



# Patient's Guide to Lung Transplantation

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MOUNT SINAI - NATIONAL JEWISH HEALTH

## Respiratory Institute



Icahn School  
of Medicine at  
Mount  
Sinai



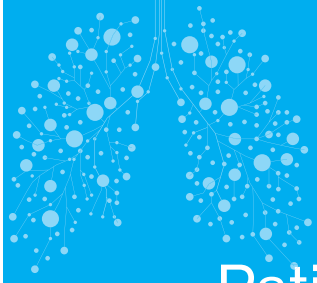
National Jewish  
Health



# A Guide to your Lung Transplant

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# Patient Rights and Responsibilities



## Patient Rights and Responsibilities

As a patient you have the **right** to:

- Respectful and considerate care
- Privacy
- Clear, complete, and understandable description of your condition and treatment choices
- Ask questions and expect answers about benefits and risks before you give your permission for any procedure or research study
- Refuse a diagnostic or therapeutic procedure, treatment, or research study
- Access your medical record
- Contact a customer service representative if you have concerns or complaints about the care you receive
- Leave the hospital as soon as possible with instructions about caring for yourself at home

As a patient you have the **responsibility** to:

- Provide correct and complete information about your health and past medical history
- Provide accurate and updated insurance information to the Transplant Center
- Report changes in your general health condition, symptoms, or allergies to the responsible caregiver
- Report if you do not understand the planned treatment or your part in the plan
- Follow the recommended treatment plan you have agreed to, including instructions from nurses and other health personnel
- Keep appointments
- Treat others with respect
- Understand the consequences of refusing treatment or not following the instructions you are given by the Transplant team



# The Advance Directive

## What is an advance directive?

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An advance directive is a document you create in case you become unable to decide or communicate about your health care. It states your wishes for medical treatment as well as who will make health care decisions on your behalf. Your advance directive may be used to accept or refuse any procedure or treatment including life-sustaining treatment.

Once you have completed an advance directive, it becomes part of your medical record. Everyone responsible for your care must respect your wishes as stated in your advance directive.

## Why is it important to have one?

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As a patient, you have the right to accept or refuse any procedure or treatment, including life-sustaining treatment. If you become unable to make or communicate your own decisions, those caring for you will need to know your wishes.

## How do I create one for myself?

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There are several types of advance directives. The Transplant Center will connect you with a social worker who will be able to help you decide which type of advance directive is best for your needs. You can also talk with your referring physician, a transplant coordinator or pulmonologist, your family, close friends, and others you trust to help prepare the document.

- **The Proxy Directive**, also called a *durable power of attorney*, lets you name a health care representative. This person is usually a family member or close friend. They will make health care decisions on your behalf if you are unable to do so.
- **The Instruction Directive**, also called a *living will*, lets you state which kinds of medical treatments you would accept or reject in certain situations.
- **The Combined Directive** allows you to both name your health care representative and address your treatment wishes, all in the same document.

### **What do I do with my advance directive once it is completed?**

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Once you have completed your advance directive you should discuss it with your doctors and provide them with a copy. You should also give copies to your designated health care representatives and your family members, or to others close to you. Bring a copy with you anytime you go to a hospital, rehabilitation center, nursing home, or any health care facility.

### **As you begin to consider and prepare your advance directive, please remember:**

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- It may be helpful to include your loved ones in discussions and decision making
- Your physicians and “health care representative” should also be consulted
- Inform people such as family, close friends, and members of the Transplant team about your advance directive
- If desired, you can complete both a living will and durable power of attorney for health care
- A lawyer is generally not necessary for creating an advance directive, but may be helpful in the process
- Your advance directive can be changed or revoked by you at any time
- Advance directives only go into effect when you can no longer make decisions for yourself







# Introduction

Welcome to the Lung Transplant Program at The Mount Sinai Hospital. Our dedicated team of doctors, nurses, and other specialists is committed to helping you achieve an improved quality of life.

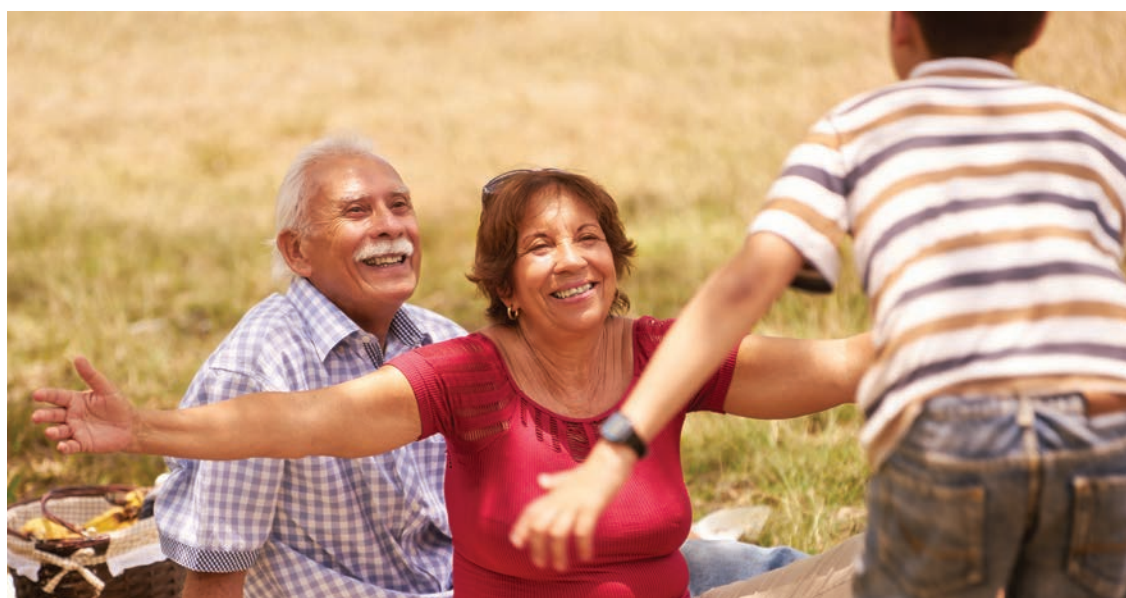
We have created this handbook to help guide you and your support persons through the process of lung transplant. Our goal is for you to feel prepared for all aspects of this experience, including the transplant evaluation, placement on the waiting list, the lung transplant surgery, and the process of recovery.

