

Mycobacterial Care Program



INDIVIDUAL CARE PLAN





Welcome to National Jewish Health. At National Jewish Health we are sincerely dedicated to the health and happiness of our patients and their families. We strive to achieve the very highest quality patient care and treatment programs. As a pledge of our desire to reach and maintain this goal, we promise you that:

- Every patient will be treated with importance and receive our best efforts.
- Every patient will always receive medical care based on the most up-to-date knowledge.
- Every patient will receive the greatest respect and privacy possible.

You will receive excellent care, rehabilitation and education during your stay at National Jewish Health. The Mycobacterial Service is world renowned for clinical expertise and excellence. National Jewish Health is the recognized leader in management of difficult-to-treat cases of mycobacterial disease.

The goal of this education booklet is to provide you with the information you need to better manage your disease. We hope you will find this booklet helpful and informative during your stay at National Jewish Health and as you return home. Please ask your doctor or nurse if you have any questions about the information discussed here. We look forward to being your partners in your health care.

Sincerely,

Mycobacterial Team Members

National Jewish Health

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Your Evaluation at National Jewish Health

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Your Evaluation

Test Facts





You and Your Team of Health Care Providers at National Jewish Health

At National Jewish Health, we strive to provide you with all the tools you need to manage your lung disease. This will help you feel better and participate in activities that you enjoy. To this end, you may be scheduled to see a variety of care providers who work as a team to make sure that you have these tools.

You may be scheduled to see care providers from some or all of the following areas to help us understand your lung disease and recommend the best treatment plan:

Pulmonary Physiology Service (PPU):

Care providers from the Pulmonary Physiology Service will work with you to see how well your lungs are working. Various tests of your breathing and your ability to exercise may be a part of this. If you have tests scheduled in the PPU, you will be given written Test Facts. Test Facts describe the breathing tests you are scheduled for and how to prepare for the testing.

Respiratory Care Service:

You may be scheduled with one of the Respiratory Therapists. They may teach you new techniques to bring up sputum and inhale various medicines. They may also help you bring up sputum for various tests.

Molecular Diagnostics Laboratory:

Your health care provider may recommend that you have blood, sputum (phlegm) or other tests completed. If there are any special instructions before you take these tests, the staff will explain these to you.

Institute for Advance Biomedical Imaging®:

You may be scheduled for X-Rays, CT Scans, PET-CT, MRI or other advanced imaging scans. You will be provided with Test Facts that describe the testing you are scheduled for and how to prepare for the testing.

Rehabilitation Service:

Pulmonary rehabilitation has been shown to improve your quality of life. This helps by improving your ability to do daily activities. It also helps decrease your shortness of breath. A referral to Rehabilitation Services will include an assessment of your tolerance to walking, your current muscle strength and endurance, and your overall fitness. Once your specific needs are defined, you will be instructed in an exercise program that's right for you. While in the program you will learn how to monitor and adjust your home program for ongoing success.

Patient Education Classes:

The patient education classes will give you and your family information and tools to help you manage your disease. Plan to attend the classes during your evaluation. The patient education classes are free for patients and family members.

Psychosocial Medicine:

Having breathing problems may lead to you feeling down or anxious about all the changes in your life. We know the way you think and feel about your disease has an impact on its management. The health and behavioral evaluation is an assessment of what challenges you might face in dealing with your lung

disease. The assessment also includes the strengths you bring to fighting this illness. The assessment will help the team understand the mental part of your health. Together with the psychologist, you will develop a plan to help you stay on top of the challenges you face in living with NTM.

Clinical Nutrition:

A Registered Dietician will review your current diet and supplements. The Registered Dietitian may recommend changes to ensure adequate calories, protein, vitamins, minerals and fluids. Diet plays an important role in our body's immune system and our general well-being. Maintaining an appropriate weight can improve lung function. It can also reduce risks for disease, and improve our long-term health.

Smoking Cessation:

If you smoke or have a family member who smokes there are options to help you give up smoking. Ask your health care provider. You may be referred to a variety of resources we have available at National Jewish Health. You can meet with a health care provider who will help you find ways to give up smoking.

Minimally Invasive Diagnostic Center (MIDC):

Your health care provider may recommend you have a procedure that will be done in the MIDC. Bronchoscopy, PICC Line placement and pH probe are a number of procedures that are done in the MIDC. If you have tests scheduled in the MIDC, you will be giving written Test Facts. Test Facts describe the procedure you are scheduled for and how to prepare for the procedure.

Other Specialists:

Depending on your individual needs, your health care provider may recommend that you see other specialists, including other physicians, respiratory therapists, and nurses.



Your Health Care Team

Please complete the following information with help from your doctor or nurse.

My Disease is:

My Nurse is:

My Doctor's Names Are:

Fellow:

Attending:

My Respiratory Therapist is:

My Rehabilitation Therapist is:

My Behavioral Health Practitioner is:

The Unit Coordinator is:

Respiratory Isolation:

- YES
- NO

Comments or Special Information I Need to Know:



Your Evaluation at National Jewish Health

The first step in finding the diagnosis and the best treatment is a good evaluation. Your doctor will complete a detailed history and physical exam. Based on this information your doctor will have you do a number of tests.

These may include:

- Chest X-ray
- Chest CT Scan
- Blood Testing
- Oxygen Levels
- Sputum Culture (three samples)
- Pulmonary Function Testing
- Exercise testing
- Audiograms (on admission and monthly, thereafter **only** if on specific medications)
- Eye exams (on admission and monthly, thereafter **only** if on specific medications)

You will receive **Test Facts** information sheets before some of these test. Test Facts give you information about how to prepare for the test and what to expect during the test.

Alcohol and Mycobacterial Disease

Alcohol and Medication Interactions – Discuss your alcohol consumption with your health care provider. Alcohol can interact with many medications. Alcohol can interfere with the way the medication is metabolized by the liver. Alcohol can also enhance the effect of some medications, in a way that leads to unwanted symptoms. Since you will be on a number of medications to treat your mycobacterial disease ask your health care provider if you can drink alcohol and how much.

Alcohol affects many of the body's systems. People with mycobacterial disease need to be concerned with alcohol's harmful effects on the following four major systems of the body.

Respiratory System – Alcohol consumption may decrease the breathing rate and suppresses the ability to cough. This causes mucus to stay in the lungs which increases the chance of infection.

Digestive System – Chronic alcohol consumption may lead to poor dietary intake and liver problems. Poor dietary intake is often a problem for people with mycobacterial disease because nutrients found in foods are essential for the healing process and tolerance of medical treatments. Chronic alcohol use may cause stomach upset and may add to the stomach upset caused by some of the medications.

Hepato-Biliary System – Liver problems can be dangerous for people with mycobacterial disease. The liver's job is to filter toxins and excrete the waste. If the liver is damaged or compromised by alcohol use, the medications are not excreted as they should be and the body can be damaged by the large amounts of toxins in the body.

Cardiovascular System – Chronic alcohol consumption can cause anemia (low amounts of red blood cells) and can decrease a person's ability to stop bleeding when injured. This can be **very** dangerous to people with mycobacterial disease if there is bleeding in the lungs. The body will not be able to stop the bleeding and this situation could be fatal. Anemia will also cause fatigue which may add to the fatigue one already experiences with mycobacterial disease.

In addition, studies have shown that cigarette smoking is more common in people who are regular drinkers. Smokers also inhale deeper when they are consuming alcohol. Heavy alcohol use, therefore, increases the cancer causing effects of smoking.

Remember to ask your health care provider if you can drink alcohol and how much while you are taking medications to treat your mycobacterial disease.

