

U^{OF}L Health

Trager Transplant Center



Lung Transplant Program

Important Information

Now that you are considering a lung transplant, the recovery process may depend on your understanding of what to expect before, during and after the transplant. Please read each section carefully, jot down notes in the margins and ask questions about anything you do not understand or concerns you may have.

At UofL Health – Trager Transplant Center, we consider lung transplantation when conventional medication or surgery cannot improve the function of your failing lungs. Transplantation offers many people the chance not only to survive but to return to a more normal, productive life.

The lung transplant team seeks to thoroughly educate every candidate about transplantation. Post-transplant management can be difficult and demanding. Furthermore, you and your family should understand the risks, limitations and benefits of transplantation before making any decisions.

It is important to understand that a lung transplant does not “cure” lung disease. Daily medications and rigorous follow-up appointments will be crucial to maintain the rest of your life. The transplant team is committed to helping each patient, as long as the patient is committed to the demand and requirements of transplantation. Your attitude about the process and your participation in your care will play a vital role in the ultimate success of your transplant story.



Bring your lung transplant manual with you to each visit. Use it to refer to and jot notes in when you see the doctor or the coordinator.

Lung Transplant Program Informational Booklet

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Trager Transplant Center

Financial Considerations

The following information regarding the financial costs of lung transplantation will help you begin financial planning. You will need to know how much your insurance will pay for the lung transplant and for immunosuppressant medications. It is unlikely that one single source will cover all of the costs and it is often necessary to draw on savings accounts, investments, monies from fundraising efforts and federal and private assistance options.

Before Your Evaluation

Before you come for your evaluation, call your insurance company's case manager to see if your insurance covers lung transplantation. (See sample questions to ask.) Get a copy of your benefits for lung transplantation including deductible and co-payment amounts. The Financial Coordinator for Lung Transplantation will help you consider the financial arrangements you will need to make for transplantation.

Contact your financial coordinator at 502-587-4985 if:

- You have any questions regarding your insurance
- You do not have insurance
- You do not have benefits for transplantation, or
- You are denied coverage for a transplant.

Contact your social worker at 502-587-4612 if:

- You need help applying for disability
- You would like to discuss other financial assistance options.

During Your Evaluation

Most insurance companies require a review of your evaluation results to see if you meet their criteria to pay for a lung transplant. You may be asked to sign a consent form authorizing Jewish Hospital to release the medical information from your evaluation to your insurance company.

If you are a candidate for a lung transplant, we will work with you in obtaining insurance approval from your insurance company. If your insurance carrier denies authorization of benefits, the lung transplant program will be happy to write a formal appeal for you. However, please be advised that gaining insurance approval is ultimately your responsibility.

During the lung transplantation evaluation process, you will meet with a social worker to discuss social issues in detail and a financial coordinator.

Lung Transplant Costs

The cost of a transplant varies from patient to patient based on how sick the patient is before the transplant and whether single, double, or heart-lung transplant is required. Here are some of the charges you can expect:

- Hospital charges relating to the heart transplant admission (the day of admission to the day of discharge) range from \$99,800 to \$276,000. The average hospital charge for transplant admission is \$196,350.
- Physician charges from the date of transplant, including 90 days of follow-up care, average \$54,000.
- Annual outpatient immunosuppressant medications following transplantation cost between \$15,000 and \$25,000.

Billing

Authorization by your insurance company for medical services provided by physicians and Jewish Hospital does not guarantee full payment of all charges. Medical services are provided to you with the expectation that you will make the payment in full, not your insurer. If you will not be able to pay the balance on your account in full, the hospital and clinic business offices will be happy to work with you to set up payment arrangements. To arrange a payment plan or learn more about medicare reimbursement, please call the financial coordinator.

You will be responsible for the following:

- All deductibles, co-payments and non-covered services as outlined in your health plan.
- Any balance between charges and what your insurance carrier pays as “usual and customary charges.”

Ask your insurer for a copy of its usual and customary charges and an explanation of how it derives them.