We hope that this handbook will give you an idea of what to expect and answer some of the questions you may have. All of this information will be discussed with you during your evaluation. We encourage you to return to this handbook at any time.

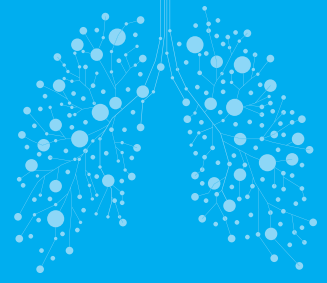
A Lung transplant is not appropriate for everyone. This is why an extensive evaluation is completed. If your health care team determines that you are not a candidate for transplant, you will be provided with alternative options to manage your disease.

In order for you to decide if you want to proceed with a lung transplant, you must learn about the risks, benefits, and alternative treatments, if any. Take the time to think about your options and make an informed decision about lung transplant.

You have the right to refuse transplantation. If you choose not to have a transplant, treatment for your lung disease will continue. However, your condition could worsen and limit your life expectancy.







# What Is a Lung Transplant?

Your lungs are essential. They are what allow you to breathe. They also allow your other organs, such as your heart, to work properly.

A lung transplant is a procedure in which either one (single) or both (double) lungs of a patient are removed and replaced with healthy lungs from a deceased donor.



The decision to complete a single or double lung transplant is based on a few different factors. These factors include the underlying lung disease; the age of the patient; and whether or not the patient has had prior surgery in the chest. Most importantly, the availability of donor lungs determines the decision.

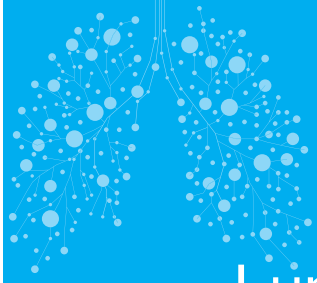
Lung transplant is a high-risk procedure. Most patients, however, see a significant improvement after their transplant. Most patients come off oxygen and can function normally on room air. Many are able to return to work, engage in regular daily activities, travel, and live a normal life.

There are short-term and long-term risks associated with lung transplant. They will be discussed further and explained to you in detail during your evaluation. All patients that receive a lung transplant will require medications to prevent their body from rejecting the new lungs. These medications are called “immunosuppressants,” and they must be taken for life.

Currently, the estimated average survival rate following a lung transplant is about 97 percent at one month, 88 percent at one year, 72 percent at three years, and 65 percent at five years.

All patients that receive a lung transplant will require medications to prevent their body from rejecting the new lungs. These medications are called “**immunosuppressants**,” and they **must be taken for life**.





# Lung Transplant Evaluation

An evaluation will be completed to determine if you are a candidate for lung transplant. It is done on an outpatient basis, meaning you do not have to stay in the hospital, unless you are critically ill and require hospitalization. The evaluation involves many diagnostic tests, blood work, and one-on-one evaluations by all members of the transplant team.

Your transplant team includes the following providers:

**Transplant pulmonologist:** A doctor who specializes in diagnosing and treating lung disease. Your pulmonologist manages your lung disease before the surgery. They also work with your surgeon to manage your condition after surgery and to monitor your progress.

**Transplant surgeon:** This is the doctor who performs the transplant surgery. After surgery, while you are in the hospital, this surgeon will care for you on a daily basis together with your pulmonologist.

**Transplant coordinator:** These are registered nurses or advanced practice nurses who are responsible for coordinating all elements of your care. They will be your point of contact if you have questions or if you are not feeling well. Your transplant coordinator will support you in taking charge of your care after surgery.

**Social worker:** Your transplant social worker will meet with you to discuss housing needs, insurance issues, financial concerns, and disability. They will also provide you with emotional support and counseling, as well as referrals to community agencies.

**Dietitian:** Your dietitian works with you and your doctor to develop a nutritional plan with all the nutrients you need to be healthy. They will guide you with tips and instructions to maintain a healthy diet before and after your transplant surgery.

**Financial coordinator:** This team member meets with you to verify your insurance coverage for transplantation, including the surgery, hospital admission, and medications after transplant. If you do not have the necessary coverage, your financial coordinator and transplant social worker will do their best to assist you in finding additional insurance coverage. If your insurance coverage changes in any way at any phase of the process, please notify the financial coordinator.

Your **transplant coordinator** is your point of contact for any questions about any of your care.



### Lung Transplant Evaluation Testing

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**Blood work:** You will have many tubes of blood drawn during your evaluation. You will be tested for the following:

- **Blood type:** Your blood type allows us to know if a potential donor matches with you. This test will be done twice for confirmation.
- **Human leukocyte antigen (HLA) typing:** This test tells us your tissue type. It is used to determine genetic markers that make your immune system unique. This is also used to determine if a potential lung donor is a match for you.
- **Panel of reactive antibodies (PRAs):** This test looks for whether you have existing antibodies to other people's tissue types. It may be affected by previous blood transfusions, pregnancies, or previous transplants. This test will have to be repeated every three months, or in some cases more frequently, while you are waiting for transplant.
- **Kidney and liver function:** Checking your baseline kidney and liver function helps us be sure that those organs are functioning properly before transplant.
- **Viral infections:** These tests screen for HIV and for Hepatitis A, B, and C.
- **Past infections:** We screen for any antibodies against infections such as chicken pox, measles, mumps, rubella, and tuberculosis.
- **Vitamin and mineral levels:** If your vitamin or mineral levels are low, you may need to take supplements.
- **Arterial blood gas (ABG):** A blood sample will be drawn from an artery in your arm. This will measure your lung's ability to carry oxygen and remove carbon dioxide from your bloodstream.

