Preparing for Your Lung Transplant

PATIENT GUIDE

UAB MEDICINE
COMPREHENSIVE TRANSPLANT INSTITUTE
Knowledge that will change your world
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Introduction

Welcome to UAB Hospital.

The purpose of this booklet is to provide you with information about lung transplantation. It will provide specific information that you will need during the pre-transplant waiting period.

We invite you to share this booklet with your family and friends. The transplant team will be talking with you about the information in this booklet. Please feel free to ask questions. We're here to help.

Lung Transplant Program

HEART-LUNG TRANSPLANTATION
In 1988, the first heart-lung transplant was performed at UAB. Since then, more than 30 heart-lung transplant surgeries have been performed.

LUNG TRANSPLANTATION
Lung transplantation began at UAB in 1989. More than 600 lung transplants have been performed since that time.

The overall success of the UAB Cardiothoracic Transplant Program is a result of the joint efforts and expertise of the transplant team.
We consider you, your family, and caregivers the central focus of the transplant team. The UAB transplant team works closely with you throughout the transplant process. The UAB transplant team comprises the following members:

**TRANSPLANT SURGEON**
The transplant surgeon performs the lung transplant operation. Along with the transplant pulmonologist, the surgeon will closely monitor your care before and after surgery.

**TRANSPLANT PULMONOLOGIST**
The transplant pulmonologist is the doctor who will monitor your care before and after surgery. The pulmonologist is skilled in treating lung disease and determining if a transplant would benefit you. After surgery, the pulmonologist will manage your care with the surgeon and monitor your progress after discharge.

**TRANSPLANT COORDINATOR**
The transplant coordinator is a nurse who is responsible for “coordinating” your care through your hospital stay and as an outpatient. The transplant coordinator acts as a liaison between you and your doctors and will be your contact person for all of your health needs, beginning with your transplant evaluation testing and continuing on after transplant.

**TRANSPLANT SOCIAL WORKER**
The transplant social worker will help you with the “social aspects” of your care. The social worker can provide information on insurance and the financial part of the transplantation. They can help arrange transportation, lodging, and support services for you and your family.

**TRANSPLANT ASSISTANT**
The transplant assistant is the record-keeper for the transplant team. They will know when you are scheduled to return to the clinic or the hospital and will assist in making any specific appointments you may need.

**OTHER MEMBERS OF THE TRANSPLANT TEAM**
During your hospital stay you will meet many new people, including the nurse taking care of you, the nurse practitioner, the physical therapist, the diettian, the psychologist/psychiatrist, the pharmacist, the respiratory therapist, and, if needed, other medical personnel.

**NORMAL LUNG FUNCTION**
Your two lungs are located inside your rib cage and are divided into sections called lobes. The right lung has 3 lobes and the left lung has 2 lobes. Each lobe is made of spongy tissue containing breathing passages called bronchial tubes. Air flows in and out of the lungs through these tubes.

**WHY DO I NEED A LUNG TRANSPLANT?**
There are several conditions that cause your lungs to not work properly. These lung diseases lead to symptoms such as shortness of breath and limit the amount of activity you can do.

The following is a list of some of the diseases treatable with lung transplantation, including but not limited to:

**Interstitial lung diseases**
Examples:
- idiopathic pulmonary fibrosis
- sarcoidosis
- lymphangioleiomomatosis (LAM)

**Obstructive airway diseases**
Examples:
- chronic obstructive pulmonary disease (COPD)
- emphysema due to alpha-1 antitrypsin deficiency

**Pulmonary vascular disease**
Examples:
- Eisenmenger’s Syndrome with cardiac repair, atrial septal defect (ASD), ventricular septal defect (VSD), patent ductus arteriosis (PDA)
- idiopathic pulmonary hypertension