Understanding Mycobacterial Disease

Your Lungs and How They Work

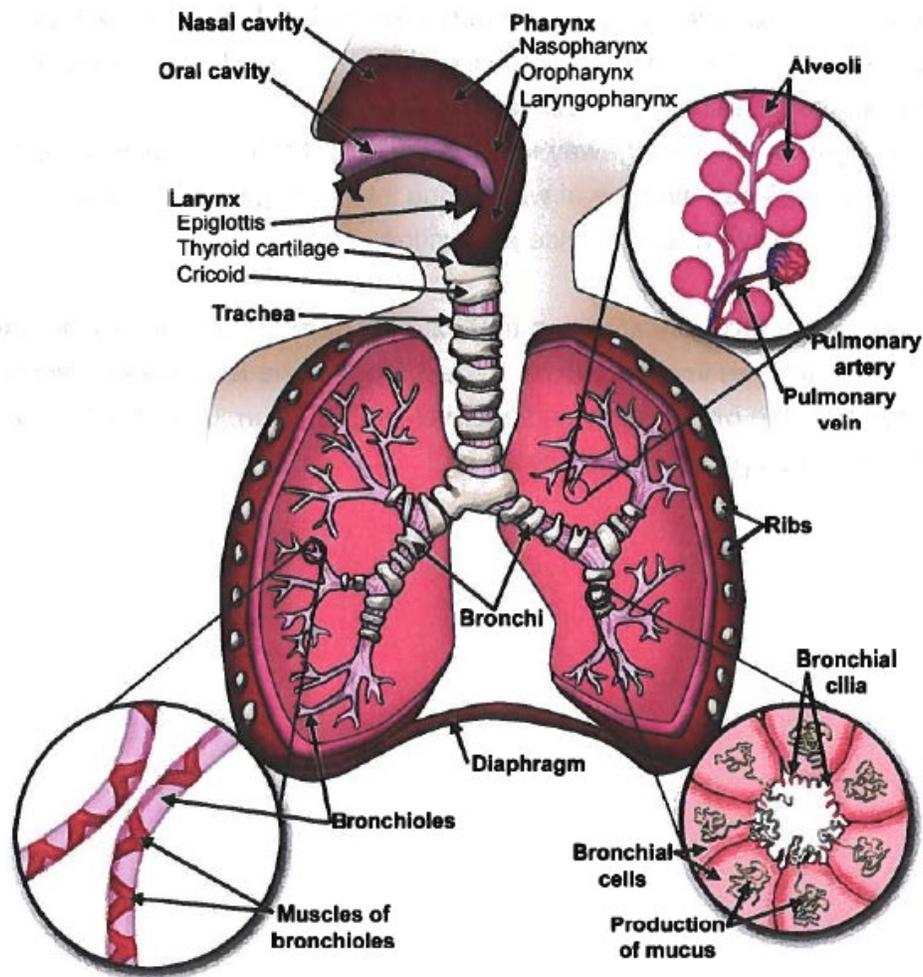
Bronchiectasis Med Fact

Mycobacterial Disease Med Fact



Your Lungs and How They Work

Your lungs are part of the system for breathing. This is the respiratory system. The respiratory system serves to provide oxygen to the blood, which the heart pumps through the body. It also removes carbon dioxide, a gas your body does not need, from the blood. In addition to the lungs you need the mouth and nose, the trachea and diaphragm to breathe. Let's look at what each does now.



The Upper Respiratory System

Nose

- The nose is divided into two parts (nares and nostrils) by the septum.
- The nose functions as a passageway for air going to and from the lungs. The nose is the organ for smell and aids in voice production and sound. The nose moistens and warms air. Then the cilia and mucus lining help cleanse the air.

Sinuses

- The four sets of sinuses: The Maxillary, Sphenoid, Ethmoid and Frontal.
- The function of the sinuses is to lighten the skull and improve the quality of the voice. However, mucus can obstruct the openings of the sinuses.

Pharynx

- The pharynx is a tube-like structure about five inches long (in the adult). The pharynx extends from the base of the skull to the esophagus (located in the back of the throat). The pharynx also contains the tonsils (adenoids).
- The pharynx is the passageway for food and air. The epiglottis is a flap that closes over the airway during swallowing to help protect the airway. The pharynx also plays a role in voice production.

Larynx

- The larynx is a tube-like structure that extends from the pharynx to the trachea. The larynx contains the vocal cords. Another name for the larynx is the “voice box.”
- The larynx is the organ responsible for voice production. It also acts as a passageway for air from the epiglottis to trachea.

The Lower Respiratory System

Trachea (Windpipe)

- The trachea is a tube-like structure in front of the esophagus. It connects the larynx to the bronchi. The trachea is opened by cartilage and smooth muscle.
- The trachea is the next passageway for air to reach the lungs.

Lungs

- The lungs are located in the chest cavity. The lungs are light, spongy, elastic, cone-shaped organs. The right lung is larger and broader than the left lung. The right lung has three (3) lobes and the left lung has two (2) lobes.
- The lungs provide space where air and blood meet for rapid exchange of gases (oxygen and carbon dioxide).

Bronchi

- The bronchi are tube-like structures that branch from the trachea into the right and left lungs. Small muscles encircle the bronchi. The bronchi branch into smaller tubes called bronchioles or bronchial tubes.
- The bronchi are the passageways for air to reach the interior of the lungs.

Airways (Bronchial Tubes)

- The airways become smaller and smaller, like branches on a tree. The airways are lined with tiny, air-like structures called “cilia.” Cilia lines most of the respiratory system. The airways are also lined with cells that produce mucus. In addition, smooth muscle surrounds the airways.
- The airways are the passageway for air to reach the alveoli and the airways continue the air-cleaning function.

Alveoli (Air Sacs)

- Alveoli are elastic, hollow “grape-like” structures at the end of the airways. There are approximately 300 million alveoli in the mature lungs.
- The alveoli is the site where gas exchange (oxygen and carbon dioxide) takes place between the blood and the lungs.

The Muscles used for Breathing

Diaphragm

- The diaphragm is the largest muscle of respiration. The diaphragm divides the abdominal and chest cavities. As the diaphragm contracts and relaxes with each breath, the pressure changes in the lungs and causes air to move in and out of the lungs.

Intercostal Muscles

- The intercostal muscles assist in respiration and are located between the ribs. Along with the diaphragm, the intercostal expand the size of the chest cavity.

The Respiration Process

Respiration is another word for breathing. Respiration describes the process of breathing in fresh air for our bodies to use and getting rid of waste air that our bodies have already used. We need to breathe to exchange carbon dioxide (CO₂) and oxygen (O₂). Oxygen is used by all the body cells for energy. When carbon dioxide levels in our body are high, the brain is stimulated to begin respiration or breathing. The diaphragm and intercostal muscles contract, causing the rib cage to expand and the diaphragm to move down. The air then moves into the alveoli (air sacs). Oxygen crosses into the blood vessels and carbon dioxide travels into the alveoli. Oxygen rich blood gets to the heart to be pumped to the cells of the body. The blood rich in carbon dioxide first goes to the heart and then to the lungs to be exhaled.

What is Chronic Lung Disease?

Chronic lung disease is a general term used to describe long-term illnesses of the breathing system. The following **Med Facts** will describe several chronic lung diseases in more detail.

Healthy Lifestyle

A healthy lifestyle is important for everyone, especially for people with mycobacterial disease.

A healthy lifestyle includes:

- **Regular Exercise**
- **Eating Well and Maintaining a Healthy Weight**
- **Smoking Cessation**



Regular Exercise

Exercise and staying active are an important part of rehabilitation for chronic lung disease. You may believe that people with chronic lung disease are too short of breath to exercise. This is a myth. The truth is that regular exercise can help you feel less short of breath. Regular exercise improves your heart and muscles. It can help you feel good about yourself.

Remember, exercise is good for you!



Eating Well and Maintaining a Healthy Weight

An important part of rehabilitation for chronic lung disease is eating properly. This involves choosing healthy foods that can work to heal and repair your body and make it stronger.





Smoking and Mycobacterial Disease

An important step in managing mycobacterial disease is quitting smoking. Cigarette smoke contains about 4,000 harmful toxins that can irritate airways and damage lung tissue. Cigarette, cigar and pipe smoke are known risk factors for heart disease, chronic lung disease and many forms of cancer. People with mycobacterial disease, whose lung function is impaired by the disease, are at an increased risk from smoking. Smoke impairs the body's ability to fight infection. You risk your health and the health of others around you when you smoke. Cigarette, cigar or pipe smoke puts you at a greater risk when you have a mycobacterial disease.

When you quit smoking, your breathing and response to your medicines may noticeably improve. Even if you have smoked many years, you will benefit from quitting.

Giving-Up Smoking Resources at National Jewish Health

After discussing your smoking habits with your health care team, you might decide to find out more about giving up smoking during your treatment at National Jewish Health. Family members are welcome to participate also. We can provide a giving-up smoking program adaptable to your lifestyle. The program at National Jewish Health will provide written materials and counseling aimed at understanding your particular smoking habit and providing alternative coping behaviors. This can assist you to quit smoking now or at some time in the future.

Ask about the following resources here at National Jewish Health:

- The Booklet: *Understanding Giving Up Smoking*
- The Class: *Tools for Giving Up Smoking – Trying Again*
- Quit Line at **1-800-Quit-Now (800-784-8669)**.

Don't be discouraged if you have tried to quit – one time or many times – in the past. More services and quitting aids are now available to help you quit and remain smoke free.

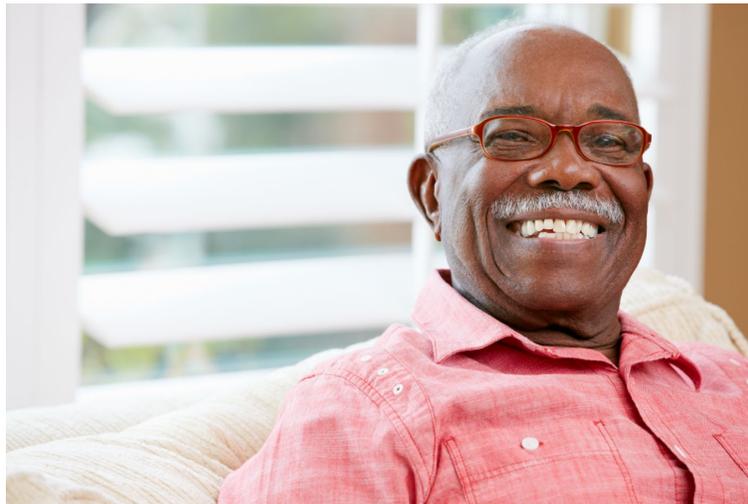
The Five Steps to Help You Quit Smoking

There are a lot of different ways to give up smoking. Research has been done to learn which ways are successful. Studies have shown that you have the best chance of quitting for good if you follow these 5 steps.

- 1. Get ready.**
- 2. Get support.**
- 3. Learn new skills and behaviors.**
- 4. Get medication and use it correctly.**
- 5. Be prepared for difficult situations or setbacks.**

Once you give up smoking it is important to avoid being around tobacco smoke. This will help decrease irritation to your lungs. Also, a smoke free environment is healthier for everyone!