### Lung Transplant Evaluation Testing – continued

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**Lung tests:** The purpose of these tests is to get a full understanding of the extent and severity of your lung disease.

- **Pulmonary function test:** This is a breathing test which measures the capacity of your lungs. We will ask you to breathe in and blow out through a special tube.
- **Six minute walk test:** This is a test that measures your ability to walk for six minutes over a hard flat surface. It measures how far you can walk and how much oxygen you require to make it through the six minutes.
- **Chest X-ray:** This is a picture of your heart, lungs, rib cage, and surrounding muscle, tissue, and lymph nodes. It will help us identify heart disease, monitor the degree of your lung disease, and identify any other problems in your chest.
- **Chest CT scan:** This is a computerized image that shows the changes in your lung tissue causing your lung disease. It is also used to detect and evaluate nodules or tumors in your lungs. It allows us to see any injury or abnormalities in the chest, including in the heart, blood vessels, lungs, ribs, and spine.
- **VQ scan:** This test measures the airflow (ventilation) and blood flow (perfusion) to your lungs. It is used to look for blood clots in the lungs. It also helps us see which of your lungs is working best.
- **Sniff test:** This test is used to evaluate the function of your diaphragm, which is the muscle underneath the lungs. It is a quick and simple test in which we take X-rays as you breathe in rapidly through your nose.





### Lung Transplant Evaluation Testing – continued

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**Heart tests:** These tests will tell us if your heart is functioning properly and if it can withstand a serious surgery.

- **Right and left heart catheterization:** This is a minimally invasive procedure. A catheter is inserted through your groin or arm and threaded into the right and left sides of your heart. It is used to measure the pressures inside your heart as well as to determine if there are any blockages in your blood vessels. You will be given some medication for this test that will put you to sleep. You must be fasting for this test. This means that the night before the procedure, you cannot have anything to eat or drink after midnight.
- **Echocardiogram:** This is an ultrasound of your heart. It is a non-invasive procedure that shows the size, structure, and movement of different parts of your heart. It allows us to detect if there are any problems with the valves or chambers of your heart.

**Vascular tests:** These tests are done to check the most important blood vessels in your body to make sure there are no blockages or other issues.

- **Carotid dopplers:** This is an ultrasound of your neck used to examine the carotid arteries. It can show narrowing or blockages in the arteries due to coronary artery disease.
- **Bilateral upper and lower extremity dopplers:** This is an ultrasound of your arms and legs to examine your circulation. It will show any blood clots or narrowing of veins and arteries.



### Lung Transplant Evaluation Testing – continued

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**Gastrointestinal (GI) tests:** These tests are done to look at the function of your esophagus, stomach, and the rest of your digestive system.

- **Esophagram (barium swallow):** This is a test used to check your esophagus and stomach. It helps determine if the food you swallow is travelling down your digestive tract properly. For this test, you will drink a thick white drink with a substance called “barium” in it. This allows the doctor to see your organs through an X-ray machine.
- **Esophageal manometry:** This test measures the function of the lower esophageal sphincter (the valve that prevents reflux, or backward flow, of stomach acid into the esophagus) and the muscles of the esophagus. This test will tell your doctor if your esophagus is able to move food to your stomach normally.
- **Abdominal ultrasound:** This is a non-invasive test that shows the size and structure of the organs in your abdomen. It checks your kidneys, liver, gallbladder, pancreas, spleen, and abdominal aorta.
- **Gastric emptying study (only done in some cases):** This test checks how quickly food leaves your stomach. You should have nothing to eat or drink after midnight the night before this test. Before the test, they will give you egg whites to eat with some tasteless radioactive material. Then you will lie on a table while a camera takes pictures (X-rays). The radioactive material allows the camera to follow the food through the digestive process. The test usually takes three-four hours, as they take pictures at different times throughout the digestive process.
- **Endoscopy (only done in some cases):** This test is used to check the esophagus, stomach, and some parts of the small intestine (duodenum). It is used to look for ulcers, inflammation, tumors, infection, or bleeding. A thin, flexible tube called an “endoscope” is inserted through your mouth into your esophagus. You will be given numbing medication so you don’t feel discomfort in the back of your throat. You should have nothing to eat or drink after midnight the night before this test.

### Lung Transplant Evaluation Testing – continued

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#### Osteoporosis screening:

- **DEXA scan:** This test is done to screen for osteoporosis, which is a thinning of the bones. It is a quick and painless procedure in which you lie flat on your back while an X-ray machine scans your body.

**Cancer screening:** Every patient will undergo cancer screening based on their age and risk factors. Tests include:

- **Colonoscopy:** This test screens for colon cancer. A tube with a camera called a “colonoscope” is inserted into your rectum. You will be put to sleep for this procedure. You should have nothing to eat or drink after midnight the night before the procedure.
- **Mammogram:** This test is done only on people who have breasts. It is used to screen for breast cancer by taking X-ray pictures of breast tissue.
- **Pap smear:** This test is done only on people with female reproductive systems. It is used to screen for cervical cancer.

**Clearance by other specialists:** You will need to get clearance from the following list of doctors. If you do not already see a doctor in one of these specialties, we will refer you to one.