**Infectious lung diseases**
Examples:
- cystic fibrosis
- bronchiectasis

**Miscellaneous**
Examples:
- acute respiratory distress syndrome (ARDS)
- bronchoalveolar carcinoma

**Heart-Lung Transplantation**
The following is a list of diseases treatable with heart-lung transplantation.

- Eisenmenger’s Syndrome
- idiopathic pulmonary hypertension

A lung or heart-lung transplant is considered when all other medical and surgical treatments have been tried. The decision to perform a single or bilateral heart-lung transplant depends on many factors and will be made by the transplant team based on all available information.
In order for your physicians to decide if you are a candidate for a transplant operation, they schedule you for tests and consultations. If you are in the hospital, you may have your evaluation during your inpatient stay. Most evaluations take place as an outpatient in The Kirklin Clinic of UAB Hospital. Evaluation testing usually takes one week. However, the results of these tests may or may not provide all of the information needed to determine if a transplant is right for you. Additional testing might be ordered by your physicians.

The evaluation:

1) gives the transplant team an overall picture of your general health
2) may reveal conditions that need to be treated or further investigated before transplant surgery, and
3) may uncover a problem that makes transplantation a poor choice for you

During the evaluation, members of the transplant team gather information about your medical condition and will provide you with information about transplantation.

THE EVALUATION USUALLY PROCEEDS IN THE FOLLOWING WAY:

LUNG TRANSPLANT – EVALUATION TESTS

The transplant doctor or nurse practitioner and other members of the transplant team will perform a physical examination and order some or all of the following tests:

GENERAL TESTS

- Complete medical history and physical examination
- Laboratory studies: These tests allow the transplant team to evaluate your other organ systems.
  - Fasting cholesterol/lipid profile
  - Creatinine clearance – this test evaluates your kidney function by saving your urine for 24 hours.
  - ABO blood type
  - Antibody screen
  - Human leukocyte antigen (HLA) tissue typing – this allows the transplant team to find a suitable lung donor for your tissue type.
  - Lymphocyte cytotoxicity screen (panel reactive antibodies) — detects any antibodies your body may have developed that could have an impact on your body’s ability to accept or reject the transplanted organ.

- Nutrition evaluation
  A dietitian will talk to you during the evaluation regarding your diet.

- Pharmacy evaluation
  A pharmacist will talk to you during the evaluation about medications you may be prescribed after transplantation.
Initial Evaluation

- **Pre-transplant education class**
  The transplant coordinator will lead a class during your evaluation that will provide information to you and your family about transplantation. You will be asked to sign a consent form affirming your willingness to undergo a transplant evaluation and acknowledging that you have read the information provided.

- **Psychiatric evaluation**
  The psychiatric and/or neuropsychological evaluation will take place during your evaluation. You will meet with a psychiatrist and/or psychologist who will interview you. This is a routine test that every potential transplant candidate must complete. (See “Finding Hope While You Cope,” page 19.)

- **Radiographic and nuclear studies:**
  - CT scan of the chest
  - Ventilation perfusion lung scan – this test tells if all areas of your lungs are getting equal amounts of oxygen and blood flow.
  - Pulmonary function test – this test tells the doctor how much air can get in and out of your lungs.
  - Cardiac evaluation – includes a cardiac catheterization (depending on your age and other medical factors), and evaluates for pulmonary hypertension.
  - Gastrointestinal tests – these tests reveal if you have significant reflux that may affect your transplant.

- **Social service evaluation**
  The transplant social worker will visit with you and ask questions about your lifestyle, family, and finances. The social worker also will be able to help you arrange housing for your out-of-town family when you are waiting here for your transplant. (See “Finding Hope While You Cope,” page 19.)

- **Virological and microbiological profile testing:**
  Viral studies provide the transplant team information for your care after transplant.
  - **Viral Studies:**
    - Cytomegalovirus
    - Epstein-Barr virus
    - Human immunodeficiency virus
    - Hepatitis A, B, and C
  - **Other Studies:**
    - Syphilis
    - Toxoplasmosis
    - Tuberculosis
  - **Fungal Studies:**
    - Histoplasmosis

**THE TRANSPLANT DECISION**
After all of your tests and procedures are complete, the transplant team will meet and decide if transplantation will benefit you. You may be informed of this decision while you are in the hospital, at a return clinic visit, or via telephone.
The Waiting Period

BEFORE YOUR SURGERY

■ Waiting

“How long will I have to wait for a lung?”

