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. As always, you have the right to change your mind at any time.

The entire multidisciplinary transplant team (referred to as “transplant team”) is here to help you with both your decisions and your care. We will provide the best care possible for you before and after your lung transplant. Your transplant team is a group of health care professionals who have special training and experience in transplantation. The team includes:

- Transplant Surgeons/Doctors.
- Transplant Nurse Coordinators.
- Nurse Practitioners.
- Staff Nurses.
- Registered Dietitians.
- Licensed Social Workers (LSWs).
- Licensed Clinical Social Workers (LCSWs).
- 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 need to name two caregivers who will be able to take turns caring for you at home after your surgery. One caregiver should be with you 24 hours a day, 7 days a week for the first 8 weeks after you are discharged. The caregivers will help you with:

- Daily care such as bathing, dressing, and going to the bathroom.
- Taking your medications.
- Meals.
- Taking you to your to appointments.
After 8 weeks, the caregivers need to be available for continued support for 1 year. They will help you with:

- Daily care as needed.
- Emotional support.
- Getting to doctors’ appointments and clinic for blood work.

You will also meet privately with members of the transplant team. They will review this brochure with you and ask you to sign a form stating that:

- You have read the information.
- You have had a chance to ask questions about the lung transplant evaluation and surgery.

*To arrange for TDD/TTY, auxiliary aids and foreign language interpretation services, call the Patient Representative Department at 312-926-3112, TDD number 312-926-6363. Issues related to the Rehabilitation Act of 1973 should be directed to the director of Employee Relations or designee at 312-926-7297.

Para asistencia en español, por favor llamar a el departamento de representantes para pacientes al 312-926-3112.

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 doctor 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.

**Opportunities for Your Feedback**

At Northwestern Memorial Hospital, our belief and commitment is *Patients First*. This means that we want every patient to receive the best care and service.

There will be a certain team member who goes above and beyond your expectations. Sometimes, as hard as we try, we may fall short of our goal. In any case, good or bad, we want to hear your comments. In fact, we appreciate hearing from you about your entire transplant experience. 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:

- Please feel free to take 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 Representative Department at 312-926-3112.

---

**Transplant Physician and Surgeon On Call**

*On Call* means *Available to you…*

- 365 days a year.
- 24 hours a day.
- 7 days a week.
- No more than an hour away.
Feel free to 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: 1-888-894-6361.

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.

Oxygen is needed by each and every part of the body. 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.
- Pulmonary Hypertension.
- Cystic Fibrosis.
- Bronchiectasis.
- Emphysema.
- 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 doctor 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 lung (also called Bilateral Lung).

**Indications for Lung Transplant**
You will be considered for a lung transplant if you have:

- An acute (sudden) onset of irreversible lung damage.
- Had lung disease for a long time.
- Lung disease that will lead to death or hurt your quality of life.
- Had treatments that did not work (and others are not expected to work).

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

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, in 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 Surgical Intensive Care Unit for 1 to 3 days. You will then be transferred to a surgical floor for the rest of your stay. Most patients leave the hospital after 5 to 7 days.

During your hospital stay:

- All members of the transplant team will visit.
- You will begin to learn about your new medicines.

These medicines lower your body’s normal immune response and help your body accept the new organs and prevent rejection. 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

The Scientific Registry of Transplant Recipients (SRTR) transplant center keeps records of all transplants done in the United States. Your doctor will explain the lung transplant results with you. In general, 80% of transplanted lungs still “work” 1 year after the transplant. You can go to the federal website www.srtr.org or www.optn.org to view results from transplant centers in the US. This 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 can 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.

If a donor has tested negative for HIV, Hepatitis B, and/or Hepatitis C, they may still be at risk of being infected if they meet certain criteria. A donor is a high-risk donor if they:

- Have had sex with an infected person.
- Are an IV drug abuser.
- Have received some types of blood transfusions.
- Have been exposed to infected blood or breast milk.

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–housework, cooking, driving. They have the energy to enjoy pastimes and some sport activities. Many patient work outside of the home also.
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 your decision, no matter what you decide.

Transplant Evaluation Process

Medical Evaluation
Your first clinic appointment (today) starts the process of learning about lung transplant and seeing if 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 medical doctor who specializes in lung disease and lung transplants. This doctor will manage your lung disease and will:
- Often prescribe medicines.
- Work closely with your primary care doctor 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, 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 process.

Consults
Psychosocial evaluation – You will meet with the social worker and psychologist. A psychosocial evaluation will find out if you and your family can manage the stresses (emotional, physical, and financial) with having a lung transplant. It is important to have a support system at home to help with issues, such as:
- Depression.
- Stress.
- Feelings of guilt and anxiety about depending on others for help.

Infectious Disease – You will meet with an infectious disease doctor 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.
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. There is a Transplant Nurse Coordinator on call, 24 hours a day, 7 days a week, to help deal with any lung-related emergencies.

The transplant nurse practitioner works closely with others in the transplant team to care for you.

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(s) to cover the costs of the evaluation, surgery, medications, post-transplant care, etc. 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 doctor, 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 doctor. We tell the doctor 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 doctor 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.
- Chemistry panel.
- Prothrombin time (PT/INR).
- Infection status (CMV/EBV/Hep A/B/C/HSV/Varicella).
- Possible antibodies that you have developed (HLA/PSA).

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, your lungs, and your 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.

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.

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 doctor 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 for 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 (e.g., programs to help pay for the medicines, supplemental insurance policies, fundraising, etc.).

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 the costs of these anti-rejection medicines are high. You need to know **before** the transplant how to 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 your 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.

**Medicare Approval**
If a transplant is not done in a Medicare-approved transplant center, it could affect your ability to have your anti-rejection drugs paid for under Medicare Part B.

**Ongoing Education**
Once you have agreed to an evaluation for a lung transplant, you must attend an information/education session. This may be a one-on-one meeting or a group classroom session. This session will teach you and your family member and/or power of attorney about:

- Reasons for having a lung transplant.
- Risks/benefits of having a lung transplant.
- How the lung transplant program works.
- Who may be accepted to receive a lung transplant.
- What is involved in the workup.
- Lung transplant surgery.
- What to expect after you get a lung transplant.
More education will be done as needed. This may include any changes to the NM Lung Transplant Program, such as:

- New practices.
- Outcomes (results).
- Program staff.
- Medicare approval status.

**Ongoing Evaluation**

While you are waiting for your lung transplant, the transplant team will monitor and review your health. Your team will discuss the results with you and let you know if anything has changed.

**Confidentiality**

As with all patient information, please know that all of your medical information is private. Anything that you discuss will remain confidential. Hospital personnel who are involved in your care may review your medical record. If you are accepted for a lung transplant, data about your case (including your identity) will be sent to the Organ Procurement and Transplant Network (OPTN). This is where you are registered for a lung transplant.

**Patient Right to Decline Transplantation or Specific Organ Offer**

You have the right to refuse a lung transplant or to refuse a lung that is offered without losing your place on the waiting list. You can refuse a lung transplant at any time. Your healthcare team is available to discuss and answer questions.

**Health Information Resources**

For more information, visit Northwestern Memorial Hospital’s Alberto Culver Health Learning Center. This state-of-the-art health library is located on the 3rd floor of the Galter Pavilion. Health information professionals are available to help you find the information you need and provide you with personalized support at no charge. You may contact the Health Learning Center by calling 312-926-LINK (5465) or by sending an e-mail to hlc@nm.org.

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