

If you have any questions, please ask any member of the transplant team.

Lung Transplant Evaluation

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

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

It is important to understand this information so that you can make informed decisions about your health that are best for you. This brochure, and discussions with your care team, will help provide you with information about lung transplant.

Know that there may be other treatment choices for you. 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.

The entire multidisciplinary transplant team (referred to as the “transplant team”) is here to help you with your decisions and your care. We are dedicated to providing the best care possible for you before 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
- Clinical coordinators
- Patient financial liaisons
- Physical therapists
- Occupational therapists
- Pharmacists

If you decide to pursue an organ transplant at Northwestern Memorial Hospital, you will receive detailed information about what to expect before and after surgery. You will also meet privately with members of the transplant team.

During and after your hospital stay, the transplant team welcomes any questions you may have. Please contact us at 312.695.5864.

A transplant surgeon and physician are “on call” for you every day for any daily or urgent needs. If this changes for any reason, we will let you know right away.

Transplant Physician and Surgeon On Call

On call means we are available to you:

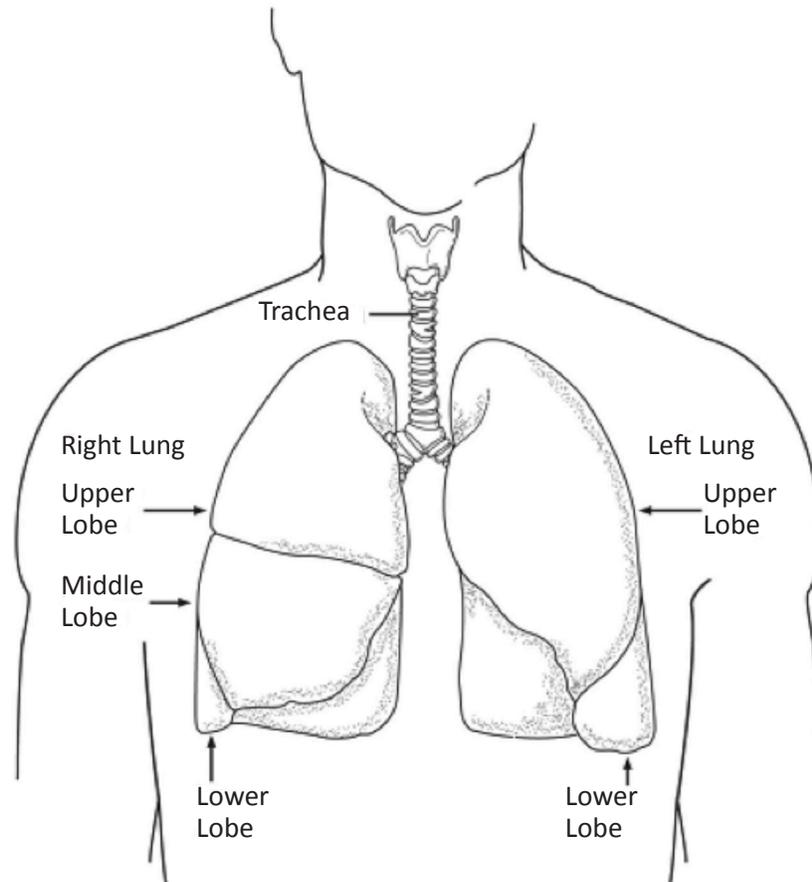
- 365 days a year
- 24 hours a day
- 7 days a week

We are no more than an hour away.

The lungs and lung transplant

Your 2 lungs—right and left—are found in the chest. Each lung is divided into sections called lobes. The lungs perform 2 main functions:

- Bring in oxygen with each breath you take.
- As you exhale, they give off or release carbon dioxide, a waste product produced by the body.



Each and every part of the body needs oxygen. Without it, the body cannot function.

One of the first signs that there may be a problem with your lungs might be “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
- Cystic fibrosis
- Emphysema
- Pulmonary hypertension
- Bronchiectasis
- Sarcoidosis

We will talk about your specific disease at your first clinic appointment and throughout your time with us.

When your lungs no longer work as they should and it affects your ability to perform daily activities, then a lung transplant may be an option.

Having a lung transplant may help restore your lung function and allow 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 organs

Transplant options include:

- Single lung
- Double (bilateral) lung

Indications for lung transplant

You will be considered for a lung transplant if you have had any of the following:

- Acute (sudden) onset of irreversible lung damage
- 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 to you about your specific diagnosis.