***UofL Health – Jewish Hospital and UofL Physicians are separate entities.
Therefore, you will receive separate bills from:***

- *Jewish Hospital for inpatient and outpatient hospital services*
- *Doctors’ fees and medical services from UofL Physicians*

Sample Questions to Ask Your Insurance Company

1. Do I have benefits for lung transplantation?
2. What is my transplant maximum benefit?
3. What is my lifetime maximum benefit? How much have I used toward that maximum?
4. What is my annual maximum benefit? How much have I used toward this maximum?
5. Is organ acquisition covered? If yes, is there any limitation on how much my insurance will pay?
6. Does my insurance plan have “Centers of Excellence” for transplant services? If yes, is Jewish Hospital an approved transplant center and in my network?
7. What are my deductibles, co-payments and out-of-pocket expenses? How much have I paid this year toward my deductible and out-of-pocket expenses?
8. What are considered usual and customary charges? How much am I likely to pay?
9. Do I need to obtain authorization/precertification for outpatient office visits and medical services, such as pulmonary function studies or bronchoscopies?
10. Are outpatient prescription drugs covered? Specifically immunosuppressant medications, such as Imuran®, CellCept®, Prograf® or Valcyte®? How much is my responsibility for paying for outpatient prescription drugs?
11. Is there a mail-order pharmacy that I may use that provides a higher level of benefit?
12. Is there a specific nurse case manager who will coordinate my transplant care? If yes, what is his/her name and number?
13. Do I have any transportation or lodging benefits?
14. Are ambulance or air ambulance services covered at the time of transplantation?
15. Am I in a pre-existing period of coverage so that treatment for my condition is not covered? If yes, what conditions need to be met to pass the pre-existing period?



Please request a copy of your health insurance policy and bring it to your evaluation.

Transplant Evaluation

A primary care doctor or pulmonologist has referred you for evaluation because your lung function is very poor and they think no other medical or surgical therapy will help you. Your medical records were sent to us to review and during this visit, you will be interviewed, examined and counseled about what we think is the best plan for your care. This may include a full evaluation for lung transplantation. The realities of having and living with a lung transplant will be explained and discussed and additional testing after the evaluation will be required.

Smoking is an ABSOLUTE contraindication to lung transplantation. You MUST be smoke-free for six months to be considered for a transplant. If you are smoke-free for six months and have three negative urine tests for nicotine, then we will have you come in for an outpatient evaluation. You must avoid smoke-filled areas and ask family members not to smoke. If you are exposed to secondhand smoke, you may have a positive urine nicotine test.

Tests

The evaluation consists of meeting many different people who will perform different tests. Tests may include:

- VQ scan (ventilation/perfusion lung scan)
- Chest CT (computed tomography)
- Six-minute walk
- EKG (electrocardiogram)
- Abdominal ultrasound
- Neck and Leg ultrasounds
- Bone density scan
- Pulmonary function test (PFT)
- Echocardiogram
- Heart catheterization
- Blood work
- Urine collection

Meeting the Team

It is important that you meet all the members of the lung transplant team during the evaluation. Each brings special knowledge that will help us determine your suitability for a lung transplant. The transplant team will review the results of your evaluation, and a plan of care is presented to you for consideration. This may or may not include the next step towards transplantation – being placed on the waiting list for a donor lung or lungs.

Transplant Surgeon

The transplant surgeon will perform your lung transplant surgery and will be in charge of your care immediately following your surgery. The transplant surgeon will also follow your progress as needed after you are discharged from the hospital.

Transplant Pulmonologist

The transplant pulmonologist will provide overall supervision of your medical care and, while you are on the waiting list, should be kept informed of your condition and consulted by your local pulmonologist. He or she may see you occasionally during your waiting time and, for the first few months after transplant, will see you routinely to perform bronchoscopies, adjust your medications and monitor your progress.

You will see the transplant pulmonologist less frequently as time goes by except when you experience problems. A pulmonologist is available 24 hours a day for urgent problems that may occur after hours. Once you have returned home, your local physicians need to be aware of your transplant and consult the transplant pulmonologist as needed.