Once you have become a transplant candidate, you will be entered into the United Network for Organ Sharing (UNOS) national database online. This system allows the most suitable patient to be selected for a given organ. This is based on a number of factors, including blood type and size. There is no definite length of time a person waits. You will be transplanted when an acceptable donor has been identified for you.

■ Phone Contact

“How will I be notified of a possible donor?”

It is very important for you to make a list of phone numbers while you are waiting. Because of the time factor, the team must be able to contact you as soon as possible after a potential donor has been identified. You must be available 24 hours a day. If you will be traveling out of town or will be unavailable for some reason, you must let your coordinator know. If you have any changes in your contact information, let your coordinator know.

■ Clinic

“Who will see me while I am waiting?”

The transplant team will see you in the Transplant Clinic on the fourth floor of The Kirklin Clinic of UAB Hospital as often as needed to manage your health while you are waiting. The transplant team will usually see you every 4-12 weeks. Sometimes you will be seen by the transplant surgeon and transplant pulmonologist when you come to clinic. Some of your tests may need to be repeated or updated while waiting for transplant.

■ Standby

“When will you call me about the possibility of surgery?”

The transplant coordinator will call to inform you of the possibility of surgery. You will be instructed not to eat or drink until you are notified again. On the second phone call you will be told to come to the hospital or that the donor was unsuitable for you. Please remember that the transplant surgery may be canceled at any time during your waiting period.

■ Healthy Living

“What do I do while waiting for transplant?”

Exercise regularly, as directed by your physician, while waiting for your transplant. Continue to work, as tolerated. Enjoy your life, but refrain from drugs, alcohol, and all forms of nicotine. Maintain a healthy weight.
The Day of Surgery

Admission
“Where do I go to be admitted?”
The transplant coordinator will make accommodations and tell you where to go to be admitted.

Consent Forms
“What papers will I have to sign?”
You will be given a form to sign that gives us permission to do the transplant. This is routine and necessary for any surgery. You also may be asked to sign other consent forms that give us permission to use a special medicine or perform certain procedures.

Special Tests
“Will I have any tests done before surgery?”
Special bloodwork and a chest x-ray will be done before you go to surgery.

Shave and Prep
“What will be done to prepare me for surgery?”
The nursing staff will shave you from your neck to your ankles. This is to remove hair where germs hide and reduce your risk of infection after surgery.

Medication
“What medicine will I take before surgery?”
Special medicines to prevent rejection of your new lungs may be started before surgery. These are called immunosuppressants. It is important that you do not take any medicine you bring from home, unless instructed to by the transplant physicians.

Transfer to Surgery
“What will happen when it is time to go to the operating room?”
You will be taken to the operating room on a stretcher. Your family may walk with you to the elevators, then they will go to a waiting room either in the Heart and Lung Transplant Intensive Care Unit (HLTICU) or a waiting area for the Cardiovascular Intensive Care Unit (CICU).

THE OPERATION
Depending on the type of surgery (single vs bilateral lung), your surgery may last 6–12 hours. Your family will receive updates on the surgery every 2–3 hours or as deemed appropriate by the surgeon.

What to Bring When Called in for Transplant

- Tennis shoes (you will need these daily for walking)
- All home medications including nebulizers
- Glucometer
- Assistive devices
- Money (for vending machines and local dining)
- Hearing aids
- Glasses
- Cell phone charger
- Dentures
- Insurance cards
- Enough oxygen to get to UAB and back home

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Immediately After Surgery

Immediately after surgery you will go to the Cardiovascular Intensive Care Unit (CICU). This unit is staffed by highly trained nurses and nurse practitioners who will care for you during your surgical recovery.