- **Ophthalmologist:** Eye doctor
- **Dermatologist:** Skin doctor
- **Dentist:** You may need to get a few teeth pulled if your dentist believes they can be a source of infection.
- **Transplant infectious disease physicians:** These doctors will make sure all of your vaccines are up to date. They will also determine the course of antibiotics that will be right for you post-transplant and, if needed, before the transplant.

# Eligibility for a Lung Transplant



After you have completed all of your evaluation tests and consults, your case will be presented to the Lung Transplant Selection Committee for review. This Selection Committee meets once a week: all members of the lung transplant team are present. They will discuss your case carefully to determine if lung transplantation is appropriate for you. After the Selection Committee meets, you will receive a letter letting you know their decision.

The decision will fall into one of three categories:

- 1. Accepted for Listing**
- 2. Deferred**
- 3. Declined**



# Eligibility for A Lung Transplant

## 1. Accepted for Listing

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You will be placed on the United Network for Organ Sharing (UNOS) waiting list as a candidate for transplant at Mount Sinai if you meet the criteria for transplantation. You must, however, also be cleared from a social, nutritional, and financial perspective. Furthermore, no issues can be found with any of the other major organs in your body.

## 2. Deferred

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Your condition does not meet the criteria for transplant at this time. Further testing, treatment, or support is necessary before a final decision can be made. Examples of this might include:

- A medical problem like coronary disease that needs specific treatment before transplant
- Counseling for a psychiatric diagnosis
- Treatment for alcohol or drug abuse
- Not having a caregiver or adequate support system

If you are deferred, the transplant team will help you complete additional testing or treatment. Once completed, your case will be presented to the Selection Committee again.

## 3. Declined

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Your condition does not meet criteria for transplantation at Mount Sinai, and is unlikely to do so in the future. This decision might be reached because:

- Something is found during your evaluation process that disqualifies you as a transplant candidate. Examples of this include cancer anywhere in your body or failure of any organ other than your lungs.
- In the judgement of the team, it is unlikely that transplantation would improve survival. Examples of this could be malnutrition or being too frail to withstand transplant surgery.
- You are deemed unable to understand or follow the treatment regimen before or after transplant.
- You do not have a plan for a caregiver to be present throughout the entire transplant process.

The Lung Transplant Selection Committee will review your case carefully and will send you a letter with their decision.





# Placement on the UNOS Lung Transplant Waiting List

Once the Selection Committee has determined that you are a good candidate for lung transplant, your name will be added to the lung transplant waiting list through an online database operated by the United Network for Organ Sharing (UNOS).

UNOS is the national clearinghouse for organ allocation. It was created to maximize the limited supply of organs and to give candidates a fair chance to receive the organ(s) they need, regardless of gender, age, religion, lifestyle, financial, or social status. UNOS manages the national transplant wait list and matches donors to recipients 24 hours a day, 365 days a year, for every transplant center in the country.

You will be notified by a member of our transplant team in writing that you have been successfully “listed.” Being “listed” means that your information is entered into the UNOS database, and you become eligible to receive donor organ offers.

The day you are placed on the list is when your waiting time begins. We cannot predict how long you will have to wait for a matching donor. The average waiting time is about six months to a year, but it is possible to get a donor sooner. Finding you a match is primarily based on three factors: blood type, size (height), and your lung allocation score (LAS), which is explained below.

## **Lung Allocation Score (LAS)**

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The Lung Allocation Score, or “LAS,” is a number that each patient receives which determines their place on the wait list. The score is based on how sick a person is and how likely they are to survive and benefit from a lung transplant. Factors that affect the score include the type of lung disease, the amount of oxygen being used, weight (BMI), cardiac status, and physical fitness, among other things. Generally, the sicker a patient is, the higher the score. The score ranges from 0 (healthiest) to 100 (sickest) with the average score being between 30 and 50.

Your **Lung Allocation Score (LAS)** determines your place on the wait list and is based on your health status.



### Multiple Listing

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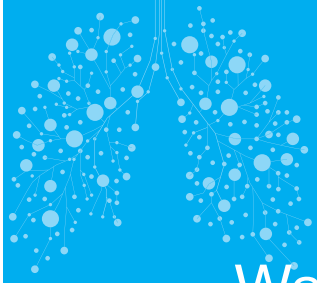
While you wait for a transplant, you can choose to be placed on the waiting list at more than one transplant center. This may increase your chances of getting a donor offer faster. However, the two transplant centers cannot be in the same local area (you cannot be listed at two transplant centers in New York, but you could, for example, be listed at a center in New York and a center in Pennsylvania).

If you choose to get listed at another center, you will have to undergo an evaluation at that center as well. We will send the test results you had done at Mount Sinai, but the other center may choose to repeat some testing or have you take additional tests. Being approved for listing at Mount Sinai does not guarantee that you will be approved for listing at another center, as each center has its own listing criteria.

It is important to check with your insurance provider to see if there are additional costs associated with multiple listing that your insurance may not cover.

**UNOS** is the organization that manages the transplant waiting list and matches donors to recipients.





# Waiting for a Lung Transplant





## Waiting for a Lung Transplant

Most patients wait for their lung transplant at home. During the waiting period, you may be enrolled in a pulmonary rehabilitation or physical therapy program. It is important to avoid infection and be in the best health possible before your transplant. You will need to eat a healthy diet and maintain a healthy weight. Avoid smoking, second hand smoke, all tobacco replacement products, and alcohol use. You will undergo random blood and urine screening to look for these substances.

While on the waiting list, you will be expected to attend appointments with pulmonary rehab and your primary care doctor. You will also need to be seen in the transplant clinic every four to six weeks. It is very important that you keep all of your scheduled appointments.

You will also be expected to notify your transplant coordinator with any changes (see below).

