

Lung Transplant Evaluation

Welcome to the Lung Transplant Program at Northwestern Memorial Hospital. A lung transplant can be a lifesaving operation. This brochure describes what you need to know about a lung transplant, including:

- › The evaluation process
- › What to expect before and after surgery

If you have any questions, please talk with your physician or nurse.

You should understand this information so that you can make informed decisions about your health.

You may have other treatment options. You have the right to know what those are. You can choose a treatment other than transplant, or you can choose no treatment at all. You have the right to change your mind at any time.

Getting started

Your transplant team is here to help you with your decisions and your care. We are dedicated to giving you excellent care before, during and after your lung transplant. Your transplant team is a group of healthcare professionals who have special training and experience in transplantation. The team includes:

- › Transplant surgeons and physicians
- › Transplant nurse coordinators
- › Nurse practitioners
- › Staff nurses
- › Registered dietitians
- › Licensed social workers
- › Licensed clinical social workers
- › Transplant assistants
- › Physical therapists
- › Occupational therapists
- › Pharmacists

If you choose to have an organ transplant at Northwestern Memorial Hospital, we will give you detailed information about what to expect throughout the process. You will also meet with members of the transplant team.

We are happy to answer your questions at any time. Please contact us at 312.695.5864 (TTY: 711).

A transplant surgeon and physician are on call for you every day for any regular or urgent needs.

Transplant Physician and Surgeon On Call

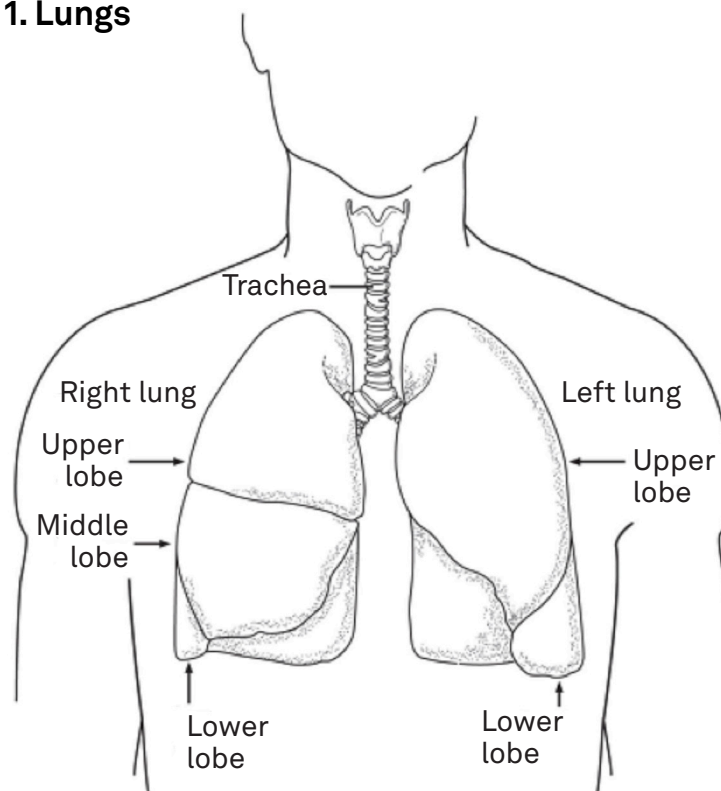
On call means we are available to you 24 hours a day, 7 days a week.

Contact us at **312.695.5864** (TTY: 711).

How the lungs work

You have 2 lungs in your chest. Each lung is divided into sections called **lobes** (Figure 1).

Figure 1. Lungs



Your lungs have 2 main functions:

- › When you breathe in, they bring oxygen to your blood.
- › When you breathe out, they release carbon dioxide, a waste product made by the body.

When your lungs do not work well

Every part of the body needs oxygen. Without it, the body cannot function.

One of the 1st signs that someone may have lung problems is that they have shortness of breath.