- Discuss the importance of making your environment smoke free with family members and friends.
- Encourage the family members and friends who smoke to quit. If they are not ready to quit, ask them not to smoke in your home or car.



Medication Therapy

Medication Therapy

My Medication Schedule

Managing Your Medication Supple Med Fact

Potential for Drug – Food Interactions Med Fact

Medication Information Sheets

Your health care provider will provide you with medication information sheets for medications you are taking. This information is the most current information about medications



Medication Therapy

The following section details medications and fluids that are important in the treatment of mycobacterial diseases. Your health care provider will give you medication information sheets for the medications you are prescribed. It is important to know:

- Medication brand names and medication generic names,
- Why you are taking the medication
- How to take and store the medication
- Precautions, side effects and warnings
- Medications and foods to avoid,
- Reasons to call the health care provider right away
- When you should not use this medicine.



Following the medication plan that your doctor prescribed is very important in the treatment process. Please read the information about the medications you are taking very carefully. Review your medications with your nurse, and if you have **any** questions about the medications, please ask your doctor, nurse or pharmacist.

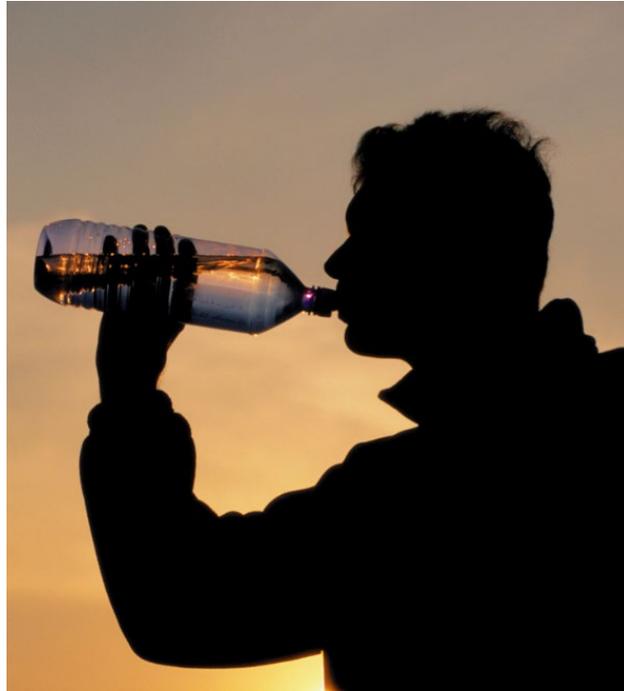
You may be taking inhaled medications. Your doctor or nurse will recommend a method that works best for you. They will review how to inhale the medication and how to clean the equipment. They will also give you Med Facts that detail the information for the devices you will be using. Practice taking your inhaled medications with your nurse.



Remember, it is very important to take the medications exactly as your doctor prescribes.

Fluid Intake

Adequate fluid intake is very important to prevent thickening of mucus in the airways. Adequate fluid intake also helps the kidneys remove byproducts of medications. If you have GERD your health care provider may make specific recommendations for restricting fluids, especially before bed.



Techniques to Bring Up Mucus (Bronchopulmonary Hygiene Therapy)

In some lung conditions, such as bronchiectasis, mycobacterial disease and chronic bronchitis thick mucus may collect in the airways of the lungs. This makes breathing more difficult and increases the chance of getting pneumonia or other infections. **Improved clearance of mucus is the cornerstone of the management when excess mucus is in the airways.** Airway clearance measures to help clear the mucus include:

- Deep coughing
- Huff coughing
- Airway clearance devices
 - Aerobika®
 - Acapella®
 - Flutter valve
- Vest Systems
- Postural drainage
- Chest percussion

These airway clearance measures are important for people with mycobacterial diseases. The best technique/s for you will be prescribed by your health care provider. Correct technique using these devices is very important. **A member of your health care team will show you how to use these techniques. They will also observe your technique. It is also important to have your technique checked periodically to make sure you continue to use it correctly to obtain the most benefit.** Each technique will be described in more detail.

- **Deep coughing** – Cough effectively by taking a deep breath. Hold the breath for 2-3 seconds. Use your stomach muscles to forcefully expel the air. Avoid a hacking cough or merely clearing the throat. A deep cough is less tiring and more effective in clearing mucus out of the lungs.
- **Huff coughing** – Huff coughing is an alternative to deep coughing if you have trouble clearing your mucus. Take a deep breath that is slightly deeper than normal. Use your stomach muscles to make a series of 3 rapid exhalations with the airway open, making a “ha, ha, ha” sound. Follow this by controlled diaphragmatic breathing and a deep cough if you feel mucus moving.
- **Airway Clearance Devices** – These are small devices you exhale into. This helps loosen and mobilize the mucus. The Aerobika® and Acapella® are examples of airway clearance devices. Sometimes these devices are used when you are lying in the postural drainage positions (See drawings that follow this description). The AerobiKA® may also be used with a nebulizer. Your health care provider will show you how to use the airway clearance device correctly.



- **The Vest™ and the Smart Vest® System** – The Vest and the Smart Vest consist of a vest and air pulse generator. Each has an inflatable vest you put on. The vest is attached to the generator with tubing. The generator pulses air into the vest, which causes the vest to shake your chest to help dislodge the mucus from the airway walls. Your health care provider will show you how to use either vest.
- **Postural drainage** – This technique uses gravity to promote drainage of mucus from the lungs.
 1. Place pillows on the bed or on the floor beside the bed and a box of tissues close by.
 2. Lie on the bed with hips elevated 12-18 inches on a stack of pillows,
OR,
Lie on the bed with your trunk over the side, head and arms resting on the pillows.
 3. You will lie on your stomach and each side. Stay in each position 10-20 minutes. (See drawings that follow description)

You can do any of the above airway clearance measures by yourself. Someone will need to help you with chest percussion (clapping) and vibration.

- **Chest percussion** *This is sometimes called clapping.*
A friend, family member, or health care professional will need to help you with this.

You will stay in the postural drainage position for chest percussion.

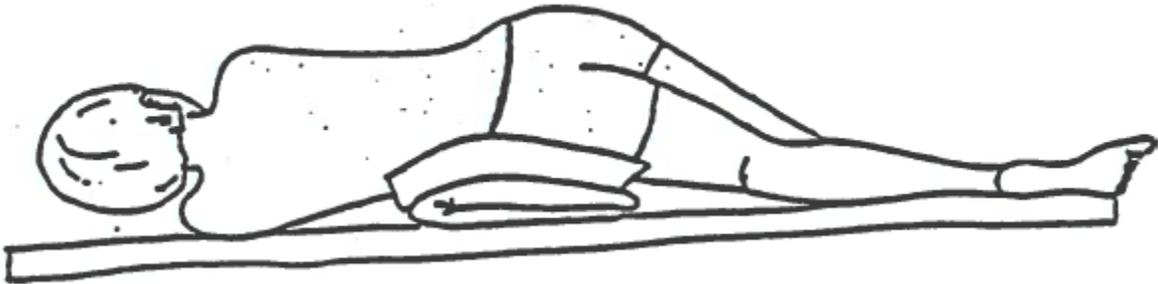
1. Place a towel over the chest for comfort.
 2. The helper will hold their hands in a related **cupped** position. Do **not** slap with a flat hand.
 3. Keeping the wrists loose and moving the arms and elbow, clap over the rib cage, taking care not to hit directly over the heart, abdomen or the kidneys.
 4. Using a smooth rhythm, the helper will clap for about one minute at a time.
 5. Clapping should be firm, but not painful. When done correctly, this will make a popping sound. *(With just a little practice, this technique is easy to master.)*
- **Vibration**
A friend, family member, or health care professional will need to help you perform this therapy. Vibration is performed in the same area as chest percussion. Stay in the postural drainage position.
 1. You should first take a deep breath in and then fully exhale (using pursed lip breathing). The helper tenses their shoulder and arm muscles to produce a gentle shaking movement while you exhale.
 2. After three or four vibrations, you should cough. The cough should be sharp and deep, using the abdominal muscles to force the air up through the airways. Avoid a hacking cough or merely clearing the throat, which are not effective in clearing the mucus out of the lungs.
 - **Chest therapy positions**
These positions are used to help gravity promote airway clearance. They can be used with the Acapella devices, postural drainage, percussion and vibration. Your health care provider will show you which positions are best for you to use.

Position One: Drains the Lower Back Lung Segments



- Face lying with hips elevated 18-20 inches on a stack of blankets or pillows.
- Clap from below the shoulder blade to approximately three inches above the bottom of the ribs and not over the backbone or kidney.

Position Two: Drains the Lower Right Lung Segments



- Side lying with hips elevated 18-20 inches on a stack of blankets or pillows.
- Clap over mid portion of the side of the chest.

Position Three: Drains the Lower Front Lung Segments



- Back lying with hips elevated 18-20 inches on a stack of blankets or pillows.
- Clap from below the nipple line to the bottom of the ribs, but not over the stomach.

Position Four: Drains the Lower Left Lung Segments



- Side lying with hips elevated 18-20 inches on a stack of blankets or pillows.
- Clap over the mid portion of the side of the chest.