You will be expected to do breathing exercises and walk several times a day after surgery.

The major tubes and equipment you may see when you wake up from surgery are:
- Intravenous lines, arterial lines: tubes placed in the top of your arm and the wrist or neck to monitor blood pressure and draw blood samples. They also carry fluids, medications, and liquid food.
- Central Venous Pressure (CVP) line: a special intravenous line that measures blood pressure in the right atrium of your heart.
- Respirator/Ventilator (endotracheal tube): a tube attached to the respirator that helps you breathe by moving air in and out of your lungs. You will be unable to speak with this tube in place.
- Nasogastric (nose) tube: a tube inserted through the nose into the stomach; it drains fluids from the stomach, prevents vomiting, removes gas, and directs medicines and liquid food directly into your stomach.
- Chest tubes: tubes that drain blood and fluid from the chest cavity.
- Foley catheter: a tube that drains urine from the bladder.
- Electrocardiogram (EKG) wires (heart monitor): an electronic device attached by soft rubber pads that records each heartbeat.
- Extracorporeal Membrane Oxygenation (ECMO) machine: not always required but may be deemed necessary by the surgeon; provides continuous support for your lungs by using tubes called cannulae, placed in large blood vessels to pump blood through an oxygen chamber that removes carbon dioxide and adds oxygen, until you can breathe on your own.

After the Transplant

Once you have recovered from surgery you will be transferred to the Heart and Lung Transplant Intensive Care Unit (HLTICU). Your coordinator will come to your room and provide a post-operative teaching booklet. This guide will help you remember all the new information you will need to learn and understand. The booklet has sections on the following:

- Immunosuppression: Immunosuppressants are drugs that you must take for the rest of your life. These drugs help keep your immune system depressed to prevent rejection of your new lungs.
- Rejection: Rejection occurs when your body recognizes the new lungs as foreign and tries to destroy them.
- Transbronchial biopsy and BAL: A biopsy is the only definite way to detect rejection in the lungs. A bronchoalveolar lavage (BAL) is a "washing" of your lungs to look for possible infection.
- Vital signs: Your temperature, weight, and pulse will need to be monitored every day.
- Infection: Since your immune system is suppressed, you will be more susceptible to infections.
- Clinic visits: begin twice weekly and adjusted by the transplant physician
- Lab work: as frequently as daily if necessary
- Follow-up medical care: annual surveillance testing, possibly including colonoscopy, mammogram, dental, pap smear, prostate exam, dermatology, bone density, etc.
- Diet: You will be instructed by the nutritionist if you have dietary restrictions.
- Activity: Exercise is very important after transplant, but be sure to follow the transplant team’s recommendations.
- Medications: Compliance with medications is vital to survival after transplant.
- Miscellaneous information

Your coordinator, nurses, and physicians will review all of the information in this guide with you before you are discharged following your transplant surgery. You are expected to stay within 45 minutes of UAB for, on average, 100 days, following discharge.
COST OF TRANSPLANTATION

This section explores some of the costs involved in transplantation and highlights related financial considerations.

Costs related to serious illness — trips to the doctor, hospital admissions for treatment, tests, initial diagnosis, consultations with medical specialists, specialists consulting with specialists — can add up quickly. While many factors affect costs from patient to patient, transplantation is expensive and can pose a financial challenge.

The information below, provided by the U.S. Department of Health and Human Services, gives approximate cost ranges for different types of transplant procedures. Your transplant could cost much less — or much more. Estimated costs shown represent the TOTAL cost. Your out-of-pocket portion, after insurance coverage, should be less than the total cost.

<table>
<thead>
<tr>
<th>Organ</th>
<th>Estimated First-Year Cost</th>
<th>Estimated Annual Follow-Up Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lung</td>
<td>$150,000 - $350,000</td>
<td>$200,400</td>
</tr>
<tr>
<td>Heart-Lung</td>
<td>$150,000 - $350,000</td>
<td>$200,400</td>
</tr>
</tbody>
</table>

In almost all cases, transplant centers require a minimum guarantee and/or payment for the transplant when the patient is evaluated or listed for transplant. UAB Transplant will want the commitment from the insurance company or other carrier in writing in advance.