Transplant Coordinator

The transplant coordinator is a bachelor's or master's-prepared registered nurse who is specially trained to care for patients before and after lung transplantation. The coordinator will help arrange your evaluation, teach you and your family about transplantation and follow your progress in the hospital and at each clinic visit after you are discharged. They will help answer your questions and provide support to you and your family.

Social Worker

A social worker is available for supportive counseling for you and your family during this challenging and stressful time. If you need information about local housing, fund-raising and other transplant resources, the transplant social worker will assist you.

Financial Coordinator

The financial coordinator will review your insurance coverage for transplantation. He or she can help you understand the cost of transplantation, and answer questions about insurance coverage, and direct you to the appropriate personnel regarding these questions.

Psychologist

A psychologist will meet with you to obtain a general mental health history. He or she may recommend counseling to deal with emotional needs or issues, such as depression or alcohol, drug or tobacco use, that might affect the outcome of the transplant. A psychiatrist will be available for any developing needs and might be recommended to you if they feel necessary. They may request you have additional follow up with a psychiatrist.

Clinical Nutritionist

Our clinical nutritionist will see you before and after your transplant to evaluate your diet and to help you maintain a healthy weight and healthy lungs. After your transplant, it is not uncommon to have difficulty maintaining your weight and blood cholesterol levels. Eating a balanced low-fat diet is very important, but can be challenging at times. The nutritionist will be available to see you regularly after transplant to discuss these issues.

Pharmacist

The transplant pharmacist may begin working with you the day you transfer to the surgery floor. It is important for you to clearly understand your medications and how each affects your body. The pharmacist will explain the actions, dosages and side effects of your medications. The pharmacist will be available during each hospitalization and by phone to answer questions about your medications.

Physical / Occupational Therapist

A physical or occupational therapist may help pre-transplant patients understand what exercises are prescribed by the transplant pulmonologist. He or she is specially trained to help you regain your strength after surgery and will refer you to a pulmonary rehabilitation program in the early weeks after transplant. Exercise is important to your recovery. It can reduce complications after transplant surgery, improve your endurance and help you maintain a healthy lifestyle.

Chaplain

Transplantation often poses many spiritual issues. A chaplain can visit with you while you are at Jewish Hospital and is on call 24 hours a day. The chaplain can help you and your family deal with conflicting emotions and difficult spiritual questions that are often associated with transplantation.

Staff Nurses

Staff nurses are responsible for monitoring your day-to-day progress as well as maximizing your environment for a smooth recovery. They will teach you how to monitor your vital signs, look for signs and symptoms of infection and care for your incision once you go home.

Waiting for Your Transplant

The Waiting List

If you and the transplant team agree that you are a suitable transplant candidate, the team will place your name on a waiting list for a donor lung. The United Network for Organ Sharing (UNOS) is the national agency that regulates organ transplantation. Kentucky Organ Donation Affiliates (KODA) facilitates organ donation for the state of Kentucky. UNOS along with KODA puts your name on a national computerized transplant waiting list and helps locate donor organs.

For more information, visit: www.unos.org and www.donatelifeky.org.

Due to a critical shortage of donor organs, adults can wait up to two years or more before a suitable donor lung is available. Often patients can wait at home during this time. While you are “waiting,” you will continue followup care with your referring physician. However, it is important that we are always aware of any illnesses that occur, so please inform your coordinator of any illness you may have. You should request that your physician fax us the office notes of all your visits. We would like to see you in our clinic at least every three months. Finally, if you plan to travel while you are waiting, please inform your coordinator of your travel plans in case there are additional phone numbers needed to contact you.

Your Status on the List

You will be listed as an active status patient on the lung transplant waiting list. The results from your lab tests during your evaluation will be entered into UNOS, and a mathematical score will be generated for you. Your Lung Allocation Score, or LAS, will need to be updated every six months or at any time your condition changes.

When an organ becomes available, the patient with the highest LAS and proper blood group and body size will receive the donor lung. The more severe your lung disease is, the higher your score will be. Moving closer to the top of the list makes it more likely that you will be transplanted if a donor lung becomes available. You may be moved to the inactive list or removed from the list altogether, depending on your situation.