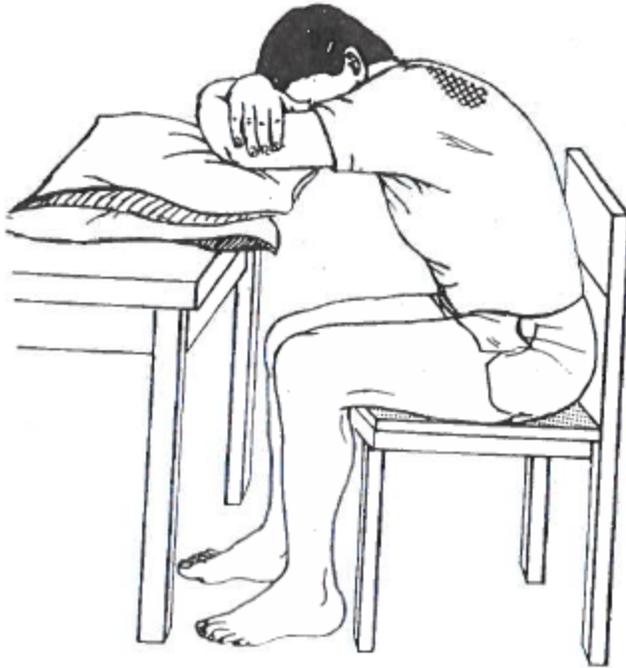
It is important to talk with your health care provider about the technique to bring up mucus that is best for you. If you are doing postural drainage and chest percussion, ask what positions will work best for you. If your doctor tells you that disease is contained in the upper lobes of your lungs, the following positions will be very important in your therapy. Remember, talk with your health care provider about your illness and developing a technique to bring up mucus that is best for you.

Position Five: Drains the Upper Front Lung Segments



- Sitting, lean back slightly. A pillow can support your lower back.
- Clap above the collar bones on both sides.

Position Six: Drains the Upper Back Lung Segments



- Sitting, lean forward onto a table. A pillow can support your arms and head.
- Clap on back just above the shoulder blades on both sides (fingers curved over the top of the shoulders).

Note: All techniques to bring up mucus should be stopped at the first sign of blood in the sputum, and your health care provider should be contacted.

Management of Hemoptysis (Bloody Sputum)

Hemoptysis is the name of a condition where a person coughs up blood in the sputum. Hemoptysis happens when any infection irritates a blood vessel in the lungs.

Notify your doctor or nurse at the first sign of hemoptysis (blood in the sputum) and save it in a tissue or collection cup for the doctor or nurse and/or laboratory to analyze. **Do not** wait a few days before notifying the doctor or nurse. Notifying your healthcare team right away may make a difference between a simple solution or an aggressive treatment.

Keep calm and do not panic. Getting upset only makes the heart work faster, which will supply more blood to the lungs, thus increasing the bleeding. In addition, panicking will increase shortness of breath.

After the first incidence of hemoptysis, save sputum in a covered cup or container instead of a tissue. The amount of bloody sputum can be more accurately measured in these containers. Ask your health care provider for a sputum container for collection of bloody sputum when you are experiencing hemoptysis.

If hemoptysis continues or increases, rest in bed. Lay down with the most diseased side of the lungs down on the bed. This position prevents blood draining to the good lung. Bed rest is prescribed because activity increases blood flow and thus, bleeding. Avoid coughing as it causes more irritation and bleeding.

People experiencing hemoptysis should also avoid hot (temperature) foods and liquids and drink cold liquids. Heat will relax the blood vessels and allow them to bleed more freely and increase hemoptysis.

While experiencing hemoptysis, the techniques to bring up mucus should be discontinued. Postural drainage is acceptable, but clapping may cause increased bleeding.

Remember, if hemoptysis begins at home call your doctor or clinic as soon as possible and follow their instructions.



Surgery for Mycobacterial Diseases

Medications are used to treat most people with mycobacterial diseases. When medication therapy is successful, there is usually no need for surgical procedures. However, some people may be less likely to respond to medications and to remain free from disease. You may not respond to medication therapy because of unsuccessful prior treatment or resistance to medications used to treat your disease. In these cases, surgery might be considered if the disease is mostly contained in one area of the lung. Surgically removing the diseased area of the lung improves the chance of controlling the disease. After surgery, it is essential to continue medication to control and prevent the spread of disease.

Usually, surgery is considered later in the treatment process. It is in the patient's best interest to have a period of treatment with medication therapy to decrease the amount of disease in the lungs. This will increase the chances of a successful surgery. If surgery is considered appropriate in your case, your doctor will discuss the procedure with you.



Your doctor will order special tests to prepare for surgery. Pulmonary Function Tests will show how well your lungs are working. A CT scan will show your lungs in greater detail than can be seen on an ordinary chest x-ray. A VQ Scan (Ventilation and Perfusion) will show what parts of your lungs are reached by the air you breathe and where the blood circulates in your lungs. These and possibly other tests will help the surgeon plan the operation which is most appropriate for you.

Since National Jewish Health does not have a surgical unit, the operation will be performed at another hospital. Arrangements will be made for your temporary transfer.

You will remain at the hospital where surgery is performed until your condition has stabilized. You will return to National Jewish Health for follow-up care.

Types of Surgical Procedures

There are different types of surgery used in the treatment of mycobacterial diseases. Your doctor may or may not prescribe one or more of the following procedures in the treatment of your illness:

Resectional Surgery

Resectional surgery refers to a type of procedure where a lung or a portion of lung is removed. This is a common procedure for National Jewish Health patients.

- Segmentectomy is the removal of less than a lobe of the lung.
- Lobectomy is the removal of a lobe of the lung.
- Pneumonectomy is removal of an entire lung.

Drainage Procedures

If a patient has a pocket of infection inside the lungs, a surgeon may use a drainage procedure. With this procedure, the infected area is opened up so the infection may be cleaned or drained outside of the body. The surgeon or doctor will explain the type of drainage procedure that may be recommended for you.

Thoracoplasty

Thoracoplasty is another form of collapse therapy. In this procedure, a few ribs are removed. This is usually done to collapse a cavity or space in the chest. This treatment is used only occasionally in the management of complications.

Living Well with Mycobacterial Disease

You have come to National Jewish Health for treatment of a lung disease. Some of you have been diagnosed with mycobacterial disease. A bewildering and distressing process has likely preceded your visit to National Jewish Health. Common problems are often shared by people with a mycobacterial disease. Behavior health practitioners are available if you have questions or concerns.

Feelings About Your Diagnosis and Symptoms

Feelings About an Infectious Disease

Effects on Relationships and Self Esteem

Adjustments for Inpatients and Day Patients

Depression and Anxiety

Sources of Support

Coping Strategies



Feelings About Your Diagnosis and Symptoms

People with mycobacterial diseases can have a wide variety of symptoms, including fatigue, weight loss, decreased appetite, fever, bloody sputum and a cough. In other cases, the illness is diagnosed without any symptoms being present. Each of these situations presents different challenges.

For the person with many symptoms there is often fear and confusion regarding new symptoms. What is wrong with me? Why can't I do the things I usually do? Am I going to be okay?

For people without symptoms, it can be a shock to be told of a serious disease that requires long-term treatment when you feel fine. It may be hard to believe the tests were accurate. Once the diagnosis of mycobacterial disease is made, typical feelings include fear, shock, denial, anger, shame, guilt. These feelings may come in waves and will gradually subside over time; however, it may be helpful to have the help of a behavior health practitioner to help in this process.



Feelings about an Infectious Disease

Shame is sometimes felt more often in infectious diseases than other chronic illnesses – shame about having a contagious disease (in the case of tuberculosis), shame regarding the need to wear a mask and be in isolation for a time. Although nontuberculous mycobacterial disease is not contagious and does not require isolation, until the test results are finalized patients are often told they might have tuberculosis. In addition, precautions to prevent the spread of infection are practiced. Being placed in isolation may be one of the most difficult aspect of the disease. People struggle with feeling dirty, like an outcast, or as some have put it – “like a leper.” If you share your feelings with other people in your situation, it may help a great deal.

Nontuberculous mycobacterial disease support groups are also a great source of comfort for people. For more information on support groups visit nationaljewish.org and search support groups. In general, the more support a person feels, the better he or she is able to cope. Even with support, however, wearing a mask and being isolated from others can be extremely difficult and distressing.



Effects on Relationships and Self Esteem

Other issues that may come up include fears of death or permanent disability, questions about the medicines and possible side effects and concerns about changes in lifestyle. You may be unable to work, leading to financial hardship for you and your family. Relatives and friends may be frightened by the diagnosis and may have trouble being supportive for a period of time. Additionally, being ill often involves a change in one's relationship. You may have to depend on others a great deal more. If you are used to being the caretaker, it can be very hard



to now need caretaking. If you are very independent, being even somewhat dependent can be very distressing. A parent who is ill must at times turn to a child for support; a spouse must turn to wife or husband in ways not previously needed. People may experience guilt, anger or sadness; family members and friends may experience similar feelings. Flexibility is needed to adjust to the demands of illness. Finding ways of maintaining appropriate independence is very important. **The goal is maintaining one's self-esteem through the challenges and difficulties of a chronic illness.**



Adjustments for Patients

It has often been a long and only partially successful treatment course prior to your arrival at National Jewish Health. Many of you have had to travel a long distance to come to Denver, leaving behind family and friends entering a strange environment at a difficult time. Some may not be fluent in English, making it hard to communicate needs, wishes and concerns. Changes in medicines are initiated, hopefully leading to improvement, but with the possibility of new side effects. Feelings often experienced by people on admission to National Jewish Health include exhaustion, hopefulness, anxiety, and confusion. You may have different feelings at various times, especially since admissions can last several weeks. With time and support, people usually adjust to the new routine and medicines.