There are many conditions that affect the lungs and prevent them from working as they should. A few examples are:

- › Pulmonary fibrosis
- › Pulmonary hypertension
- › Cystic fibrosis
- › Bronchiectasis
- › Emphysema
- › Sarcoidosis

At your 1st clinic appointment and at all of your visits, we will talk with you about your specific disease.

If your lungs no longer work as they should, you may not be able to do the things you want to do. A lung transplant may be a treatment option for you.

During a lung transplant, the surgical team removes 1 or both of your lungs and gives you 1 or 2 healthy lungs. This may help you to have a better quality of life.

Types of lung transplants

Your physician and transplant surgeon will recommend the type of transplant that is best for you. The decision is based on:

- › Your medical condition
- › Your overall health
- › Your pre-transplant evaluation
- › The availability of donor lungs

Transplant options include:

- › Single lung
- › Double (bilateral) lung

Those who are eligible for a lung transplant

A lung transplant may be an option for you if you had any of the following:

- › Acute (sudden) onset of lung damage that will not get better
- › Lung disease for a long time
- › Lung disease that will lead to death or hurt your quality of life
- › Treatments that did not work in the past and are not expected to work in the future.

Your transplant team will talk with you about your condition and eligibility.

Those who are not eligible for a lung transplant

A lung transplant is not an option for a person who has:


- › A substance use disorder, including current tobacco use or tobacco use within the past 6 months
- › Uncontrollable infection that will not go away with a transplant
- › Failure of other organs that will not get better with a transplant
- › Human immunodeficiency virus (HIV) infection with acquired immunodeficiency syndrome (AIDS)
- › Permanent brain damage or brain disease
- › Severe, untreatable heart disease

Alternative treatments

A lung transplant may not be the best option for every patient. You and your family may decide that you do not want a lung transplant. At first, your care team may try other medical or surgical options that will help your lung function. You can also choose not to have any treatment. We will support you, no matter what you decide.

Lung transplant surgery

You will need 2 caregivers who can provide care to you 24 hours a day for the 1st year after your transplant. Once we put you on the waitlist, you can get a call that a lung is available at any time. We must be able to reach you 24 hours a day, 7 days a week. You must be able to come to Northwestern Memorial Hospital right away or as directed, within a few hours of the call.



Once you are in the hospital, the care team will get you ready for surgery. Most often, your family can be with you at this time. (Visitor policies can change, such as during a community outbreak of an infectious disease. See nm.org/visitors for current policies.)

Your surgery can take 4 to 12 hours depending on whether you are getting 1 lung or 2 lungs. After surgery, you will go to the Cardiothoracic Intensive Care Unit for 1 to 3 days. You will then transfer to a surgical floor for the rest of your stay. All members of the transplant team will see you while you are in the hospital.

You will begin to learn about your new medications. These medications will help protect your new lungs. Your body will not recognize the donor lungs. That means your immune system will want to attack them. To help your body accept the new organs and prevent rejection, you will take medications to lower your body's normal immune response. These medications are called anti-rejection medications, or immunosuppressants.

You must be aware:


- › The donated lungs will always keep their original identity.
- › That means that you will need to take anti-rejection medications for the rest of your life.
- › If you stop taking these medications, your body will always reject your new lungs.
- › This will lead to organ failure.

Lung transplant results

In general, for those who have had a lung transplant, the transplanted lung still functions 1 year after transplant surgery. You can go to srtr.org or optn.org to see results from Northwestern Memorial Hospital and other transplant centers in the United States. This federal database is updated every 6 months.

Risks of having a lung transplant

As you will learn, the transplant process includes a complete evaluation. This involves a number of blood tests and exams. The transplant team will review all the screening and test results.



If they recommend a transplant for you, it is because they believe you:

- › Are likely to do well
- › Have a good chance for a better quality of life afterwards

However, a lung transplant is major surgery. It carries risk of complications or even death. You need to know about these possibilities.