Finding a Donor

Every effort will be made to find a donor quickly. The wait for a donor depends on your blood type and body size.

To find a donor match for you, we look at two things:

- You and the donor must have compatible blood types.
- You and the donor must be height-compatible.

Many people often ask questions about the age of the donor and how the donor died. The transplant team cannot give out any information to you about the donor nor do we give any information about you or your family to the donor family. The donor family has been promised that this information will be kept confidential.

We do, however, encourage you to write a letter to the donor family without revealing your identity. If you choose to write a letter, KODA can provide you with guidelines on writing a letter. To preserve confidentiality, the transplant coordinator collects and sends all letters to KODA who will then forward it to the donor family.

Contacting You

Once you are listed for transplant, you will need to be reached by home phone or cell phone so that we will be able to get in touch with you immediately when a donor becomes available.

While You Wait

Pulmonary Rehab

Your physical condition going into lung transplant plays a key role in the success of your surgery. Pulmonary rehab is required while you are on the transplant waiting list and for a minimum of one year following your lung transplant.

Anxiety is Normal

Everyone has a different experience with transplantation. You may encounter personal, physical, psychological, spiritual and financial stresses during each phase of lung transplantation. During transplant evaluation, waiting for the transplant and after the transplant, you may feel discouraged, afraid, anxious, sad or depressed. It is normal to worry that you might die before an organ becomes available. Members of your family may also experience emotional distress related to your illness and worry about the risk of death before transplantation.

Post-transplant life can be a challenge too, even if you are highly motivated and well-adjusted. Minor complications are likely for most recipients and may require treatment and hospital stays that interfere with your daily life. As a transplant recipient, you will also be recovering from surgery and taking new medications that may cause extremes in your emotions. These feelings should go away in six to eight weeks after the transplant. If they do not, please let your transplant coordinator know.

Dealing with Stress

Many transplant candidates report that keeping a positive attitude about the situation helps. Other helpful coping strategies during the waiting period include getting involved in activities and seeking support from others. Simply talking with someone may help put your feelings into perspective and relieve stress and anxiety. Check with your social worker for the time and place of support group meetings in your area. Also, there are other organizations that can provide support including, Second Wind (national and local chapters).

While you can expect these brief periods of discouragement, they should not affect your usual daily activities. If these feelings occur frequently (for longer than a week or two) or begin to interfere with your daily activities, let your doctor and coordinator know. Our goal as the transplant team is to help you openly explore and discuss your feelings at any time during the transplant process. Please do not hesitate to call us.



Going to the Hospital

The Phone Call

When a donor lung becomes available, a transplant coordinator will phone you at home first. If we cannot get in touch with you, then we will call your cell phone. Please check your phone regularly for missed calls in case we are unable to reach you. We will tell you that we have a potential donor and then ask how you have been feeling. If you have a fever, vomiting or diarrhea, we may not be able to do the transplant. The most important thing you can do while waiting for a transplant is to seek treatment quickly if you become ill, so that you will be ready at any time should a donor lung become available.

The first call you get does not always mean the transplant will occur. We will tell you that we have a potential donor. The surgeon examines each donor organ and may find that the organ isn't strong and healthy. While uncommon, if the donor organ is not functioning well, we will not do the transplant.

Leaving for the Hospital

You need to leave your house within 15-30 minutes of our call so that you can arrive at Jewish Hospital as soon as possible. If you have difficulty driving to the hospital, please call the coordinator and we will try to help you get here safely. We would not want you to lose a chance for a new lung because of transportation issues. If you have arranged to fly here, you will need to contact the air ambulance service immediately for departure and arrival times. Once travel arrangements have been confirmed, please notify your coordinator so that we know when to anticipate your arrival.