Depression and Anxiety

The stress of having a chronic illness can lead to emotional distress. At times you may feel depressed or anxious. When your lives are disrupted, we often experience some emotional difficulty. The symptoms of mycobacterial disease can include weakness, fatigue, loss of appetite and energy, shortness of breath – the very symptoms that often mark a state of depression or anxiety. To further complicate issues, some of the medicines used to treat mycobacterial infections can impact emotional functioning and cause agitation or confusion. It can be hard to sort out the various causes of depression and anxiety. It may require the joint efforts of you, your family, your doctors and nurses and at times a behavior health provider. Temporary feelings of emotional distress are very common. When the depression or anxiety is severely prolonged, however, it can lead to further disability and can interfere with the progress of treatment. It is important that you tell your health care team of any emotional upset that you are feeling so that a proper evaluation can occur. Depending on the specific cause of your depression or anxiety, medicines may be changed or new medicines may be added, different tests may be ordered, and counseling may be suggested. These are also medicines available for depression and anxiety that may be helpful.

Sources of Support

We have looked at various issues that you may have experienced as a result of your mycobacterial disease and its treatment. Chronic illnesses are severe stressors for most people. One's life is disrupted in many ways; physically, socially, emotionally and financially. Though many feelings are expressed by patients with mycobacterial disease, each person experiences his or her illness in unique ways that reflect one's individual and cultural background. Emotional support is helpful to all people. In times of sickness, our need for support is even greater.

Support can come from relatives, friends, other patients, health care providers, counselors, priests, ministries, and rabbis. The source of support is not as important as the feeling that adequate support is available.



Coping Strategies

There are coping strategies that many people find helpful. Each person has developed ways of dealing with stressful situations.

Helpful coping strategies include:

- **Talking with others** – Through talking with others we form connections and relationships. This can ease the sense of isolation so common in chronic illness, especially if physical isolation is required for a time.
- **Making your surroundings familiar** – This can help decrease the feeling of being in a strange environment. This can involve anything from favorite pictures and music to having friends and relatives visit.
- **Keeping busy** – Activity is another very helpful tool in coping with illness. You may feel weak and tired, but staying in bed all day by oneself often worsens the fatigue and weakness; it can also lead to intense feelings of boredom. Activities that may help can include relaxation exercises, reading, walking, physical therapy, taking up a hobby or even sitting quietly in a chair on the sun deck. For some people humor is a very powerful way of coping; for others, religious faith provides comfort and hope.



When there are problems coping, talking with a professional counselor can help resolve the problems. Medicines may be helpful in decreasing severe anxiety or depression. Though having a mycobacterial disease is difficult and frustrating, most people can find ways to adequately cope, looking forward to a time of improved health.



Journal Entries

Consider your exercise, diet sleep, medications and mucus production.

Date: _____

Things that went well today...

Difficulties I had today...

To make things better tomorrow, I will...

Date: _____

Things that went well today...

Difficulties I had today...

To make things better tomorrow, I will...

Questions to ask my health care team...

**Psychosocial Medicine:**

Having breathing problems may lead to you feeling down or anxious about all the changes in your life. We know the way you think and feel about your disease has an impact on its management. The health and behavioral evaluation is an assessment of what challenges you might face in dealing with your lung disease. The assessment also includes the strengths you bring to fighting this illness. The assessment will help the team understand the non-physical part of your health. Together with the psychologist, you will develop a plan to help you stay on top of the challenges you face in living with NTM.

Clinical Nutrition:

A Registered Dietician will review your current diet and supplements. The Registered Dietician may recommend changes to ensure adequate calories, protein, vitamins, minerals and fluids. Diet plays an important role in our body's immune system and our general well-being. Maintaining an appropriate weight can improve lung function. It can also reduce risks for diseases, and improve our long-term health.

Smoking Cessation:

If you smoke or have a family member who smokes there are options to help you give up smoking. Ask your health care provider. You may be referred to a variety of resources we have available at National Jewish Health. You can meet with a health care provider who will help you find ways to give up smoking.

Minimally Invasive Diagnostic Center (MIDC):

Your health care provider may recommend you have a procedure that will be done in the MIDC. Bronchoscopy, PICC Line placement and pH probe are a number of procedures that are done in the MIDC. If you have tests scheduled in the MIDC, you will be given written Test Facts. Test Facts describe the procedure you are scheduled for and how to prepare for the procedure.

Other Specialties:

Depending on your individual needs, your health care provider may recommend that you see other specialists, including other physicians, respiratory therapists, and nurses.

Nontuberculous Mycobacteria (NTM)

Bacteria, like plants and animals, have been classified into similar groups. The groups are called "families." One such family of bacteria is known as the *Mycobacteriaceae*. Within this family there are a number of species. Some species can cause human diseases (pathogenic). Other species do not cause human diseases (saprophytic).

For example, *Mycobacterium tuberculosis* is an infamous species. This is the organism that causes human tuberculosis. *Mycobacterium leprae* is the organism that causes leprosy.



What is the Difference between TB and NTM?

Nontuberculous mycobacteria (NTM) refers to all the species in the family of mycobacteria that may cause human disease, but do not cause tuberculosis (TB) or leprosy. In a U.S. study from 2010, it was estimated that approximately 30 people per 100,000 were infected with these lesser-known "cousins" of TB and leprosy. In fact, for unknown reasons, data from across the globe note an increase in case rates of infection over time.

M. avium complex is the most common NTM to cause human infection in the U.S., and it makes up around 80 percent of the infections we treat at National Jewish Health. It is often referred to as MAC. It was formerly thought to be made up of two species, *M. avium* and *M. intracellulare*. With more sophisticated tools, we appreciate that there are at least 10 different species within this complex. The three main species to cause disease are *M. avium*, *M. intracellulare* and *M. chimaera*.

Unlike tuberculosis (TB), which is spread from person to person, nontuberculous mycobacteria (NTM) infections are not considered contagious. How and why people become infected with NTM is not clear. The nontuberculous mycobacteria (NTM) causes are still under investigation.

Although the bacteria is found easily in water and soil, they do not affect most people. Doctors believe that some people who become infected have an unknown defect in their lung structure or function or in their immune systems. People who have damaged lung tissue from diseases such as emphysema, bronchiectasis, adult cystic fibrosis or previous infection appear to be at greater risk for developing a NTM infection. People who have a suppressed immune system, such as those who receive strong immunosuppressant medications like prednisone or newer immunosuppressants like TNF inhibitors, have a greater risk of developing an NTM infection. The infection may affect all organs of the body, not just the lungs. People with AIDS may also develop NTM infections.

There are studies that have shown a higher burden of infection in states with higher water vapor content. There is also supportive evidence for people acquiring the infection from their local water supply. In considering an apparent increase in the number of NTM lung disease seen over the past 25 years, it has been noted by researchers in the field that NTM are commonly recovered from home water systems.

There are several theories regarding the increasing incidence of infection. One relates to showering rather than bathing in a tub. Showering in a closed stall exposes the user to a higher aerosol concentration of NTM. In addition, to save energy, water heaters have lower temperatures now, which could allow more NTM growth in the water. The materials used in homes may be more supportive for biofilm growth, which is a hospitable environment for these organisms to grow. Water filters are now used in most homes. They remove the organic compounds that make our water taste bad, but they do not filter out mycobacteria. In fact, the filters themselves may serve as a breeding ground for organisms and allow for higher concentrations of mycobacteria compared to unfiltered water. Finally, there are data to indicate that aspiration of water, either through swallowing or gastroesophageal reflux, is a way that mycobacteria gain access to the lungs to cause disease.

What are the Different Types of NTM?

Under the microscope, nontuberculous mycobacteria and tuberculosis appear quite similar. Careful lab studies must be performed to tell them apart. Most labs are capable of distinguishing between tuberculosis and non-tuberculous mycobacteria. Interestingly, there are more than 170 different species of NTM. Fewer labs are equipped to determine exactly which NTM organism it might be and its susceptibility to antibiotics. This is important to determine the best treatment.

The importance of identifying the exact organism can be illustrated with two of the organisms, *Mycobacterium gordonae* and *Mycobacterium scrofulaceum*. These two are very similar and react the same way in many lab tests. However, they react in different ways in the human body. One organism causes disease; the other organism does not cause disease. In this case, if the organism turns out to be *M. gordonae*, treatment is seldom indicated. *M. gordonae* is often a lab contaminant and not a cause of human disease. In fact, *M. gordonae* is found in water supplies so often that it is nicknamed "the tap water bacillus." *M. scrofulaceum*, on the other hand, is known to cause disease and may require specific forms of treatment.

Other NTM species that may require treatment include: *M. avium complex*, *M. kansasii*, *M. abscessus*, *M. chelonae*, *M. fortuitum*, *M. terrae*, *M. xenopi*, *M. simiae*, *M. szulgai* and *M. malmoense*. Among the NTM, there are three species that predominantly involve the skin: *M. leprae*, *M. ulcerans* and *M. marinum*.