Possible complications

These early complications can happen in the first 30 days after lung transplant surgery:

- › Low oxygen levels in the body
- › Bleeding (that requires surgery)
- › Blood clots
- › Acute rejection (usually within the first year)
- › Infection

Later complications might include:


- › Chronic rejection
- › Infection
- › Recurrence of your disease
- › Kidney failure and other side effects of anti-rejection medications
- › Cancer
- › Diabetes
- › High blood pressure

Also, any time human tissue, blood or organs are transplanted from one human (living or deceased) to another, there is a risk of transferring disease or infection. We do everything we can to prevent the transfer of infection or disease. But, there is always some risk from the donor.

Your feelings after surgery

Most patients will have a better quality of life and manage side effects with success. But you may have **psychosocial problems** after transplant. You may:

- › Feel depressed
- › Worry about your health
- › Feel anxious and even guilty about depending on others for help



A strong support system at home is important. Your loved ones can help you understand what is happening and what your responsibilities are. Share your feelings with them. They can help you get any treatment you might need. Your transplant team members are also good resources.

Benefits of a lung transplant

With a new lung, you should have a better quality of life. Most people who had a lung transplant report that after 6 to 9 months, they are able to go back to normal activities of daily living such as housework, cooking and driving. They have the energy to enjoy pastimes and some sports activities. Many people are also able to work outside of the home.

Transplant evaluation process

If you decide to have a lung transplant, you will need to have an evaluation first.

Evaluation clinic

At your 1st clinic appointment, you will begin learning about lung transplant and whether it is an option for you. You may have some testing on this 1st visit, including blood tests and a CT scan of your chest.

The transplant pulmonologist is a physician who specializes in lung disease and lung transplants. This physician will manage your lung disease and often prescribe medications. They will work closely with your primary care physician and with any other specialized physicians you see.

If your care team believes you are eligible and would benefit from a lung transplant, you will meet one of the lung transplant surgeons. They will explain more about the transplant process and the surgery, and answer your questions. The transplant surgeon and the pulmonologist, a physician who specializes in lung care, will make most of the decisions about the tests that you may need for your transplant evaluation.

Consults

- › You will meet with an **infectious disease physician** early in the evaluation process. During this meeting, they will talk with you about:
 - Your history of infections
 - Ways to prevent infection after your transplant

- › A **dermatologist** will do a head-to-toe skin exam during your visit. They will check for any skin cancer or other skin problems, such as rashes. It is important to check for cancer and skin infection, and treat problem areas before your transplant.
- › You will have to see your **dentist** and have your teeth cleaned and checked. Your dentist will need to take care of infections or certain other problems before the transplant.


Other members of the transplant team

- › The **transplant nurse coordinators and transplant assistants** will be your main contacts during the evaluation and until the time of your transplant. They will schedule any tests or procedures you need at Northwestern Memorial Hospital. They will also talk with you and your family about the transplant process and answer questions you may have.
- › You will meet with a **dietitian** if you have specific dietary problems. They will also see you if you are overweight or underweight. Good nutrition is very important to help manage your lung disease, prevent complications and promote good health.
- › The **patient financial liaison** will look into your specific insurance benefits and coverage to make sure a lung transplant is covered. If you have questions, have bills that you do not understand or need financial help, contact the Northwestern Medicine Finance and Billing Office. If your insurance policy requires referral forms, be sure to bring them with you on the days of your visits or procedures.
- › The **social workers** offer support and counseling to you and your family.

Your evaluation plan

To become a candidate for a lung transplant, you will need a complete medical evaluation. The evaluation tests are done to:

- › Confirm that your lung(s) is/are the main cause of your illness
- › Identify the extent of your lung disease
- › Evaluate the complications of your lung disease
- › Make sure any problems you have would not be made worse by a transplant



After you meet with the physician, the transplant team will decide on a plan for your transplant evaluation. Based on your health status and needs, they will order various blood work and other tests. Depending on your test results, the plan may change.