***DO NOT EAT if you are called in for a transplant!
Bring all medication with you to the hospital.***

Arriving at the Hospital

You will be instructed by the transplant coordinator where to go when you arrive at Jewish Hospital. If you are instructed to go to the emergency department (ED), make sure you tell them that you are there for a lung transplant admission and they will direct you in the right direction. During normal business hours you will register in the Trager Transplant Center on the third floor of the Frazier Rehab Institute building. They will direct you to your room where you will be quickly prepared for surgery. This time will be very hectic. We will take your vital signs, do a chest X-ray and EKG, weigh you, do blood tests, and start your medications required for the transplant before taking you to the operating room.

Your family can wait in a special waiting room of the hospital while the surgery is taking place. This is also the place where an operating room nurse may talk with your family during surgery, most likely calling them by phone to tell them how things are going during the transplant. The surgeon will meet your family in this waiting room after the surgery.

The Lung Transplant Surgery

After arriving in the operating room, you will receive general anesthesia and be put to sleep. A breathing tube, called an endotracheal tube, will be placed down your mouth and windpipe. This tube is connected to a breathing machine called a ventilator, which will breathe for you during and after the operation. Single lung transplant surgery will last approximately three hours whereas a double lung transplant surgery will last approximately six hours. Once your incisions are closed, you are taken to the intensive care unit (ICU).

What Happens After Surgery

After surgery, you will go to the intensive care unit (ICU) where a doctor and nurses are always very close by if you need anything. At first, you will be under the effects of anesthesia. You will have many IVs, special tubes and initially, a breathing tube. You also will hear many different noises. These are normal sounds made by the equipment around you and by people talking.

When you first wake up, you may feel like you are not getting enough air. It is important to relax, and let the ventilator breathe for you. The ventilator may be very uncomfortable, and you will not be able to talk while on the ventilator. Once you are fully awake and breathe on your own, the team will work very hard to remove breathing tube. You will be able to talk immediately after the breathing tube is removed.

A typical stay in the ICU is two to three days. You will then be transferred to the transplant floor where our nurses and physical therapists will help you regain your strength, teach you how to care for yourself when you go home, and prepare you for discharge from the hospital. Tubes in your chest near the bottom of your incision and on the sides of your chest will drain the blood and fluid that collect in your chest after the operation. They are usually removed several days after the surgery. As you begin to recuperate and feel stronger, all the tubes and catheters will be removed. If all goes well, you can expect to spend one to two weeks on the thoracic surgery floor.

Deep Breathing and Coughing

Deep breathing and coughing will help expand your lungs and remove lung secretions that have settled during your surgery. A respiratory therapist will show you how to use an incentive spirometer, a device that will help you take deep breaths. You will take the incentive spirometer home with you to use the first four to six weeks after surgery.

Since you will have a chest incision, coughing may be painful. An epidural catheter may be placed to manage your pain or you may receive pain medication (through your IV) that you dose yourself through a special patient-controlled analgesia (PCA) device. The nurse will also teach you how to splint (decrease the pain by holding a pillow or your hands over your incision) while you cough.



Possible Complications After Transplant

Most people who receive a lung transplant will develop one or more complications after their surgery. Most of these complications are minor, treatable and no cause for alarm. Your transplant team will help you understand early warning signs, be available to discuss your care, and will recommend further treatment when necessary.

Donor organs are screened for various diseases in accordance with standards required by the United States Department of Health and Human Services — Centers for Disease Control and Prevention (CDC) and the United Network for Organ Sharing (UNOS). However, transplant recipients may be at risk for contracting certain diseases from the organ donor, such as various types of infectious diseases and cancers, which are not detected during the organ donor screening process.

Some of the most common complications seen after lung transplant are described below.

Acute Rejection

Rejection is a natural response of your body's immune system. The immune system acts as the body's defense against foreign invaders such as viruses, bacteria and even some types of cancers. This natural defense system will also recognize a transplanted organ as foreign and try to reject the new lung.

Acute rejection is a reaction that takes place in the tissues of the lung and is diagnosed by examining lung tissue for inflammation under a microscope. Almost all lung transplant patients will have at least one or two episodes of acute rejection in the first year. Acute rejection is treated by IV steroids.