Upfront money and/or a recognized guarantee of payment, such as a written commitment from an insurance company, is required because of the substantial direct expenses associated with the transplant and patient care.

The cost of the transplant and associated co-pays, food, lodging, and transportation expenses will be different for each patient and family. For more specific and detailed information and guidance, talk to members of the transplant team, especially the hospital business office representative and social workers.

The question, then, for most patients and families is how they will find the money necessary to pay for these costs. Solutions vary. There are different funding alternatives and combinations of alternatives. Those generally available are listed below. It’s a good idea to keep UAB Transplant social workers and the hospital business office informed about progress made in funding.

Funding for transplant can come from the following sources:

- Private funds
- Insurance
- Government funding
- Fundraising campaigns
- Charitable organizations and/or advocacy groups

Several resources are available to help you and your family pursue funding alternatives, including:

- Transplant center social workers and hospital business office representatives
- Legal services programs, helpful for patient advocacy and as information sources on eligibility requirements for government-sponsored funding programs
- Charitable/advocacy organizations, providing guidance and, occasionally, more direct assistance
- Social workers in your community
- Your lawyer, bank officials, and your community’s religious leaders
- Your state Medicaid/Medicare and Social Security offices
Rehabilitation, Returning to Work, and Quality of Life

The outcome of successful transplantation is improving both your lifespan and quality of life. Now is the time to think about your plans for rehabilitation, returning to work, and changes in lifestyle after transplantation.

Many transplant patients return to work within 6 months of receiving a transplant.

Some patients return to their previous occupations, while others pursue new job opportunities.

One of the goals of a second chance at life through transplantation is to improve your quality of life. This is best described by the patients themselves.

Compliance and Following Instructions

Following instructions (also referred to as “compliance”) provided pre-transplant is an important part of receiving a lung transplant. Research shows there is an increase in survival when you comply in the following areas:

- Taking all immunosuppressant medications as prescribed by your transplant team
- Taking all other medications as prescribed by your transplant team
- Attending all clinic visits
- Getting lab work completed as directed by your transplant team
- Calling the transplant team when you are having problems such as signs or symptoms of rejection, infection, or if you have a question about your transplant
- Staying away from smoking, including secondhand smoke, at all times

Please contact the transplant team and report any areas of non-compliance. It could save your life!

Finding Hope While You Cope

At UAB Hospital, we look at organ transplant as a holistic experience. If transplant is determined to be the best option for your care, not only will you experience significant physical and functional changes, but you will also experience emotional and mental changes. Your mental health is an important component to your post-transplant health. Your attitude, outlook, and support system greatly influence your body’s ability to rehab and care for your new lungs.

With this in mind, listed below are a few factors that the UAB Transplant Team believes will help you recover post-transplant:

- **A Strong Support System** is necessary for success. Adjusting to life post-transplant is a task that cannot be done alone. You will need a dedicated support team (family, friends, loved ones, etc.) who can assist in practical ways such as local lodging, transportation to/from clinic, assistance with medications, and encouragement!

- **Awareness of your Mental Health.** Patients can grow depressed and/or anxious post-transplant as they rehabilitate their bodies and adjust to a new organ and way of life. If you are having anxiety or depression symptoms post-surgery, please let us know. This is NORMAL and something we want to and can treat. Your support partners may notice a change in you before you do. Grief or guilt associated with the donor family, or feeling like you are a burden on your loved ones, are normal as well. PTSD (post-traumatic stress disorder) can occur with any lengthy ICU stay or major surgery.

- **Stay Positive, and Keep Stress Levels Low.** Your attitude can make a BIG difference in your recovery and physical health. Practical ways to enhance your mood before and after transplant include exercising regularly, eating well-balanced meals, and letting your body recover from the day with a good night’s rest. If needed, you can learn relaxation techniques to reduce anxiety and stress.