Please notify us about:

- Changes in your contact information including address, phone number, or emergency contacts
- Changes in your caregiver or social support system
- Changes in your insurance
- Plans to travel farther than two hours away from the hospital
- Any changes in your general health, even if they are unrelated to your lungs. This could include things like getting shingles or breaking a bone.
- Any changes in your condition including:
  - A change in oxygen requirement
  - Worsening shortness of breath
  - If you require hospitalization for any reason. *It is important for you, your caregiver, or the physician responsible for your care to call the Mount Sinai lung transplant team when you are hospitalized in a different institution.* This will ensure that we remain updated on your current medical status and initiate any transfers to our center, if deemed necessary.

Inform your **transplant coordinator** of any important changes right away—especially a change in your health status.





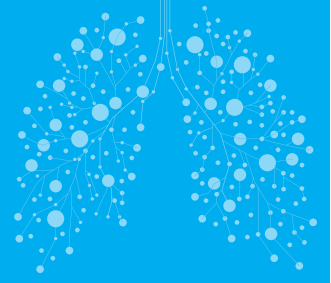
## Donor-Recipient Matching

A donor is matched to a recipient based on blood type, tissue type, and size. When an organ is available, it is first offered regionally to matching patients with the highest scores. This process is overseen by the United Network of Organ Sharing (UNOS).

Before any transplant center officially accepts any donor organs, a thorough assessment is completed on the donor. We must ensure that the donor lungs and/or heart are healthy and that no previous surgical procedures or past illnesses have damaged the tissue. For lung and heart/lung transplant, we are only able to use deceased donors.

If the donor organs are healthy, an appropriate recipient is chosen based on blood group and body size. If a potential donor matches equally with two recipients, the one who is more seriously ill at the time will receive the transplant. If both patients have the same health status, the one that has been listed longer will receive the organ(s).



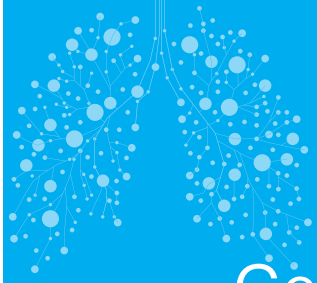


## “At Risk” Donors

When you get the call for transplant, you may be offered an organ from a deceased donor that is categorized as “at risk.” This means that the donor engaged in behaviors before their passing that may increase the chance that they had an infection such as HIV or Hepatitis C. This increased risk does not affect how well the organ works. It does mean that an infection could be carried with the organs from the donor.

Before accepting organs from an “at risk” donor, we perform two types of screening for infections. We test for antibodies to HIV, Hepatitis B, and Hepatitis C, as well as do nucleic acid testing for HIV and Hepatitis C. All of these tests must be negative before the donor organs are offered to a recipient. However, even with negative test results, there is a small chance that this donor had an infection that was not detected. Should one of these infections occur, there are therapies available for treatment.

Overall, the risk of getting an infection is extremely small: less than one percent. The decision to accept an organ at risk is completely yours. You will have a chance to discuss the risks and benefits with the transplant team before making a final decision. If you accept the organ, you will be periodically tested for infections during the first year after transplant. If you decide not to accept this type of donor, you will not lose your place on the wait list.



## Getting “The Call”

When your doctors identify a donor for you, you will receive a phone call from the transplant coordinator letting you know that it is time for your transplant.

Getting the call about a donor can happen anytime, day or night. When you get the call, you will be expected to be ready and able to come directly to the hospital. Please make sure to always have your phone with you, turned on, and to answer every phone call you get, even if you don't recognize the number.

You are responsible for your own transportation to the hospital on this day. Please let us know if you are planning on traveling farther than two hours away from Mount Sinai Hospital, as there is only a short window of time that any organ can remain outside of the body.

The coordinator will give you all the necessary information before you leave for the hospital. Do not eat or drink anything unless instructed otherwise. Depending on COVID-19 restrictions at the time, your family may be allowed to stay with you until you enter the operating room.

While you are waiting for the call, make sure you have a bag packed and ready to go. Please remember to bring a list of your medications. Also, you may want to have some cash to pay for the cost of meals and parking for your family members.

Before you get the call, you may want to practice driving to the hospital to see how long it will take you to get here. Remember, it is important to stay calm and drive safely.

**Always answer calls from numbers you don't recognize**  
— it could be the call that you have a donor and it's time to come to the hospital.





### Dry Run

While you arrive at the hospital and get settled and prepped for surgery, a surgical team from the transplant center will travel to the donor site to extract the lung or lungs from the donor for transplant.

During the surgery to remove the lungs, called “organ procurement,” the surgeon may find that the lungs are newly damaged or have become unsuitable for transplant. They may therefore decide to decline the organs. This decision is made with very careful consideration, weighing all the risks and benefits.

If this happens, the transplant surgery will be cancelled, even if you are already in the hospital. This is called a “dry run.” Your surgery will not begin until the team is sure the lungs will be accepted during the organ procurement.

If a dry run occurs, you will be sent home from the hospital. Your place on the transplant wait list will remain the same, and you will continue to wait until another suitable donor becomes available. This situation can be emotionally difficult, and our team is here to help you cope.

**A “dry run”** means that the organs are not actually suitable for transplant and the surgery is cancelled. Your place on the transplant waiting list will not change.



Left: **Scott Scheinin, MD**, Surgical Director of Lung Transplant  
Center: **Pamela Philippsborn, NP**, Transplant Coordinator  
Right: **Harish Seethamraju, MD**, Medical Director of Lung Transplant

# Lung Transplant Surgery



Left: **Scott Scheinin, MD**, Surgical Director of Lung Transplant  
Right: **Harish Seethamraju, MD**, Medical Director of Lung Transplant

## **Before Going into the Operating Room**

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Prior to your surgery, you and your family will have a conversation with the transplant surgeon or someone from their team. This discussion about the upcoming surgery will include a review of the risks, benefits, alternatives, and any donor risk factors that are applicable. This is a good time to ask any questions you may have.

