



ADVANCED ORGAN DISEASE &
TRANSPLANTATION INSTITUTE

IS LUNG TRANSPLANTATION FOR ME?



The first human lung transplant was performed by Dr. James Hardy in 1963. Since then, thousands of lung transplants have been performed throughout the world. Improved surgical techniques and better anti-rejection drugs have made lung transplantation the treatment of

choice for many patients with end-stage lung disease. It is important to be informed about ALL aspects of this process before making a decision about lung transplantation. This booklet is intended to provide general information about the procedure and transplant program.



YOUR LUNGS

The lungs are a pair of organs located in the chest cavity that perform respiration. These are about 12 inches long. The area between the two lungs is called the mediastinum, which contains the heart, trachea, esophagus and blood vessels. The lungs are protected by the ribcage.

The function of the lung includes:

- Maintaining the body's respiration, which means bringing oxygen into the bloodstream, providing energy
- Removing carbon dioxide from the body

The lung shows signs of failing when it is unable to adequately perform its functions. This may be due to pneumonia, lung disease, asthma or other problems that put more stress on bodily functions. Lung failure may occur rapidly over days — or more commonly, over months or years.

Common Lung Diseases

Most lung transplants are performed for chronic (long-term) lung diseases, such as cystic fibrosis (CF), idiopathic pulmonary fibrosis (IPF), pulmonary hypertension (PHTN), alpha 1 anti-trypsin disease and chronic obstructive pulmonary disease (COPD)/emphysema.

As the lung function continues to worsen, some of the following signs and symptoms may occur:

- Shortness of breath
- Coughing
- Noisy breathing
- Chest pain
- Fatigue

YOUR TRANSPLANT TEAM

Your transplant team will consist of the following individuals:

- **Transplant Coordinator:** A registered nurse who will guide you through the process and become your primary contact person.
- **Transplant Assistant:** A staff member who supports the transplant coordinator. He or she will call you with appointments and can answer many non-medical questions.
- **Transplant Surgeon:** The doctor who will perform the transplant procedure. You will see the surgeon in our clinic while you are on the waiting list and after surgery.
- **Transplant Pulmonologist:** The medical doctor who specializes in lung disease. You will see the pulmonologist in our clinic while you are on the waiting list and will follow up with them after the transplant.
- **Transplant Social Worker:** The medical professional who will assess family support and needs. You will need to designate support persons to help coordinate your care before and after your transplant. You will need to have another adult with you at all times (for at least three months) following the transplant. This person will need to provide transportation to your clinic visits (up to three times per week) and assist with your medication regimen.
- **Transplant Financial Counselor:** A financial counselor who will evaluate your level of insurance coverage and your out-of-pocket expenses (called co-payments) for procedures and medications. If Tampa General Hospital cannot negotiate a contract with your insurance company, we will not be able to consider you for a transplant. You will need to continue treatment with your referring physician.
- **Transplant Psychologist:** The medical professional who will assess any emotional or psychological concerns. Any history of drug or alcohol use will be discussed, and recommendations will be made regarding your candidacy. You may need to participate in documented rehabilitation/Alcoholics Anonymous and submit to random drug and alcohol screenings. Failure to present to the lab in a timely

manner, or a positive drug or alcohol screen, will terminate your evaluation and/or prompt your permanent removal from the waiting list.

- **Transplant Dietitian:** The nutritional specialist who will assess your nutritional status and discuss diets that may apply to you. The dietitian will also

address your body mass index (BMI) — a comprehensive weight assessment — and discuss diets that may help you to obtain an acceptable BMI.

- **Anesthesiologist:** The doctor who will put you to sleep at the time of surgery (or other procedures) when sedation is needed.

Other medical specialists may be consulted, if necessary, to review other medical concerns.



PRE-TRANSPLANT EVALUATION

As a transplant candidate, you will undergo a number of tests during the evaluation that will assist in determining if transplantation is the best option for you. Most evaluations are done on an outpatient basis over three days.