- **Insurance and Medical Information.** It is important to become an expert on your insurance and also on your medical care. Be sure to maintain your insurance coverage post-transplant and be familiar with your policy. Losing insurance greatly increases stress post-transplant and can lead to costly medical bills. The same holds true for medical information; take ownership of your care by engaging with the doctors and transplant team about your medication regimen and post-transplant requirements. Your doctors are here to help you, so do not be afraid to ask them questions!

- **Resources Available:** During your inpatient stay, one or more of your support team should consider participating in a support group for the caregivers of lung transplant patients. Please ask your inpatient social worker for more information. Your social worker also can refer patients to outpatient counseling services if desired.

   We are here to support you physically, emotionally, and mentally, and we are committed to your success. Remember, as we take care of you, we ask that YOU take care of YOU, too! Be aware of your emotional and mental health needs and be sure they are met, because what goes on beneath the surface can affect your post-transplant recovery.
Social Security Benefits After Transplantation

The Social Security Administration is responsible for both Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) programs. SSDI provides cash benefits for disabled workers (and their dependents) who have contributed to the Social Security trust fund through FICA tax on their earnings. SSI provides a minimum-level income for the needy, aged, blind, and disabled.

Under both programs, the law defines disability as “the inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death, or has lasted or can be expected to last for a continuous period of not less than 12 months.”

Although some patients are able to continue working while they await transplant, there are others who have been receiving benefits for a period of time due to disability caused by their cardiac or pulmonary problems. Others apply for these benefits after the need for transplant has been established.

With transplantation, the goal is to enable the patient to return to as normal a life as possible. This includes returning to work. The likelihood of losing disability benefits following transplant is significant. Studies have shown that people who return to work feel better about themselves and tend to do better physically as well. Most transplant patients are able to return to work following transplantation, and for these patients, the expectation of both the Social Security Administration and the transplant team is that they will return to work.

There are barriers to returning to work for some people, and there are people throughout the country who are working to remove these barriers. Some employers are hesitant to hire transplant patients. The Americans with Disabilities Act provides some protection from this discrimination. This, together with education, can help convince employers that transplant patients can be good, reliable employees. Patients who can maintain an employee status with their employers (whether active or “on leave”) during the wait for transplant seem to have an easier time returning to work following transplant.

Another problem for some patients is the type of work they have done in the past. Some people cannot go back to their previous job but with training could do other types of work. For these patients, Vocational Rehabilitation Services is available. VRS provides various types of assistance to enable people to return to gainful employment. This help can take the form of paying for medical services, counseling, training, and job placement. They can provide training through technical schools, junior colleges, and colleges. A referral for these services can be made by your social worker.
**Glossary of Transplant Terms**

**Allograft (allogenic graft or homograft):** Transplanted tissue, that is not your own, which has been acquired from the same species (i.e. human donor gives to human recipient).

**Antibody:** A substance produced by the immune system in response to specific antigens, thereby helping the body fight infection and foreign substances.

**Antigen:** Substances that might trigger an immune response. An antigen might be introduced into the body or formed within the body (for example, bacteria, toxins, foreign cells).

**Anti-hypertensive drug:** A drug that reduces high blood pressure (hypertension).

**Atherosclerosis:** A disease in which fatty deposits accumulate on the inner walls of the arteries, causing narrowing or blockage that might result in a heart attack. This is commonly known as “hardening of the arteries”.

**Autograft:** Transplanted tissue that is your own.

**Biopsy:** Removing a sample of tissue for examination using a small needle. It is used to determine a diagnosis.

**Blood typing:** A test that can help establish compatibility between two different types of blood. Blood types include A, B, AB, and O.

**Cardiopulmonary rehabilitation:** A professionally supervised program that provides physical fitness, education, and counseling services to help improve cardiopulmonary health and optimize physical function.