To prevent your body from acutely rejecting your new lung, you will take medications called immunosuppressants which will lower your immunity or defense against foreign agents. These medications, when taken on time and as prescribed, reduce the risk of severe rejection which can damage the lung. You will take these medications for the rest of your life.

You will have a bronchoscopy at regular intervals so the doctor can look closely at your lungs and take samples of lung fluid and tissue to determine if your body is rejecting the new lung or if you are developing an infection.

You may feel good and have no symptoms, yet still be experiencing rejection or infection. That is why we follow your progress so closely after transplant.

If you have any of the symptoms of possible rejection listed here, call your transplant coordinator.

Infection

As a lung transplant recipient, you will be more susceptible to infection because you will take immunosuppressant medications to help prevent rejection. The risk of infection from bacteria, viruses, and fungi are greatest in the early period after transplant when dosages of medicines are at their highest. That's why it is important to protect yourself from exposure to infections while in and out of the hospital.

Here's how:

- Anyone entering your room must wash their hands.
- After transplant, take your temperature each morning and night and keep a record in the daily diary that we give you.
- Avoid large crowds of people in the first month after transplant.
- Avoid people with colds or the flu.
- Carefully clean any cuts or scrapes that you receive with anti-bacterial soap (such as Safeguard or Dial) and water.
- Always call the transplant coordinator if you suspect an infection or develop a fever.
- See section on protecting yourself from infection (later in this booklet) because there are several items not on this list.

Chronic Rejection

The most common late complication of lung transplant is the development of chronic lung rejection. Chronic rejection affects up to 50 percent of lung transplant patients within five years of the transplant and is the main obstacle to long-term survival. The main functional abnormality is a decline in pulmonary function, measured by the FEV1. A patient with chronic rejection usually complains of cough which can be dry or productive, and there is a progressive difficulty in breathing.

Chronic rejection is usually treated by changing and/or increasing immunosuppression medications. Patients are also treated with bronchodilators to try to improve symptoms. You will be closely monitored for the development of infections that may be brought on by increased immunosuppression.

Hypertension / High Blood Pressure

Many transplant recipients take medications to control hypertension or high blood pressure since prednisone and Prograf®, two of the medications used to limit rejection, can raise blood pressure. Blood pressure is recorded as a top (systolic) and bottom (diastolic) number. Normal blood pressures range from 100/70 to 130/80. After transplant you will take your own blood pressure regularly and keep a record in a daily diary we give you. We will also provide blood pressure guidelines and will expect you to call us if your blood pressure goes above or below the guidelines. Untreated high blood pressure will eventually damage your heart, vision, and kidneys.

Post-Transplant Diabetes

Some of the immunosuppressant medications that you take, like prednisone and Prograf®, may increase the likelihood of you developing diabetes, especially soon after transplant when the doses of these medications are at their highest.

Diabetes is an increased level of sugar in your blood. Signs of diabetes may include excessive thirst, frequent urination, blurred vision, drowsiness, or confusion. Notify the transplant team if you notice any of these signs.

In some cases, high blood sugar can be reduced and managed by weight loss, careful diet and exercise. However, you may need an oral diabetes drug or insulin injections. If you do develop diabetes, you will be given special teaching about how to deal with this problem.

Cytomegalovirus (CMV)

Cytomegalovirus (CMV) is a very common virus. About 70 percent of adults have been exposed to CMV at some time. It usually causes a flu-like illness with fever, general body aches, and a decreased appetite that lasts two or three days. After exposure to the CMV virus, your body forms antibodies in your blood to protect you from future illness due to CMV. However, CMV remains in the body, but in an inactive state. This is similar to what happens after you have chicken pox. We are able to do blood tests to check both the transplant recipient and donor for the presence of CMV antibodies.

Because of the immunosuppressant medications, you will be at risk for infection with CMV after transplant. During the first few months, while the immunosuppressant doses are highest and your immune system is especially weak, the CMV virus can “reactivate” or “wake up”. A CMV infection can range from flu-like symptoms to more serious infections involving your gut and lungs (pneumonia).