What are the Symptoms of an NTM Infection?

Like tuberculosis (TB), nontuberculous mycobacteria (NTM) infection often affects the lungs. Therefore, nontuberculous mycobacteria symptoms are similar. Most NTM infections and resulting symptoms progress slowly. Some people may have had this infection for years before they are diagnosed. Symptoms may include:

- Fever
- Weight loss
- Cough
- Lack of appetite
- Night sweats
- Blood in the sputum (hemoptysis)
- Loss of energy
- Shortness of breath

Rarely, people will have no symptoms, and the infection is discovered when chest imaging is ordered for other reasons. In these people, we would strongly recommend observation before launching into a complicated treatment regimen. The fever is often low grade. Throughout history, tuberculosis was also

described as “consumption.” The same phenomena can occur with NTM infection. Cough is a common complaint and can be either “dry” or “productive” of sputum. The color of the sputum is not helpful in the diagnosis. Night sweats may be mild or drenching. Blood in the sputum is unusual unless there is cavity formation (holes within the lung tissue) or severe bronchiectasis (dilation of the airways). Loss of energy is also described as fatigue, and this is a difficult symptom to quantify. Some people notice they don’t have the energy to do all the activities they used to do. Some people have to take naps to get through the day. Shortness of breath may occur, but it is not universal. It may be related to an underlying lung disease, such as emphysema, which is exacerbated by the infection or simply by the infection itself.

How is an NTM Infection Diagnosed?

A nontuberculous mycobacterial (NTM) diagnosis can be more difficult to establish than a tuberculosis (TB) diagnosis. It is important for your health care provider to determine if the infection is TB or NTM because the treatment is different. If it is NTM, the specific species of NTM is also important. Because these organisms are abundant in the environment, we require more than one positive sample to be consistent with disease. In addition, it is critical for the health care provider to determine whether the NTM infection requires treatment. Some people harbor the germs and remain well. They may need to be observed without treatment. Others develop symptoms consistent with progressive illness. A diagnosis is often based on the following:

- A complete medical history and physical examination by a health care provider (often a pulmonary doctor).
- A Chest CT scan (a specialized X-ray, which produces detailed slide-like pictures) of the lungs.
- A sputum culture. Several sputum cultures are often necessary and must be done at specialized labs. One positive test does not always mean disease is present. In people that are not productive on their own, we strongly encourage a sputum “induction” (using hypertonic saline) before proceeding to bronchoscopy.
- Other procedures, such as bronchoscopy, may be required in certain cases.
- Based on the results of the tests your doctor can determine a diagnosis and the best treatment for you.

What is the Treatment of NTM?

There are different goals of therapy. Of course, the most important goal is cure. Depending on the species, that may be possible. Cure is defined by a microbiologic outcome. If sputum cultures become negative and remain negative after treatment that is a microbiologic cure. We also follow clinical symptoms and anticipate that treatment results in resolution of fevers, night sweats, cough, etc. finally, we follow imaging (CT scans of the chest) while on treatment. We monitor for improvement in nodularity, closure of cavities and decrease in inflammation.

Most of the nontuberculous mycobacteria are naturally resistant to common antibiotics. The treatment regimens recommended vary greatly depending on the species. Some of medications used to treat NTM happen to treat tuberculosis (TB) as well. To overcome drug resistance, people with NTM may need to take several different antibiotics at the same time. Typically, the regimen includes three antibiotics. Because these medications may have side effects, close monitoring is important. Furthermore, treatment may be necessary for as long as two years. The goal of treatment is to achieve “negative” sputum cultures and maintain that for 12 months before stopping. Sometimes treatment is ongoing, depending on the severity of the disease.

The most common organisms involved in human infection are *M. avium complex*, *M. kansasii* and *M. abscessus*. *M. kansasii* is easier to treat and often can be killed with only three anti-TB medications. On

the other hand, organisms such as *M. avium complex*, *M. chelonae* and *M. abscessus* are among the stubbornest germs. They are more difficult to treat. Three to five medications may be needed. Depending on how localized the disease is, surgery also may be helpful.

Living with NTM Infections

Living with a *nontuberculous mycobacteria* (NTM) infection presents unique challenges. The symptoms of NTM, as well as the long course of treatment for NTM, can take a toll on a person's state of well-being. Anxiety, depression, and fear of the future can all accompany a diagnosis of NTM and its treatment. People with NTM are often bewildered and lonely.

The good news is that you are not the first, nor the only person who suffers from an NTM infection. In fact, there are lots of people who have had NTM, and who are still infected with NTM, that are involved in support groups to help each other. Becoming involved in a support group can help alleviate the fear and anxiety you may feel. Discussing the special challenges that NTM poses with other people like you can be extremely helpful.

Bronchiectasis

What is Bronchiectasis?

Bronchiectasis (pronounced bron-kee-ek'-tas-is) is a condition of the airways in the lungs. These airways (bronchial tubes) are tube-like structures that branch from the trachea into the right and left lungs. When a person has bronchiectasis the airways are permanently and abnormally widened (dilated) and inflamed. These damaged airways can no longer clear mucus and bacteria from the lung, so exacerbations of cough, sputum production and shortness of breath can occur.



Bronchiectasis is caused by one or more infectious or inflammatory insults to the lungs. People with bronchiectasis are more likely to get lung infections. Each lung infection can make the bronchiectasis worse.

Generally, the prognosis of bronchiectasis is very good. The earlier it is diagnosed, the earlier treatment and management can be initiated preventing it from worsening. Be proactive with your doctor. Remember that the gold standard to make a diagnosis of bronchiectasis is now a high resolution CT scan of the lungs and NOT a simple chest x-ray.

How Can You Develop Bronchiectasis?

There are many causes of bronchiectasis — some are acquired and others you may be born with (congenital). The following is a list of the most important and/or common causes.

Infections

Infections can damage the airways and cause bronchiectasis. They may also be a consequence which in turn can lead to worsening bronchiectasis.

Examples include:

- Viral infections (measles, adenovirus, influenza)
- Bacterial infections (*Pseudomonas aeruginosa*, *Staphylococcus aureus*, *Klebsiella*)
- Mycobacterial infections (tuberculosis, *Mycobacterium avium*, *Mycobacterium abscessus*) and
- Fungal infections (histoplasmosis)

Immune Diseases

People with immune deficiencies such as antibody deficiencies are more likely to have repeated lung infections which can damage the airways and cause bronchiectasis.

Aspiration

Chronic pulmonary aspiration occurs when a person inhales oral or stomach material into his/her lungs. If severe or recurrent, aspiration can lead to inflammation of the airways and causes bronchiectasis. The aspiration can occur from:

- Impaired ability to swallow (oropharyngeal dysphagia) which may cause saliva or food to enter the lung.
- Gastroesophageal reflux disease (GERD) which occurs when the valve of smooth muscle between the esophagus and the stomach does not function properly. This allows contents (acid and non-acid) to flow back up into the esophagus. The stomach contents may enter the lungs and irritate the airways. Some signs and symptoms of GERD include: heartburn or sour taste in mouth, but many (possibly up to 30 percent) of people with GERD may have no symptoms (“silent” GERD).

Autoimmune Diseases

Rheumatoid arthritis, lupus, Sjogren’s syndrome and Wegener’s granulomatosis are examples of rheumatologic, autoimmune or connective tissue diseases that can cause bronchiectasis.

Genetic Diseases

- Cystic fibrosis causes impaired drainage of mucus and bacteria from the airways. This leads to recurrent lung infection and bronchiectasis. Classic cystic fibrosis is obvious at birth, but there are forms of cystic fibrosis that may not be recognized until adulthood.
- Primary ciliary dyskinesia impairs the ability of small hairs, called cilia, to clear mucus and bacteria from the airways. Recurrent lung infections can occur and cause bronchiectasis.
- Alpha₁ antitrypsin deficiency. Alpha₁ antitrypsin is a protein that moderates inflammation that occurs during infection. People who are deficient in alpha₁ antitrypsin or who have an abnormal protein may be more likely to have recurrent lung infections that cause bronchiectasis.

Obstruction of the Airways

Obstructed airways trap mucus and infections behind the obstruction which can damage the airways and cause bronchiectasis.

- Obstruction of the airways can be caused from a growth or tumor.
- Chronic obstructive pulmonary disease (COPD) and allergic bronchopulmonary aspergillosis are diseases that can cause obstruction of the airways.

What Happens in the Lungs with Bronchiectasis?

First, inflammation occurs in the walls of the airways from a number of causes just discussed. This inflammation causes injury to the airways. The resulting loss of the normal defenses in the lungs leads to impaired drainage of the airways. This makes the airways susceptible to infections. Repeated lung infections can worsen the damage to the airway walls.

What are the Symptoms?

Symptoms of bronchiectasis include a cough. The cough may be productive of mucus. With infections the mucus may be discolored, foul-smelling and may contain blood (hemoptysis). Shortness of breath, wheezing, weight loss and fatigue can also occur. Some people with bronchiectasis also have chronic

sinusitis. This requires further evaluation since bronchiectasis and sinusitis may be due to the same underlying disease.

If left untreated, symptoms of bronchiectasis may progress. Further symptoms may include increasing shortness of breath, worsening quality of life and even heart failure.