The transplant team may ask you to have the following tests and procedures completed:

- **Chest X-Ray, Pulmonary Function Tests and Blood Gases:**

Provide information regarding the health of the lungs and lower respiratory tract.

- **Electrocardiogram (EKG), Echocardiogram and Heart Catheterization:**

Provide information regarding the condition of your heart.

- **Doppler Ultrasound:** Looks at the blood flow through the vessels to the neck and leg veins.

- **CT (CAT) Scan:** A computerized image that shows the size and shape of the lungs and major blood vessels. It also helps to determine if there are any masses or tumors in your lungs.
- **Blood Tests:** Determine the blood count, blood and tissue type, blood chemistries, and immune system function. In addition, tests for infectious diseases will be performed.

Additional tests or procedures may be ordered.

Upon completion of the evaluation, your case will be discussed by all members of the transplant team, who will determine if transplantation is the best treatment option for you.

WAITING

If it is determined that lung transplantation is the best treatment option, your name will be added to the “waiting list.” This list is actually a national computerized network to which all transplant centers in the United States belong. The United Network for Organ Sharing (UNOS) oversees the network and helps to ensure that patients throughout the country receive healthy organs as soon as they become available. Priority is based on the Lung Allocation Score (LAS), which is a scientifically validated measure of medical urgency. Information on organ allocation can be reviewed at www.unos.org.

In order for a lung to be used for your transplant, the donor’s blood type and lung size must be compatible with yours. It

is important that we are able to contact you and that your transportation to the hospital is pre-arranged. A suitable lung may become available at any time. When that occurs, the transplant coordinator will contact you with instructions.

Risks of Transplantation

There are risks associated with any surgical procedure: Bleeding, poor function of the transplanted lung and infections are possible. It is possible for HIV or other viruses to be transmitted from the donor, although all donors are tested for HIV and many other infections to make this risk as minimal as possible. In addition, anti-rejection or immunosuppressant drugs can make a person more susceptible to infection or the development of a cancer or tumor.



THE TRANSPLANT

Admission to TGH

Upon admission to Tampa General Hospital for the actual transplant, a thorough physical exam will be conducted. This will include blood tests, a chest X-ray and an EKG. If the results are normal, you will be scheduled for surgery.

During Surgery

The anesthesiologist will administer a general anesthetic, which will put you to sleep. After you are asleep, additional intravenous lines will be placed to give you medications, fluids and any necessary blood transfusions.

There will be tubes placed in your bladder and mouth. The actual surgery will start about an hour after you go to sleep. The transplant surgeon will make a large incision on your chest. Your diseased lung(s) will be removed, and the new lung(s) will be inserted and attached to the blood vessels.

Normally, the surgery lasts between four and six hours; however, it may take longer in some cases. Following surgery, you will be taken to the intensive care unit.



After Surgery

As you awaken, you may experience the following symptoms:

- Pain and discomfort
- Sore nose and throat due to the tubes that were placed

During your recovery, you will experience good and bad days. You will gain strength and increase your activity level on a daily basis. However, directly after the surgery, you will have several tubes attached to your body to help you breathe, and to monitor blood pressure, provide fluids,

administer medications, drain urine and collect drainage from around your liver. The hospital stay is usually between seven to 10 days, but some patients may stay much longer – particularly those who are extremely sick or weak before their transplant. Every patient recovers at their own pace, and your willingness to take an active role in your recovery is crucial to the success of the procedure. Most patients are usually ready to return to work and a “normal life” within three to six months after surgery.



WHAT IS REJECTION?