We will send a letter to your primary care physician. We will tell the physician that you have met with us and give them a list of the tests you will need. We prefer that you have your testing done at Northwestern Memorial Hospital. But, you can do some tests with your primary care physician or at a hospital closer to your home. We will discuss this once you start the evaluation process.

Blood tests

All evaluations include 5 main types of blood tests. (You will have these same tests on an ongoing basis to monitor your health status.)

- › Complete blood counts (CBC) with platelets
- › Blood chemistry
- › Prothrombin time (PT/INR)
- › Infection status (viruses)
- › Possible antibodies that you have developed


Blood type

All transplant candidates are put on the waitlist according to their blood type (A, B, O or AB). The Blood Bank will check and confirm your blood type. They will do this at least 2 times to prevent any chance of error. Most of the time:

- › Group O can accept only blood group O
- › Group A can accept blood group A or O
- › Group B can accept blood group B or O
- › Group AB can accept blood groups A, B, O and AB

Diagnostic tests and procedures

Based on your diagnosis and the results of your initial evaluation, the care team may order other testing.



Special tests will focus on your heart, lungs and kidney function. The transplant nurse coordinators will help you arrange for any tests or procedures that will be done at Northwestern Memorial Hospital. If your insurance plan allows it, you may be able to do some of the exams near your home. You must have all tests at an approved facility.

Before each test, the transplant nurse coordinator will explain the test in detail, including what to expect and any special instructions you need to follow.

Insurance/financial support

Coverage for lung transplant varies with each insurance company. The physician will write to your insurance carrier on your behalf to request approval for the transplant.


Transplant list

After your evaluation, the transplant team will decide if you are a candidate for transplant. If you and the transplant team decide to go ahead with a transplant, we will put you on the lung transplant waitlist. You will get a letter to confirm this.

If your insurance changes or will change, please tell the patient financial liaison as soon as possible. They will check right away to make sure the new insurance will cover your transplant.

You need to understand your insurance benefits and how you will pay for all of your care before you have transplant surgery:

- › You **must** have coverage or financial resources for post-transplant care, including your medications. Depending on your policy, health problems related to the transplant may or may not be covered.
- › As with most chronic illnesses, you may not be able to get medical disability or life insurance after the transplant.
- › Because the donated lung always retains its original identity, you will need to take anti-rejection medications **for the rest of your life**. If you do not take these medications, it **will always** lead to rejection and failure of your new lung(s). But these anti-rejection medications are expensive. You need to know before the transplant how you will pay for them **after** the transplant. For this reason, it is our policy not to put patients on the waitlist until they have a plan for paying for post-transplant medications.



Please talk with the social worker or patient financial liaison before surgery if you have any concerns or questions about money or insurance. They can help you understand your policy. They can also help you look for other financial resources, such as programs to help pay for the medications, supplemental insurance policies or fundraising. They can help make sure you can always get the anti-rejection medications you need.

You can contact the patient financial liaison or social worker at **312.695.5864**.

Opportunities for your feedback

At Northwestern Memorial Hospital, we are committed to putting patients first in everything we do. This means that we want every patient to receive the best care and services possible.

You can help us meet this goal. Let us know how you feel about your entire transplant experience. Is there a team member who provided exceptional care? Is there an area where we fell short? We pay a lot of attention to your feedback as we work to provide the very best care possible.

There are several ways for you to give us your feedback:

- › Complete one of the patient comment cards in the waiting area in the outpatient clinic.
- › Complete the patient satisfaction survey you get after your hospital stay. We welcome your comments and look forward to receiving your survey.
- › Share your feedback by calling the Patient Relations Department at **312.926.3112** (TTY: 711).
- › Call the Transplant Office at **312.695.5864** (TTY: 711) and ask to speak with the lung transplant manager.

If you have concerns about your care, you can also contact the United Network for Organ Sharing (UNOS) grievance line at **888.894.6361**.

Confidentiality

All patient information is private. Anything that you discuss with your care team will remain confidential, subject only to authorized release.