Contraindications for lung transplantation

A lung transplant is not an option for patients who have:

- Alcohol or drug abuse problems, including current tobacco use or tobacco use within the past 6 months
- Uncontrollable infection that will not go away with a transplant
- Metastatic cancer
- Failure of other organs that will not get better with a transplant
- Uncontrolled HIV infection with AIDS despite treatment
- Irreversible brain damage or brain disease
- Severe, untreatable heart disease

Lung transplant surgery

You will need to identify 2 caregivers who can provide care to you 24 hours a day for 1 year after your transplant. Once you are placed on the wait list, you can get an organ at any time. We must be able to reach you 24 hours a day, 7 days a week. You must be ready to come to Northwestern Memorial Hospital right away or, as directed, within a few hours.

Once you are in the hospital, you will be prepared for surgery. Your family can be with you at this time.

The lung transplant surgery can take 4 to 12 hours depending on whether you are getting a single lung or 2 lungs. After surgery, you will go to the Cardiothoracic Intensive Care Unit (CTICU) for 1 to 3 days. You will then be transferred 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 medicines. These medicines lower your body's normal immune response, help your body accept the new organs and prevent rejection. It is important to know that the donated lungs will always retain their original identity. You will need to take anti-rejection medicines **for the rest of your life**. Failure to do so **will always** lead to rejection and organ failure.

Results of lung transplantation

In general, 80 percent of transplanted lungs still “work” 1 year after the transplant. You can go to www.srtr.org or www.optn.org to view results from Northwestern Memorial Hospital and transplant centers in the United States. This federal database is updated every 6 months.

Risks of lung transplantation

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. There may be risks, including complications or even death. You need to know about these as well.

Potential complications

Complications of lung transplantation can occur early (in the first 30 days) or later (after 30 days).

Early complications might include:

- Low oxygen levels in the body
- Bleeding (that requires surgery)
- Blood clots
- Rejection (usually in first 3 months)
- Infection

Late complications might include:

- Rejection
- Infection (different types)
- Recurrent disease
- Kidney failure and other side effects of anti-rejection medications

- Cancer
- Diabetes
- High blood pressure

There are potential **psychosocial problems** after your transplant. While most patients will have a better quality of life and manage side effects with success, it can be a difficult course. Some patients feel depressed and might worry about their health. You may feel anxious and even guilty about depending on others for help. It is important to have support systems at home – people to help you understand what is happening and what your responsibilities are, to share what you are feeling, and to get any treatment you might need. Your transplant team members are good resources for help.

Risks from the donor

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.

Benefits of lung transplant

With a new lung, you should have a better quality of life. Most patients report that after 3 to 6 months, they are able to resume normal activities of daily living such as housework, cooking and driving. They have the energy to enjoy pastimes and some sports activities. Many patients are also able to work outside of the home.

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. There may be medical or surgical options that will help your lung function. These are often tried first. You can also choose not to have any treatment. We will support you, no matter what you decide.

Transplant evaluation process

Medical evaluation

At your first clinic appointment, you will begin learning about lung transplant and whether it is an option for you. We may start some testing on this first visit, including drawing blood and getting a CT scan of your chest.

Evaluation clinic

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

You will also meet one of the lung transplant surgeons once you are considered a good candidate for lung transplantation. He or she will explain more about the transplant process and the surgery, and answer your questions. The transplant surgeon and the pulmonologist will make most of the decisions about the tests that might be needed for your transplant evaluation.

Consults

Infectious Disease – You will meet with an infectious disease physician early in the evaluation process. During this meeting, we will talk about:

- Your history of infections
- Ways to prevent infection after your transplant

Dermatology – A dermatologist will do a head-to-toe skin exam during your visit. This is to 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.

Dental visit – You will have to see your dentist and have your teeth cleaned and checked. Infections or certain other problems will have to be taken care of before the transplant.

Other members of the transplant team

The *transplant nurse coordinators* and *patient liaisons* will be your main contacts during the evaluation and until the time of your transplant. They will schedule any tests or procedures you will need at Northwestern Memorial Hospital. They will also talk to you and your family about the transplant process and answer questions you may have.

You will see the *dietitian* if you have specific dietary problems, or are overweight or too thin. Good nutrition is very important to help manage your lung disease, prevent complications and promote good health.