Your immune system protects you by rejecting anything foreign, such as an infection or a new organ. After a transplant, the immune system must be suppressed with medications in order to prevent rejection of the new lung. It is common for patients to have an episode of rejection even with medication, but it is rare for rejection to be severe enough to put the transplant at risk. Typically, the rejection is first discovered through your bloodwork, and you may not feel any different. The transplant physician may do a biopsy to determine whether there is actually rejection. Almost all rejection episodes are treated successfully with increased anti-rejection drugs. This may or may not require hospitalization. After the first several weeks, the chance of rejection decreases, as long as you continue to take your medicines.

Going Home

After you are discharged from Tampa General Hospital, you will continue to be followed by the transplant team. You will visit the clinic frequently for lab work and doctor visits.

Follow-Up Care

Your relationship with the transplant team will continue on an outpatient basis. The team will be in contact with your referring physician regarding your condition and medications. Your medications will be adjusted over time. Your transplant coordinator will remain in touch with you and will facilitate long-term continued communication. He or she is your link to a healthy outcome. It is important to keep the lines of communication open.



MEDICATIONS

A successful recovery and continued function of your new lung depends on a careful balance of your new medications. You must take immunosuppressants, drugs that suppress your immune system, for the rest of your life. The goal is to keep the body from rejecting the lung while still being able to fight infections. Immunosuppressants also have side effects. As your system becomes stable, the medication dosage may decrease. We will monitor drug levels and side effects. The following medications are used to suppress your immune system:

- **TACROLIMUS (Prograf):** The main anti-rejection drug for most patients. Side effects may include headache; nausea and vomiting; burning or tingling of the hands and feet; insomnia; elevated potassium levels and elevated blood sugar levels (hyperglycemia).
- **SIROLIMUS (Rapamune):** A newer drug that is sometimes used with, or in place of, PROGRAF or NEORAL. The side effects include elevated cholesterol and low platelet counts.

- **MYCOPHENOLATE MOFETIL (Cellcept)*:** An additional medication to prevent rejection. Possible side effects include nausea, diarrhea, poor appetite and a lower white blood cell count in some patients. *Note: Use of this drug has been known to cause birth defects. Women of childbearing age must use two forms of birth control while using this medication. For those wishing to become pregnant, this must be discussed with the transplant team prior.
- **DELTASONE (Prednisone):** A steroid related to cortisone. Like all steroids, it decreases inflammation. Possible side effects include increased appetite, stomach irritation, mood changes, increased risk of infection, high blood sugars (diabetes), skin changes and weakening of bones.

Typically, patients receive a combination of Prograf, Cellcept and Prednisone.

RESTRICTIONS

Weight gain is a common problem after a transplant, so we recommend a well-balanced diet, low in salt, cholesterol, fat and sugar. Weight gain can lead to high blood pressure, coronary artery disease and diabetes. Exercise not only helps maintain weight, but it also increases your energy, reduces stress and improves your emotional well-being. After surgery, there will be few activity restrictions, and we encourage you to be active as soon as possible.

Conclusion

Undergoing a lung transplant can be a lifesaving procedure. Our goal is to present all aspects of transplantation to assist you through this process. We look forward to working with you and your family to provide the necessary information about transplantation. For more information, contact us at (813) 844-7137.

LUNG TRANSPLANT RESOURCES

Books

- *The Lung Transplant Handbook* by Karen A. Couture
- *Transplants: Unwrapping the Second Gift of Life* by Pat Steve Helmberger
- *New Life: Lessons in Faith and Courage from Transplant Recipients* by Bob Violino
- *Take a Breath: A Transplant Journey* by Karen Kelly, MD

Websites

- The Tampa General Hospital Website: www.tgh.org
- One Breath at a Time www.obaat.org
- The United Network for Organ Sharing www.unos.org
- Pulmonary Disease www.pulmonarychannel.com
- The Cystic Fibrosis Organization www.cff.org
- Second Wind – Pulmonary Chat Room www.2ndwind.org
- Organ Procurement and Transplantation Network optn.transplant.hrsa.gov
- Pulmonary Fibrosis Foundation www.pulmonaryfibrosis.org/

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