**Catheter:** A thin, flexible instrument used to introduce or withdraw fluids from the body. A catheter also might be used to monitor blood pressure.

**Chest x-ray:** A test used to view the lungs and lower respiratory tract. A chest x-ray might be used for diagnosis and therapy.

**Cholesterol:** A fatty substance that is acquired in part from certain foods. A high cholesterol level might lead to atherosclerosis.

**Complication:** The occurrence of diseases or medical problems simultaneously in the body.

**Coronary angiography (heart catheterization):** A procedure that allows pictures to be taken of the arteries that supply the heart with blood (the coronary arteries). A right heart catheterization measures various pressures in the heart. Angiography, or left heart catheterization, shows blockages in the arteries.

**Creatinine:** A waste product in the blood that is removed by the kidneys and eliminated in the urine. Regular testing of the creatinine level serves as an indicator of how well the kidneys are functioning.

**Crossmatching:** A test that establishes the compatibility or similarity of blood between an organ donor and the intended recipient.
Glossary of Transplant Terms

Cytomegalovirus (CMV): A common virus that might be present without symptoms in healthy people but can be a serious condition for transplant patients.

Deceased donor: An individual who recently passed away from causes that don’t affect the organ intended for transplant. Deceased donor organs usually come from people who have willed their organs before death by signing organ donor cards. Permission for donation also can be given by the deceased person’s family at the time of death.

Diastolic: The lower number in a blood pressure reading. It indicates the pressure in the heart when the muscle is relaxed (the point of least pressure).

Diuretic: A drug that helps rid the body of excess water by increasing the amount of urine the body excretes.

Donor: A person who gives an organ, tissue, or blood to another person. A compatible donor is a person who has the same tissue and blood types as the person who receives the organ, tissue, or blood.

Echocardiogram: A procedure that uses high-frequency sound waves to examine the heart. This procedure might be used for the same purpose as an EKG (electrocardiogram).

Electrocardiogram (EKG or ECG): A test that records the electrical activity of the heart. An EKG helps doctors determine the causes of abnormal heartbeats or detect heart damage.

Extracorporeal membrane oxygenation (ECMO): Provides continuous support to the lungs in severe lung disease.

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Extracorporeal membrane oxygenation (ECMO): Provides continuous support to the lungs in severe lung disease by using tubes called cannulae, which are placed in large blood vessels to pump blood through an external oxygen chamber that removes carbon dioxide and adds oxygen. This may be used as a short-term therapy for recovery of your lungs or as a long-term therapy while awaiting transplant.

Gingival hypertrophy: Enlargement of the gums. This is a common side effect of the medicine cyclosporine (Sandimmune). This condition is easily managed with proper oral hygiene.

Glucose: A type of sugar found in the blood. Glucose is a vital carbohydrate for the body’s metabolism, but it can cause organ and tissue damage in excess amounts.

Graft: A transplanted tissue or organ (such as a heart or lung).

Herpes: An infection for which transplant patients are at risk. It appears as small sores on the skin, lips, or genitals. When there are no sores, the herpes virus lies dormant (not causing infection) in the body.

Hirsutism: An excessive increase in hair growth, sometimes leading to male pattern hair growth in a female. This is a common side effect of corticosteroids. It can also occur with cyclosporine (Sandimmune) therapy. Hirsutism can be easily treated with depilatory creams or other hair removal methods.

Hypertension: High blood pressure

Immune system: The body’s response mechanism for fighting against bacteria, viruses, and other foreign substances. If a cell or tissue (such as bacteria or a transplanted organ) is recognized as not belonging to the body, the immune system will act against the “invader”. The immune system is the body’s defense against disease.

Immunosuppression: The use of medication to suppress the formation of an immune response.

Immunosuppressant drug: A drug that prevents the immune system from responding to cells that it recognizes as foreign to the body. These drugs prevent the immune system from recognizing a transplanted organ, such as a lung, is not the organ a person had when he or she was born.

Infectious disease team: A team of doctors who help control the hospital environment to protect against harmful sources of infection.

