid fast bacilli (AFB). The first test will be an AFB smear which looks for the organism in your sputum sample under the microscope. When organisms are seen in the sputum, the next test performed is the culture to determine if it is NTM, which may take several weeks to become positive. Further testing beyond that is required to determine what type of NTM is in your sputum. Therefore, even your initial AFBs must always be done at a highly qualified lab.

Airway Clearance Device – A device which helps loosen and clear mucus from lungs, working by means of vibration of airways, breathing resistance or other method. For more information on these devices and methods, log on to ntminfo.org.

Alpha-1 Antitrypsin Deficiency – A genetic disorder caused by defective production of a protein called Alpha-1 antitrypsin, causing decreased activity of the protein in the lungs and a buildup of the protein in the liver, which can cause serious lung or liver damage. Alpha-1 is a known comorbidity of NTM lung infection.

Aspergillus – A fungal infection in the lungs.

Autoimmune Disorder – A condition which occurs when a patient’s immune system mistakenly attacks and destroys his or her own healthy body tissue.

Biofilm – A population of microorganisms (such as bacteria) in which cells stick to each other on a surface. These clumped cells are frequently embedded within a self-produced substance (either polysaccharide or, in the case of nontuberculous mycobacteria, lipid) which is also referred to as slime. Biofilms may form on living (e.g. lung tissue) or non-living (e.g. household pipes) surfaces and are prevalent in natural, residential, industrial, and hospital settings. They are almost always found inside water pipes.

Bronchiectasis (bron-keek-ek’-tas-is) – A condition that results from damage to the airways (bronchial tubes) of the lungs. This damage to the muscle or elastic tissue of the bronchial tubes is called bronchiectasis. For more information, see page 8 or log on to ntminfo.org.

Bronchoscopy – A flexible tube is passed through the mouth or nose and then down into the lungs in order to view the airways and collect samples from the lungs. Your doctor may use this procedure to collect sputum samples if you are unable to cough up sputum.

Chest P.T. – A type of respiratory physical therapy in which the patient receives percussive therapy with cupped hand clapping or with a vibrator to loosen and mobilize secretions, thereby facilitating mucus clearance. This is often performed in conjunction with postural drainage.

Comorbidity – The presence of one or more disorders (or diseases) in addition to a primary disease or disorder, or the effect of such additional disorders or diseases on a patient.

COPD (Chronic Obstructive Pulmonary Disease) – A generalized designation for diseases involving persistent airway obstruction such as emphysema and chronic bronchitis.

Cystic Fibrosis – A genetic chronic lung disease affecting the lungs and digestive system. CF is a significant comorbidity of NTM lung disease. For more information, log on to ntminfo.org.

Emphysema – A form of COPD in which the alveoli or small airways of the lungs are damaged, making breathing more difficult. Emphysema is usually caused by smoking.

Gram-Negative Infection – Gram-negative bacteria are a group of germs that can cause respiratory infections. Some NTM patients also get gram-negative lung infections such as *Pseudomonas aeruginosa*, *Helicobacter pylori* (*H. Pylori*), or *Klebsiella pneumoniae*.

Hemoptysis – Coughing up blood.

Immune Dysregulation – An unrestrained or unregulated immune response; an inappropriately robust or weakened immune response.

Nebulizer – A device used to administer medication to people in the form of a mist inhaled into the lungs. Be careful to clean the nebulizer carefully to prevent bacteria from being re-inhaled.

Opportunistic Infection – An infection caused by pathogens that usually do not cause disease in a host that is not compromised in some way. Perhaps due to bronchiectasis and other factors, some NTM patients later acquire opportunistic infections such as gram-negative infections.

PCD (primary ciliary dyskinesia) – An inherited disorder causing defects of motile (moving) cilia. Motile cilia are required to keep the lungs, sinuses and ears free of organisms and debris that can cause infection and disease. A person with PCD experiences chronic, recurrent infections in the lungs, ears and sinuses due to the loss of ciliary activity in those areas.

PICC – Peripherally inserted central catheter access line for infusion of intravenous (IV) medicines. Usually inserted in an arm.

Port – An access line inserted into a vein for the infusion of intravenous (IV) medicines.

Postural Drainage – Positioning a patient so that gravity helps clear secretions. The patient is positioned or tilted at an angle usually with head and lungs downward. Chest P.T. may also be done at the same time.

Probiotic(s) – Also called “good bacteria” or “helpful bacteria,” probiotics are living microorganisms that are the same as or similar to those found naturally in the human body, particularly the lower gastrointestinal tract, which contains a diverse and complex community of bacteria.

Pseudomonas (*Pseudomonas aeruginosa*) – A gram-negative lung infection that some NTM patients experience.

Pulse Oximeter – A medical device that measures the amount of oxygen in your blood. It is put around your finger.

Sjogren’s disease – A chronic autoimmune disease in which the immune system attacks the patient’s moisture-producing glands. It can also cause dysfunction of other major organs as well as extreme fatigue and joint pain. The vast majority of those affected are women.

Sputum/Mucus/Phlegm – Thick secretions found in lungs, airways and sinuses that your body produces to help remove dust, bacteria and other small particles.

Tinnitus – Ringing in the ears, which may be caused by taking certain antibiotics. Tinnitus may also sound like high-pitched whining, buzzing, whooshing, or roaring.