How is Bronchiectasis Diagnosed?

A multiple step process usually leads to the diagnosis of bronchiectasis. Many factors are considered and different tests are completed. The evaluation for bronchiectasis often includes:

- A complete medical history and physical examination by a health care provider.
- A chest CT scan (a specialized X-ray which produces detailed slice-like pictures) of the lungs.
- Breathing tests, called pulmonary function tests. These determine the presence and severity of abnormal airflow out of the lungs.
- Specific screening or diagnostic tests for some of the possible underlying diseases that may cause bronchiectasis, based on the history and physical examination.

How is Bronchiectasis Managed?

Bronchiectasis management is long-term and is directed at:

- Improving the clearance of sputum, also called bronchopulmonary hygiene
- Treatment of infections
- Treatment of associated conditions (such as GERD and sinusitis)
- Improving muscle strength and endurance through pulmonary rehabilitation
- Identifying the need for surgical resection of affected segments or lobes of the lung

Your health care provider will evaluate your history and recommend the best management plan for you.

Bronchopulmonary Hygiene Therapy

Improved clearance of mucus is the cornerstone of the management of bronchiectasis and includes several components. They include:

- Inhaled medication (bronchodilator and/or inhaled steroid, saline)
- Airway clearance measures (oscillating positive expiratory pressure device, high-frequency chest wall oscillation vest).

Your health care provider may recommend one or more of them depending on your individual needs.

Inhaled Medication

Inhaled Bronchodilators - An inhaled bronchodilator medication opens the airways by relaxing the smooth muscles around the airways. This type of medication is available in a number of inhaled forms. Commonly used inhaled short-acting bronchodilators include:

- ProAir®, Proventil® HFA, Ventolin® HFA (albuterol)
- Xopenex® (levalbuterol)

Inhaled long-acting bronchodilators may also be used. They include:

- Serevent® (salmeterol)
- Foradil® (formoterol)
- Spiriva® (tiotropium)

Inhaled Steroids – Inhaled steroids reduce and prevent swelling inside the airways. Common inhaled steroids include:

- Flovent® (fluticasone)
- Pulmicort® (budesonide)
- QVAR® (becolmethasone)
- Asmanex® (mometasone)
- Azmacort® (triamcinolone)
- Aerobid® (flunisolide)

Inhaled Steroid and Long-Acting Bronchodilator Combinations

Common combinations of inhaled steroid and long-acting bronchodilator include:

- Advair® (fluticasone and salmeterol)
- Dulera® (mometasone and formoterol)
- Symbicort® (budesonide and formoterol)

Inhaled hypertonic saline may be used to loosen airway mucus for easier airway clearance.

Airway Clearance Measures

Airway clearance measures are treatments designed to clear trapped mucus from the airways.

- Oscillating positive expiratory pressure devices (OPEPD): These include devices such as the Aerobika®, Acapella® or the Flutter Valve® that help clear mucus from your lungs. These are small devices you inhale and/or exhale into.
- High-frequency chest wall oscillation vests: These include The Vest®, SmartVest® and AffloVest® are inflatable vests that you put on. The vest shakes your chest to help dislodge the mucus from the airway walls. Sometimes the Aerobika® or Acapella® is used **after** the inflatable vest. Once the mucus is dislodged, the device can help clear the mucus.
- Postural drainage and clapping use gravity to promote drainage of mucus from the lungs.



Each technique can be prescribed by your health care provider. Correct technique using these devices is very important. Make sure a health care provider, often a Respiratory Therapist, experienced in the use of the device shows you how to use it. It is also important to have your technique checked periodically to make sure you continue to use it correctly to obtain the most benefit.

Treating Infections

Antibiotics are used to treat bacteria and other infectious organisms causing infection in the lungs to improve respiratory symptoms and prevent further damage to the airways. For example, treating *pseudomonas aeruginosa* may entail 2-3 weeks of intravenous antibiotics when symptoms are severe. Sometimes inhaled antibiotics are given to prevent exacerbations of pseudomonas. Treatment of mycobacteria may require multiple antibiotics taken for a year or longer. Rotating or chronic antibiotics to prevent infections are not encouraged because this promotes the development of drug-resistant

organisms. However, long-term azithromycin may sometimes be beneficial for people who experience frequent bronchiectasis flare-ups.

Treatment of Associated Conditions

Treatment of any identified specific causes, including those listed under “Causes of Bronchiectasis” is important. Examples include:

- Treatment of chronic infections with non-tuberculous mycobacteria,
- Treatment of antibody deficiency with immune globulin if appropriate,
- Treatment of swallowing disorders and GERD that cause chronic pulmonary aspiration. The MedFacts, Gastroesophageal Reflux Disease, discusses this topic in more detail.
- Prompt treatment or removal of any foreign object, growth or tumor causing obstruction of the airways,
- Treatment of other chronic lung disease
- Treatment of chronic sinusitis. The MedFacts, Sinusitis, discusses this topic in more detail.

Pulmonary Rehabilitation may improve your overall health. A well-rounded rehabilitation program includes education, exercise and eating well and can help you stay healthy and feel good.

Resective Surgery is occasionally indicated – usually only if bronchiectasis is very localized in the lung and medical treatment and other therapies are not effective.

What about a Healthy Lifestyle?

A healthy lifestyle is important for everyone. Here are some tips to consider:

- Exercise regularly as directed by your health care provider. This helps you breathe easier by improving your muscle strength and tone and helps improve clearing the mucus from the airways.
- Eat a well-balanced diet and drink plenty of fluids.
- Give up smoking and avoid exposure to passive smoke. Ask your health care provider for techniques to help you give up smoking.
- Get a flu shot every year in the fall. Get the pneumococcal vaccines as recommended by your health care provider.

Living with Bronchiectasis

- Living with bronchiectasis is a unique and special challenge that you and your family must deal with on a daily basis. But the more you know about bronchiectasis, the better suited you are in managing the various aspects of your disease. As you take control, your quality of life will improve.
- Be sure to talk with your health care provider if you have questions or concerns about your plan. Write down any questions you have and ask your health care provider at your next appointment.

On the Go with Oxygen

People with chronic lung disease may need oxygen therapy. Oxygen therapy is used to normalize the oxygen level in blood during sleep, rest, activity and during acute illnesses in the hospital.

Oxygen is in the air we breathe and is necessary to live. When we breathe in, oxygen enters the alveoli (air sacs), and passes through their walls into the blood. When the lungs cannot transfer enough oxygen into the blood, supplemental oxygen may be needed.



What are the benefits of oxygen therapy?

There are many benefits of oxygen therapy. In many adults with chronic lung disease, studies have shown that long-term oxygen therapy has improved quality and length of life. Oxygen can decrease shortness of breath when you are active and allow you to do more.

How will I know if I need oxygen?

It is sometimes difficult for you to know when oxygen therapy is required. If the oxygen level is low in your blood, you may experience symptoms such as: shortness of breath, irritability, morning headaches or ankle swelling. If you notice any of these symptoms, see your health care provider. He or she can review your overall medical condition and decide what treatment you need. Your oxygen can also be low without any symptoms. Just because you feel well doesn't necessarily mean you don't need oxygen.

What tests can be done to determine the need for oxygen?

There are two methods to test the oxygen level in the blood: oximetry and arterial blood gases. One or both methods may be used to determine your need for oxygen therapy.

Your oxygen level can be measured as a percentage of your blood's oxygen carrying capacity. This is called oxygen saturation. Oxygen therapy may be necessary if your saturation is below 89 percent. To measure oxygen saturation in your blood, a small clip is placed on the finger or earlobe. This is a simple, convenient, painless way to determine your need for oxygen. This test may be done at rest, during sleep and while you are walking.

The second method of testing is the arterial blood gas. While this blood test is more complex, the results can give your health care provider more information about how your lungs are working. For this test, blood is drawn from an artery in your wrist, and both oxygen and carbon dioxide levels are measured.

How do I get an oxygen therapy prescription?

When the test determines that oxygen is needed, your health care provider will write a prescription for oxygen. The prescription will tell you how much oxygen to use and when to use it. The amount of oxygen you need to use is called the flow rate. You need to understand when to use the oxygen and how much to use during sleep, rest and activity. Remember, oxygen is a medication and should be used only as prescribed. Because oxygen is a medical therapy, it, should be paid for by Medicare and other insurance companies; however, you may have a copay. Check with your insurance carrier to verify your oxygen benefit.

What types of oxygen systems are available?

There are three systems which can supply oxygen: concentrators, compressed gas systems and liquid systems. Each system has advantages and disadvantages. It is important to choose the system that best fits your lifestyle.

Concentrators are commonly used, because they are convenient for both the patient and the oxygen supply company. There are two types of concentrators: Stationary concentrators plug into an electrical outlet and take oxygen from the room air. These systems can add to the monthly cost of electricity, may be noisy and may produce additional heat. You will receive a backup system in case there is a power outage. If you are active, you may need an additional system to use when you go outside your home. Portable oxygen concentrators are oxygen machines that draw in oxygen with the use of a battery, electricity or DC power, for example, the power port in your car. They are smaller and lighter than stationary concentrators.



Compressed gas systems are readily available across the country. Steel or aluminum cylinder tanks, which contain oxygen gas, are available in several sizes.



Liquid systems have two parts — a large stationary container and a portable unit with a small lightweight tank. You can refill your portable unit from the stationary unit. The oxygen supply company will visit at least monthly to refill the stationary unit.