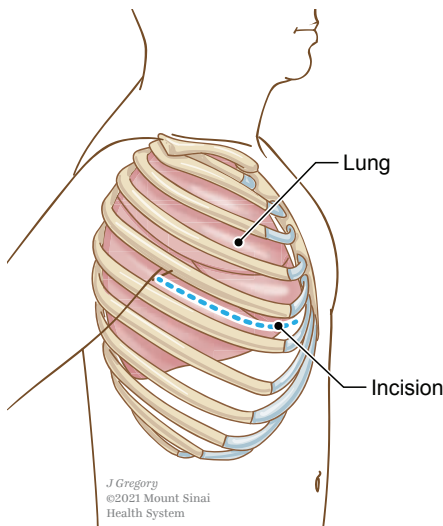
You will sign consent for surgery, anesthesia, and blood products (or a consent to refuse blood products, if that is your preference).

## In the Operating Room

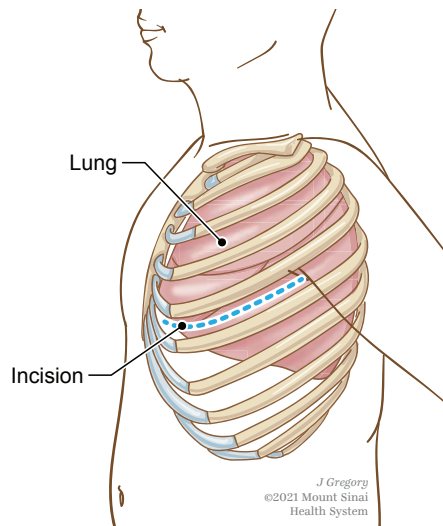
When you arrive in the operating room, you will be put to sleep under general anesthesia and will remain fully sedated throughout the entire surgery.

You will be intubated. This means a tube will be placed through your mouth into your throat and down into your windpipe. The tube will be used to help you breathe throughout the surgery.

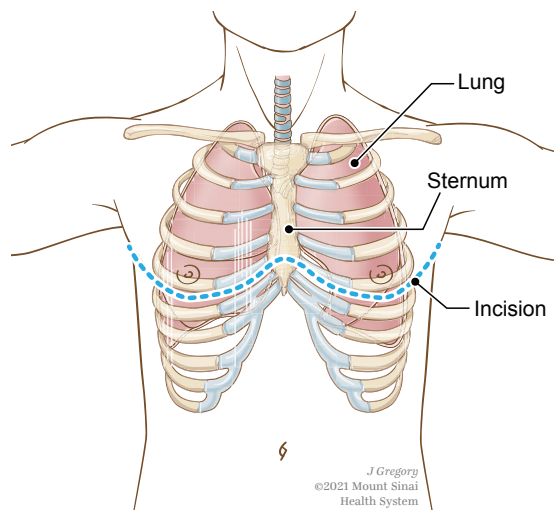
The surgery will begin with an incision, or cut. It may look different depending on whether you are having a single or double lung transplant:



Right Lung



Left Lung



Double Lung Incision called "Clamshell Incision"

### Single Lung

The incision will be made on the side and back of the chest corresponding to the lung that will be transplanted. This is called a *thoracotomy incision*.

### Double Lung

The incision will be made under the breast line, across the entire front of the chest, from armpit to armpit. This incision will also break through the breastbone, or sternum (*clamshell incision*).

## Lung Transplant Surgery

### **In the Operating Room** – continued

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Your lung(s) will be removed and replaced with the donor lung(s).

During the surgery you will remain on a ventilator, which will help you breathe while they operate on your lungs. Sometimes you may be placed on a machine called cardiopulmonary bypass, which also helps oxygenate your blood while the lungs are being operated on.

The surgeon will finish by closing the incision with staples.

The entire duration of transplant surgery is as follows:

**Single lung transplant: about three to four hours**

**Double lung transplant: about six to eight hours**

When the surgery is finished, you will be taken to the intensive care unit (ICU), where you will be closely monitored for several days.

### **What to Expect When You Awake**

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It can take anywhere from 6 to 24 hours to wake up from anesthesia. The tube helping you breathe will remain in place until you are fully awake and stable enough to breathe on your own. This could take anywhere from a few hours to a few days. After the breathing tube is removed, you may need some oxygen for a day or two, but you will soon be able to breathe on your own with no oxygen, as long as there are no surgical complications.

You will be connected to a display monitor that allows the doctors and nurses to see your vital signs and how well you are breathing. You will also have several tubes coming out of your chest which are there to drain any blood, fluid, or air from the surgical site. There will be multiple intravenous (IV) lines which may be in your neck, arms, or groin area; a urinary catheter which will be removed shortly after you wake up; and a feeding tube inserted through your nose or mouth which is used to feed you until you are able to swallow.

### **Hospital Recovery**

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Once you are ready to leave the ICU, you will be transferred to another floor, called a “step-down” floor. This is where you will be encouraged to walk around, participate in physical therapy, and continue learning about your new medications. Chest X-rays and blood draws will be performed regularly to monitor your progress.



### Exercise

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You will be provided with a small breathing device called an incentive spirometer. This will help you exercise your new lungs by taking deep breaths and pushing the air out. In between exercises you will be asked to cough, which will help clear your lungs. These exercises are extremely important to ensure that your lungs expand and function properly.

Physical therapy is the most important part of your recovery. It will begin the day after your surgery.



Your **transplant coordinator** will make sure you are prepared to go home with all of the information, medication, and scheduled follow-up appointments you need.