The *transplant financial liaison* and *social workers* will help you with your insurance. The financial liaison will explain your specific benefits and coverage. He or she will know if you need to apply for more insurance to cover the costs of the evaluation, surgery, medications and post-transplant care. If you have questions, have bills that you do not understand or need help, the transplant financial liaison can assist. 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* are also there to offer support and counseling to you and your family.

As part of our transplant protocol, you will also meet with the *transplant psychiatrist*. This will happen at a follow-up appointment. You can meet with the psychiatrist alone or with your family member(s).

The plan

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

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

- Confirm that your lung is 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 do have would not be made worse by a transplant

Blood tests

All evaluations include 5 main types of blood tests. (These same tests are also done 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 placed on the wait list according to blood type (A, B, O or AB). Your blood type will be checked and confirmed by the Blood Bank. All patients must have ABO typing done 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, other testing may be ordered.

Special tests will focus on your heart, lungs and kidney function. The transplant clinical coordinators will help you arrange for any tests or procedures that will be done at Northwestern Memorial Hospital. If insurance coverage permits, some of the exams may be able to be done near your home. All tests must be done at approved facilities.

Before each test, the transplant coordinator you 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. For this reason we have a transplant financial liaison to help you learn about the benefits your insurance plan offers. The physician will write to your insurance provider on your behalf to request prior approval for the transplant.

Transplant list

After your evaluation is completed and if the transplant team decides that you are a candidate for transplant, you can be placed on the lung transplant waiting list. You will receive a letter verifying this.

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

It is important to understand your insurance benefits. You **must** have coverage or financial resources for post-transplant care, including your medicines. 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. The social worker or transplant financial liaison can help you understand your policy and help you look for other financial resources, such as programs to help pay for the medicines, supplemental insurance policies or fundraising.

Because the donated lung always retains its original identity, you will need to take anti-rejection medicines **for the rest of your life**. If you do not take these medicines it **will always** lead to rejection and failure of your new lung(s). But these anti-rejection medicines are expensive. You need to know **before** the transplant how you will pay for them **after** the transplant. For this reason, it is the transplant center's policy not to put patients on the waiting list until there is a plan in place for paying for post-transplant medicines. Please talk to the social worker or patient financial liaison before surgery if you have any concerns or questions about money or insurance.

Your transplant social worker can work with you on many transplant issues, including how to make sure you can always get the needed anti-rejection medicines.

You can reach the transplant financial liaison or social worker at 312.695.5864.

Opportunities for your feedback

At Northwestern Memorial Hospital, we are committed to putting *Patients First*. This means that we want every patient to receive the best care and services possible.

You can help us achieve this by letting 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:

- You can complete one of the patient comment cards that are kept in the waiting area in our outpatient clinic.
- A patient satisfaction survey will be mailed to your home after your hospital stay. We welcome your comments and look forward to receiving your survey.
- You can always share your feedback by calling the Patient Relations Department at 312.926.3112.

- You can call any member of the organ transplantation leadership team:
 - Lead transplant nurse coordinator: 312.695.6626
 - Director: 312.695.5864

If needed, you can contact the United Network for Organ Sharing (UNOS) grievance line at 888.894.6361.

Confidentiality

As with all patient information, please know that all of your medical information is private. Anything that you discuss will remain confidential, subject only to authorized release.

Northwestern Medicine – Health Information Resources

For more information, contact Northwestern Memorial Hospital’s Alberto Culver Health Learning Center (HLC) at hlc@nm.org, or by calling 312.926.5465. Health information professionals can help you find the information you need and provide you with personal support at no charge.

For more information about Northwestern Medicine, please visit our website at nm.org.

Para asistencia en español, por favor llamar al Departamento de Representantes para Pacientes al 312.926.3112.

The entities that come together as Northwestern Medicine are committed to representing the communities we serve, fostering a culture of inclusion, delivering culturally competent care, providing access to treatment and programs in a nondiscriminatory manner and eliminating healthcare disparities. For questions, please call either Northwestern Memorial Hospital’s Patient Representatives Department at 312.926.3112, TDD/TTY 312.926.6363 or the Northwestern Medical Group Patient Representatives Department at 312.695.1100, TDD/TTY 312.926.6363.

Developed by: NMH Lung Transplant Team