Intensive care unit (ICU): A special nursing area devoted to providing continuous and immediate care to seriously ill patients.

Intravenous (IV): Delivery of drugs, fluids, or food directly into a vein.

Lower GI (gastrointestinal) series: A series of x-rays used to determine intestinal abnormalities.

Lung transplantation: A medical procedure in which a diseased lung is removed from a patient and replaced with a new lung that has been obtained from a deceased person. Transplanting both lungs is also possible.

Noncompliance: Failure to follow instructions given by health care providers, such as not taking medicine as prescribed or not attending follow-up appointments.

Opportunistic pneumonias: Several types of pneumonia that don’t normally cause disease except under certain circumstances. Lung transplant patients are at risk for contracting these types of pneumonias because their immune systems are weakened by immunosuppressant drugs.

Over-the-counter drug: A drug that can be bought without a prescription. Some common over-the-counter drugs are aspirin, acetaminophen (Tylenol), ibuprofen (Advil, Nuprin), cough medicines, cold and flu medicines, antihistamines, laxatives, and antacids.

Physical therapist: An expert who can recommend exercises to help you maintain flexibility and regain your strength.

Pre-transplant evaluation: A series of interviews and tests for patients who are being considered for a lung transplant. It is the second step in the transplant evaluation process following the initial consultation. After this evaluation, the transplant team decides if a lung transplant is a suitable treatment.

Pre-transplant screening: A series of interviews and physical exams for patients who are being considered for lung transplant. It is the first step in the transplant process and designed to discover if the patient has any condition that would immediately rule him or her out for a lung transplant.

Pulmonary function test: A test used to reveal lung capacity and function and to determine the blood’s capacity to transport oxygen.

Pulmonologist: A staff doctor with extensive training in lung disease. The pulmonologist monitors your lung health during and after your transplant.
Pulmonary function tests (PFTs): Tests that measure the volume of air that is inhaled and exhaled. PFTs also measure gases, such as oxygen and carbon dioxide, in the lungs. The PFTs give information about how severe a patient’s lung disease is and the rate at which it is progressing.

Recipient: A patient who receives an organ, tissue, or blood from another person.

Rejection: An immune response that occurs when the body tries to reject a transplanted organ. The immune system sees the organ as a foreign “invader” and acts against it. If left untreated, rejection can result in organ failure.

Side effect: An unintended response from a drug that can affect tissues or organs beyond those that the drug benefits.

Spirometry test: A breathing test that provides information about the extent of your lung disease and how well your lungs function.

Stress test: A test using exercise to evaluate cardiovascular fitness.

Systolic: The top number in a blood pressure reading that indicates the force of the heart muscle’s contractions as blood is pumped through the heart’s chambers.

Thrush: A yeast infection for which transplant patients are at risk. It can occur in the mouth or vagina.

Tissue typing: A test that evaluates the compatibility, or closeness, of tissue between the organ donor and recipient.

Transplant coordinator: A registered nurse who coordinates all of the events leading up to and following your transplant. The transplant coordinator helps arrange your pre-transplant tests and helps find a suitable organ donor.

Transplant surgeon: The staff doctor who performs the transplant surgery. The transplant surgeon follows your progress while you are in the hospital and monitors your post-transplant care after you are discharged.

Trough levels: Refers to the 12-hour period between an evening dose of your immunosuppressant drug and blood work completed the next morning. Important: Do not take a morning dose of your immunosuppressant drugs until the blood work has been completed.

United Network for Organ Sharing (UNOS): An organization that established and enforces regulations to ensure equality in organ transplantation and in the distribution of donor organs.

Ventilation perfusion (VQ) scan: A picture that shows the blood flow to the lungs and how much air each lung receives. This information helps the lung transplant team decide which lung to transplant.

Ventilator: A machine that helps a patient breathe. For lung transplant patients, a ventilator is used after surgery to help the new lung expand completely.

Xenograft: Transplanted tissue acquired from a different species.