### Discharge from the Hospital and Follow-up Care

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The total hospital stay after a lung transplant can range between 10 and 21 days if there are no major complications. You will be discharged from the hospital as soon as the transplant team feels you are ready to return home. In some cases, a stay at a rehabilitation center may be necessary before transitioning home. These decisions will be made based on your progress after surgery.

Your transplant coordinator will ensure a smooth transition from the hospital to home. They will order a month's supply of medications for you ahead of time, teach you and your caregivers about how to care for yourself at home, and provide you with important phone numbers in case you need to call and report any issues. Before you leave the hospital, the transplant coordinator will give you a date and time for your first follow-up appointment at the Respiratory Institute.

Once you go home, you will need to be very closely monitored by the lung transplant team for the first few months.

Initially, the follow-up appointments in the clinic will be once weekly. You will have a chest X-ray, breathing test, and blood work done before seeing the transplant pulmonologist and transplant coordinator at every appointment. Occasionally, you may have to come back a second time that same week for a repeat set of blood work.

As time goes on, these appointments will become less frequent, depending on how you progress in your healing process. Following the first three months after the transplant, we will be seeing you once per month for the rest of the first year. After that, we will see you once every three months.



### Monitoring for Rejection

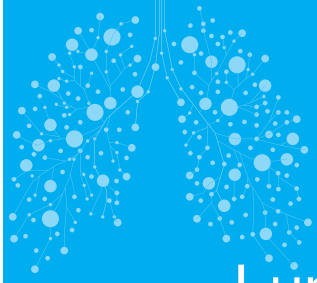
Your immune system always protects your body against things it doesn't recognize. Just like a virus or bacteria, a transplanted organ is considered "foreign" by your body. This means that your immune system will try to attack and destroy the organ. In order to prevent this from happening, you will be given immunosuppressive (anti-rejection) medications. These medications will weaken your immune system so that it cannot fight your new lung(s) and reject them. You will need to take these medications every day for the rest of your life.

Most of the time when rejection happens, you will have no symptoms in the early stages. This can make it difficult to diagnose rejection. Therefore, we need to be proactive and look for rejection routinely so that we find it early. If caught early, an episode of rejection can usually be treated successfully. If an episode of rejection is left untreated, it can cause permanent damage to the transplanted lung(s).

We check for rejection by doing a lung biopsy. This is done through a bronchoscopy. The bronchoscopy is done as a same-day outpatient procedure. You will be put to sleep for this procedure. You will need to make sure you have someone who can drive you to and from this appointment. These biopsies will be done every two weeks for the first 10-12 weeks after transplant. Then they will be done every three months for the first year. They may be done more frequently if your doctor has any suspicion that your body may be rejecting your lung(s).

**Rejection** usually has no symptoms at first. We actively look for it by doing bronchoscopies with biopsies. If caught early, it can be treated successfully.





# Lung Transplant Complications

Complications can happen during any part of the transplant process, even years after transplant. Below is a list of some of the possible complications of lung transplant, which may result in death or disability.

## 1. **Surgical Complications**—include, but are not limited to:

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- Bleeding during or after surgery
- Infection during or after surgery
- Abnormal heart rhythms (arrhythmias)
- Hypotension (low blood pressure)
- Kidney failure which may require the use of dialysis
- Use of ECMO (extracorporeal membrane oxygenation)—a machine that helps to oxygenate the blood while the lungs are not functioning properly
- Pericardial tamponade—a collection of fluid or blood around the heart, preventing it from beating properly
- Respiratory insufficiency—inability to breathe without the assistance of a ventilator machine, which could lead to a tracheostomy. This can happen for various reasons, including:
  - **Primary graft dysfunction**—a complication that can happen in the first 72 hours after transplant in which the donor lung(s) don't function properly
  - **Hyperacute rejection**—when the recipient's body rejects the donor lung(s) immediately, usually due to unrecognized antibodies. This is an extremely rare complication.
  - **Infection**

Complications can happen during any part of the transplant process, even years after transplant. It is very important that you always report any new symptoms immediately.





## Lung Transplant Complications

### 2. Medical Complications – include, but are not limited to:

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**Infection** – this can happen immediately after transplant or many years after the transplant.

- Infections include bacterial infections (such as pneumonia), viral infections (such as the flu, COVID-19, shingles), and fungal infections. They can happen in any part of the body, not only in the transplanted lungs. You will always be at an increased risk of catching infections after a transplant due to the anti-rejection medications you will have to take which weaken your immune system.

**Rejection** – when your immune system recognizes the donor's lung and attempts to fight it (as explained above). There are two major types of rejection:

**Acute rejection** – can happen at any time, immediately after transplant or many years later

- Can be caused by multiple factors, including but not limited to: taking anti-rejection medications incorrectly or irregularly; infections; reflux disease
- May cause symptoms such as fatigue, low-grade fever, cough, or shortness of breath, but often has no symptoms. Routine lung biopsies are done to check for rejection that may be present without symptoms.
- Develops over a short time and can usually be successfully treated with medications as long as it is recognized and treated promptly

**Chronic rejection** – Bronchiolitis obliterans syndrome (BOS)

- Narrowing of the airways in the lungs which eventually causes shortness of breath and coughing
- Usually diagnosed sometime after the first six months post-transplant
- Worsens over time, and sometimes patients may need oxygen again
- Can be caused by multiple factors, including but not limited to: repeated episodes of acute rejection; infections; reflux disease; no known cause
- There is no treatment to stop or reverse BOS, but there are treatments used to try to slow down its progression
- Eventually BOS progresses to a severe state, at which point the patient may be evaluated for a second transplant if appropriate. If not, there are no further options for treatment at that point.
- BOS is the leading cause of death in lung transplant recipients

### 2. Medical Complications – continued

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**Kidney failure** – when the kidneys are not functioning properly; may lead to the need for dialysis.