ABOUT NTM INFO & RESEARCH

NTM Info & Research (NTMir) is a 501(c)(3) non-profit organization formed on behalf of patients with pulmonary nontuberculous mycobacterial (NTM) disease for the purpose of patient support, medical education and research.

Our story begins with Fern Leitman, an NTM patient who co-founded NTMir with her husband Philip. Fern’s battle began when she was in her mid-twenties. While living in New York City, she was diagnosed with pulmonary NTM infection and was treated successfully over a two-year period. Twenty years later, Fern became ill a second time with pulmonary NTM disease.

Fern began treatment at National Jewish Health in Denver in 1996 under the care of Dr. Michael Iseman. Throughout her illness, Fern needed more than 26,000 doses of intravenous antibiotics. She was hospitalized more than 30 times and spent an aggregate of more than 14 months in hospital. Every day, she took at least three antibiotics. Her daily regimen included at least 18 prescription, vitamin and supplement pills to help support her health, three or four inhaled treatments and an IV medication three times a day, as well as two rounds of airway clearance therapy.

Before and during her treatment at National Jewish, Fern met dozens of NTM patients just like her, with delayed diagnoses, frightened and often unfamiliar with many aspects of NTM lung disease.

After more than two decades, Fern lost her fight with NTM lung disease. She passed away in October 2014.

Her legacy lives on in NTMir, which evolved from our website, ntminfo.org. The website was developed to help those and other patients. A brochure was created based on the content of the site and distributed to pulmonologists and infectious disease specialists in the United States and abroad.

In an unanticipated response, the website generated over two million hits during its initial period. People logged on from 22 countries, the United States government and major institutions. There was a clear need to develop an organization that could speak for patients and the physicians trying to help them, and from this, NTM Info & Research was launched.

Since its inception, NTMir has funded leading studies. One study confirmed the suspected link between household water and infection. Another showed that NTM is more prevalent than previously thought, has impacted women more than men, and affects older populations more than younger ones. This study further confirms what Fern, Philip and an increasing number of experts already knew - NTM is an emerging infectious disease with devastating consequences.

In addition to funding research, NTMir has successfully lobbied Congress to recognize NTM as a serious disease pathogen. The organization works with the National Institutes of Health and other leading centers of excellence to further study of the disease, has helped form more than 30 patient support groups, and helps recruit patients for important clinical trials of new medications. NTMir has worked to secure approval for off-label use of a key drug proven effective against NTM and to ensure that medications vital to NTM treatment are prioritized when in short supply.

What We Do

- Fund or co-fund NTM research.
- Host physician and patient education meetings across North America.
- Develop and maintain strong relationships with leading researchers and clinicians.
- Host scientific meetings attended by leading researchers and clinicians
- Provide an online Physician Referral List so patients can find doctors who know how to treat their NTM lung disease appropriately.

- Assist patients who e-mail and call, providing comfort and guidance so they can improve the success of their treatment.
- Provide encouragement and guidance to support groups across North America
- Distribute “Insight: A Patient’s Perspective,” the seminal NTM lung disease informational pamphlet, around the world in ten languages.
- Maintain the foremost informational website on NTM lung disease as a gateway to support, patient education, and the newest information regarding NTM data and treatments for medical professionals’ use.

Our Accomplishments

- Established Rapid Information Pilot Studies (RIPS)[™], funding scientific research that can quickly provide early stage answers to important questions and provide the base data for major research grant applications.
- Established the NTM Patient Registry to help accelerate clinical trials for new drugs to treat NTM lung disease.
- Teamed with the American Lung Association to jointly fund research.
- Published the first Nutrition Guide for NTM lung disease patients.
- Established an online Physician Referral List.
- Testified in Congressional Appropriation Hearings on Capitol Hill.
- Secured language amendments for the fiscal 2006 - 2010 budget years directing the National Institutes of Health and the Centers for Disease Control and Prevention to address the concerns of NTM patients.
- Successfully coordinated compassionate use availability for the drug Lamprene/Clofazimine, so patients who have no alternative can receive this life-sustaining medication.
- Worked to ensure that Amikacin, a drug vital to the treatment of NTM lung disease, is prioritized for NTM patients when in short supply.
- Helped ensure a strong patient presence at the FDA’s Patient-Focused Drug Development meeting.

Our Goals

- Partner with researchers to establish new medical research and multi-center trials.

- Engage new researchers in the NTM lung disease field.
- Partner with industry to find better treatments for NTM lung disease.
- Improve patient outcomes.
- Seek government, industry, and community funding to implement these goals.

We hope you have found this pamphlet helpful. If you would like to support our work, you can donate online at **ntminfo.org**. You can also donate by phone or by mail at the address and phone number listed below. Your gift will help us fund further research, as well as science and patient conferences.

NTM Info & Research

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NTM Info & Research is a 501(c)(3) nonprofit organization

Ready to learn more?

Log on to ntminfo.org!

- Expanded information on treatments, side effects and epidemiology.
- Online forum – a place for patients from all over the world to connect and give each other helpful information and advice.
- Tips from other patients.
- Downloadable versions of our brochure in English as well as other languages including Spanish, Chinese, French, German, Japanese and Korean.
- Listings of clinical trials that are currently recruiting patients.
- News and helpful links to other sites, including [BronchandNTM360social](https://www.facebook.com/BronchandNTM360social), an online social forum for NTM and bronchiectasis patients.
- Findings of the studies funded by NTMir.
- Ways to get involved and advocate.

All this and more is available online.



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Nontuberculous Mycobacteria

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