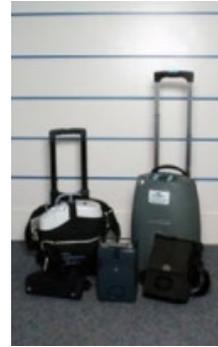


If your oxygen needs change, the type of system can also be changed. The oxygen supply company should explain and demonstrate whatever system you choose.

How does the oxygen get from the system to my body?

Oxygen is commonly delivered by a small plastic tube called a cannula. The cannula is placed into the nostrils and delivers oxygen to the airways. Oxygen can also be delivered by a face mask or by a number of other devices.

An alternative to a nasal cannula is a trans tracheal oxygen (TTO) catheter. A TTO catheter is a thin tube that is surgically placed in your neck and sits in your windpipe. Oxygen is delivered through the catheter directly into your windpipe (trachea). Talk with your health care provider if you are considering trans tracheal oxygen.



What is a conserving device?

Your health care provider may consider an oxygen conserving device for you. These devices can conserve oxygen, making tanks last longer. However, conserving devices do not work for every person on oxygen. You will need to be tested to confirm this device will work for you. This can be done by your oxygen company. Ask your health care provider for more information on these devices.

What are some common concerns about oxygen?

You may be concerned about how oxygen therapy may change your lifestyle, how oxygen affects your body and whether oxygen therapy is safe. You may worry that oxygen treatment will prevent you from leaving your home. However, many convenient portable systems are available. In fact, oxygen therapy allows you to be more active by providing the oxygen that your body needs. Oxygen therapy does not cause any harm to your lungs or your body, if used as prescribed. You will not develop an addiction to oxygen. Oxygen therapy is very safe. The only thing you need to remember about safety is that oxygen is flammable: keep your face and your oxygen away from flames. Talk with your health care provider if you have specific safety concerns.

Can I travel with oxygen?

Many people travel while using oxygen. Advance planning is important when considering a trip.

Traveling with Oxygen

What is the cost of oxygen while traveling?

Most insurance companies pay for oxygen in 30-day increments. No other oxygen company can bill your insurance for oxygen, as your local oxygen vendor is billing. If you are taking a trip, you should ask your oxygen company about the company travel policy. Some oxygen companies have national locations and can accommodate your travel. Locally owned oxygen companies may also locate oxygen companies at your destination and may assist in paying the travel oxygen expense for you. You may have to pay the travel oxygen expense out of your pocket. This cost will vary by destination and company policy.

Are there portable oxygen concentrators for travel?

Portable oxygen concentrators are the only delivery devices allowed on airplanes. See below for more information. Compressed gas and liquid tanks are not allowed. There are a number of portable concentrators on the market. Examples of portable oxygen concentrators include:

- Inogen One
- AirSep LifeStyle
- AirSep FreeStyle
- SeQual Eclipse
- Respironics EverGo.

All these portable units provide a demand flow, or pulsed oxygen delivery. The SeQual Eclipse is an example of a portable concentrator that also delivers a constant flow of oxygen up to 3 liters per minute. No one has made a portable oxygen concentrator that will accommodate over 3 liters of continuous flow oxygen at this time. Pulsed portable oxygen concentrators run on settings instead of liter flow rates. At this time, the highest setting a portable oxygen concentrator will go to is a setting of 6. Please note this is not a liter flow at 6, and you should be tested on your selected portable oxygen concentrator to confirm it is meeting your oxygen needs. The battery time varies per product, as do flow settings. If you would like additional information regarding portable concentrators, or other oxygen systems, contact your oxygen provider.

What should I consider when traveling by air?

Many airlines are allowing the use of portable oxygen concentrators to provide in-flight oxygen. There are a number of these devices approved for airline use, including Inogen One, AirSep LifeStyle, AirSep FreeStyle, SeQual Eclipse and Respironics EverGo. Contact your individual airline to obtain a list of approved devices and required documentation for use of portable concentrators on their airplanes. You will be required to use the battery on the portable concentrator during the flight. Ask your provider to rent or loan you enough batteries to last the duration of your flight. The FAA requires enough batteries to run the concentrator for 150 percent of travel time (including layovers).

What should I consider when traveling by train?

You can bring your own oxygen on board a train in the U.S. at no charge. Amtrak has specific weight requirements that can be obtained on www.amtrak.com, or you can inquire at the time you make your reservation. For travel in other countries, contact the carrier.

What should I consider when traveling by ship?

You can bring your own oxygen on board cruise ships. If you are bringing your own oxygen on board a cruise ship, the cruise ship may not charge you. You may incur a charge if you have to obtain oxygen from an oxygen company that is not affiliated with your home oxygen vendor.

What should I consider when traveling internationally?

There are a number of companies assisting with oxygen for international travel. You will be provided with oxygen concentrators and compressed gas oxygen systems when traveling internationally

The internet holds many resources for travel with oxygen, local and internationally. You also can find resources for support groups on websites provided by the American Lung Association and other medical related websites.

Language Assistance is Available Free of Charge 303-398-1355



Español: Spanish	Si usted habla español los servicios de ayuda en su idioma están a su disposición de forma gratuita.
Tiếng Việt: Vietnamese	Nếu quý vị nói Tiếng Việt, chúng tôi có dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho quý vị.
中文: Chinese -traditional	如果您說中文，您可以獲得免費的語言協助
汉语（简体）: Chinese -simplified	如果您讲中文，我们可免费为您提供语言服务
한국어: Korean	귀하께서 한국어를 하시는 경우, 무료 언어지원 서비스를 이용하실 수 있습니다
Русский: Russian	Если вы говорите на языке, то для вас доступны бесплатные переводческие услуги
የሚናገሩ ከሆነ: Amharic	እርስዎ አግርኛ የሚናገሩ ከሆነ፣ የቋንቋ እርዳታ አገልግሎቶች በነፃ ይገኛሉ
عربي: Arabic	ان اجم عىوغلللا قدعاسملا تامدخ لكل رفوتتف عىبرعلا ةغلللا شدحتت تنك اذا
Deutsch: German	Sprechen Sie Deutsch Dann erhalten Sie hier kostenlose Sprachassistentz.
Français: French	Si vous parlez français le service d'assistance linguistique est gratuit.
नेपाली: Nepali	यदतिपाईँ नेपाली बोलनुहुन्छ भने तपाईँका लागनिशिल्क भाषा सेवा उपलब्ध छन्
Tagalog:	Kung nagsasalita ka ng Tagalog, may maaaring kuning mga libreng serbisyo ng tulong sa wika.
話させる方は: Japanese	日本語をご希望の方は、無料の通訳サービスをご利用になれます。
Somali:	Haddii aad ku hadasho Soomaali adeegyada caawimadda luqadda ayaa laguugu heli karaa kharash la'aan.
Oromo:	Afaan Oromoo dubbattu, tajaajila deeggarsa afaaniibilisaan argachuuf lakk
Farsi: Persian	دش ابىم دوچوم نابز هب طوبرم ناگىار تامدخ، دىنك ىم تبحص ىسراف نابز هب رگا. ىسراف:
Bassa: Kru	M̐ dyi B̐ásóò-wùdù po-nyò j̐in, gbo-kpá-kpá se wídí péè-péè d̐ò k̐ d̐é wuḍu-dù b̐é múèè n̐ dà.
Igbo:	· Ọ bụrụ na ina-asụ ịgbò, enyemaka na-ahazi asụsụ dịrị gị n'efu. Kpọọ
Yorubá:	Tí o bá ńsọ Yorubá Àwọn ọ̀nà ìrannilọ̀wọ̀ nípa ti èdè wà lófẹ́ẹ̀ lófò

NON-DISCRIMINATION STATEMENT

National Jewish Health strives to provide barrier-free, all-inclusive healthcare for all patients and visitors. National Jewish Health complies with applicable federal civil rights laws, in that, no one is, nor will be denied or excluded from access to services, programs or activities on the basis of disability, race, gender identity, ethnicity, color, religion, sex, origin, age or socioeconomic status. National Jewish Health and its contractors do not and will not discriminate on the basis of disability, race, gender identity, ethnicity, color, religion, sex, origin, age or socioeconomic status.

NATIONAL JEWISH HEALTH PROVIDES:

- **Free aids and services to people with disabilities to communicate effectively with us, such as:**
 - Qualified sign language interpreters
 - Written information in other formats (large print, audio, accessible electronic formats, other formats)
- **Free language services to people whose primary language is not English, such as:**
 - Qualified interpreters
 - Information written in other languages

If you need assistance with these services, please inform admissions, the nurse, your physician or the [Patient Care Advocate Office at 303-398-1076](tel:303-398-1076).

If you believe that National Jewish Health has failed to provide these services or discriminated in any other way on the basis of disability, race, gender identity, ethnicity, color, religion, sex, origin, age or socioeconomic status, please contact the [Patient Care Advocate Office at 303-398-1076](tel:303-398-1076).

You can also file a civil rights complaint with the U.S. Department of Health and Human Services, Office for Civil Rights at:

U.S. Department of Health and Human Services

Office of Civil Rights
200 Independence Avenue, SW
Room 509F, HHH Building
Washington, D.C. 20201

Phone: 1-800-368-1019
(TDD) 1-800-537-7697