**Medication-related side effects** – can be short-term or long-term

**Short-term medication side effects:**

- Nausea/vomiting
- Loss of appetite and unintended weight loss
- Tremors/shakiness
- Mild to moderate hair loss

**Long-term medication side effects:**

- Onset or worsening of hypertension (high blood pressure)
- Increased blood sugars which may lead to the development or worsening of diabetes
- Increased risk of catching infections
- Kidney dysfunction
- Osteoporosis (thinning of the bones)
- Increased risk for developing cancer within the transplanted lung or in any other part of the body, especially skin cancer

### 3. Emotional/Psychosocial Complications

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Lung transplant surgery is life changing, not just for you but also for your family members.

Adjusting to life after transplant can be challenging, as you usually have to alter your daily routines and habits to accommodate for your care.

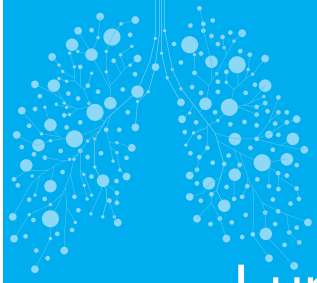
Lung disease and transplant can cause a significant financial strain.

The psychological impact of end-stage lung disease and transplant can be manifested in the following ways:

- Depression
- Anxiety
- Post-traumatic stress disorder
- Sleep disorders
- Feelings of guilt (these could be towards the donor/donor's family as well as towards your own caregivers)

Resources provided to you to help you cope emotionally include support groups, transplant psychiatrists, and transplant social workers. You should always inform your transplant pulmonologist and/or transplant coordinator if you are experiencing any of the above and help will be provided.





# Lung Transplant Medications

No matter how much time goes by after your transplant, your body will never recognize your new lung(s) as your own. Your body will always try to fight them.

For that reason, you will take immunosuppressive (anti-rejection) medications for life. If you do not take your medications regularly, or if you take them incorrectly, your body will reject your lung(s).

Patients are usually put on three different anti-rejection medications. These medications are extremely important to maintaining the health of your new lung(s). Over time your transplant team may reduce the dose and number of medications.

## Anti-Rejection Medications

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- Tacrolimus (Prograf) or Cyclosporine (Neoral)
- Mycophenolate mofetil (Cellcept) or Mycophenolic acid (Myfortic)
- Prednisone

All of the above medications are necessary to prevent rejection, but will make you more susceptible to infection. Therefore, you will also be started on antibiotics to prevent viral, bacterial, and fungal infections.

**You will take immunosuppressive (anti-rejection) medications for life.** If you do not take your medications regularly, or if you take them incorrectly, your body will reject your lung(s).





**You will receive a written list of your medications,**  
which you should carry with you at all times.



### **Infection Prevention Medications**

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- Bactrim (SMX/TXP) or Mepron (Atovaquone)
- Valcyte (Valganciclovir)/Acyclovir
- Voriconazole (V-Fend) or Posaconazole (Noxafil)

You will also be placed on medications to help reduce some of the side effects of the anti-rejection medications.

### **Maintenance Medications**

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- Blood pressure medication
- Diuretics
- Cholesterol medications
- Medications to lower your blood sugar (may be insulin)
- Antacids (proton pump inhibitors)
- Multivitamins
- Minerals such as calcium, magnesium, etc.
- Stool softeners

Before you are discharged, you will receive in-depth education about all of the medications you will be taking. You will also receive written instructions about which medications you must take, including the dose and the frequency. We recommend that you carry a copy of this list with you at all times, and bring it to every transplant follow-up appointment.

### Information About Medications

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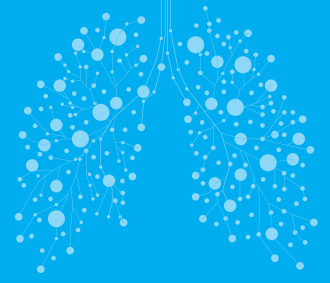
You are responsible for taking the medications that have been prescribed for you. It is important that you have a good understanding of the following:

- The name and purpose of each medication
- Dose (milligrams) of each medication
- When to take each medication
- How to take each medication
- How long to continue taking each medication
- Main side effects of each medication
- What to do if you forget to take a dose
- When to order more medication so you do not run out
- How to get your medication
- What you should avoid (such as drinking alcohol) while you are taking medications

Reminder: Never stop taking your medications or change the dosage without your Transplant team's approval, even if another doctor told you to do so. Never take any other types of medications or supplements (including herbal supplements) without discussing it with your Transplant team.



Please refer to *“What to Expect After Lung Transplant”* for information regarding how to take care of yourself at home, lifestyle changes, and long term complications of lung-transplant.



## Additional Resources



The following organizations and associated web sites provide general information, answers to frequently asked questions, and patient testimonials about lung transplantation:

<https://optn.transplant.hrsa.gov> – The Organ Procurement and Transplantation Network (OPTN) is the unified transplant network established by the United States Congress under the National Organ Transplant Act (NOTA) of 1984.

[unos.org](https://unos.org) – United Network for Organ Sharing (UNOS) is the organization contracted to administer the OPTN. Its main purpose is to help transplant candidates, recipients, and their families understand organ allocation practices and transplantation data.

[liveonny.org](https://liveonny.org) – LiveOnNy is the non-profit, federally certified organ procurement organization (OPO) for the state of New York. An OPO is a program that acquires and coordinates placement of donated organs for patients on national transplant waiting lists.

MOUNT SINAI - NATIONAL JEWISH HEALTH

# Respiratory Institute

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**Respiratory Institute**

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