If either you or your donor were positive for CMV antibodies you will be given antiviral medications for the first few months after transplant. As your doses of immunosuppressants are lowered over time, your risk of CMV will decrease as well and the anti-viral medication can be stopped. If you develop an active CMV infection again, you will be treated with medications.



Medications

After your transplant, you will have to take certain medicines for the rest of your life. These medicines are very important and must be taken exactly as prescribed and on time for the transplanted organ to work properly. Failure to do this may result in organ failure and death.

Learning About Your Medications

Prior to your discharge from the hospital, our coordinator will teach you and your support team about all your medications. We will review with you the purpose, dosage and possible side effects of each medicine. To help you feel more comfortable taking these medications, we will ask you to begin administering and keeping your own medication records in the hospital a few days before your discharge.

All transplant patients take Prograf® (or Gengraf®), CellCept® (or Imuran®), and prednisone to help prevent rejection of their new organs. The following pages explain what's important to know about these medicines. You may be placed on medications other than these after transplant. Please ask your transplant coordinator for information about those medications.

Where to Get Your Medications

We work closely with Pharmacy Plus which is located within the transplant campus, to ensure you have all the medications you will need after your transplant.

Prior to your discharge, a coordinator will obtain your medicines and provide you with written prescriptions. It is your responsibility to contact your pharmacy when you run low on medications or to contact our office when you need new prescriptions, so that you will always have all of your medicines. Your prescription usually will be for a month's supply along with three to 11 refills depending on the medication.

We recommend that you keep a one or two week supply on hand. If you are interested in a mail-order pharmacy, please let the coordinator know. She can give you phone numbers to call. If you decide to use a mail-order pharmacy, it is your responsibility to call and initially set up the service, and then the coordinator will call in the prescriptions.

Mail-order pharmacies will get medicine to you in a few days after you call them or can ship it to you routinely every month. After you contact them with your new medication dosages, the pharmacy asks us to verify the changed prescription. Mail-order pharmacies usually bill your insurance company directly.



Always bring your medications in their bottles with you for any office visit, procedure, or hospital admission.

Tips for Taking Medications

- Know the medicines that you are taking and their side effects.
- Tell the transplant coordinator if you experience any side effects.
- Keep a record of medicines you are taking, including the frequency and dose. Bring it with you each time you see a healthcare professional.
- Talk to the transplant coordinator before adding, stopping or changing any medicine, including over the counter medications and those prescribed by other physicians such as your local doctor.
- Keep medicines in a dry place, away from heat or light, and out of the reach of children.
- If you miss a dose, DO NOT double the dose; take the next dose as directed.
- Take medicine as instructed by the coordinator and NOT as written on the medicine bottle.

Frequently Used Medications

ANTI-REJECTION MEDICATION (Immunosuppressants)

You will take immunosuppressants for the rest of your life to protect your new lungs from rejection. Immunosuppressants alter your immune system so that it will not reject your new lungs. These medicines also make you more susceptible to illness and infection. All immunosuppressive drugs cause side effects, but not all of the side effects occur in everyone.

Prograf® (Tacrolimus)

Prograf® (Tacrolimus) is a potent medication that lowers the risk of rejecting your lung. It comes in 0.5 mg, 1 mg and 5 mg capsules. The dose will vary depending on the blood levels of the medication. If you have swallowing difficulties, your physician may instruct that the capsule be punctured and its contents emptied under your tongue.

Special instructions:

- Must be taken every 12 hours.
- If possible, take it first thing in the morning on an empty stomach an hour before breakfast. This allows your body to absorb the medicine better and in lower doses.
- Take Prograf® at the same times each day and in the same relationship to other medication since they can alter how Prograf® gets absorbed in your body.
- Must be taken one hour before eating or two hours after eating.
- Do not take with other medications.
- Do not consume grapefruit or grapefruit juice while you are on cyclosporine; the interaction can dangerously increase the medicine's level in your blood.
- Take each dose with a full glass of water.

Potential side effects:

- Increased risk of infection
- Damage to kidneys
- Increased potassium
- Increased blood pressure
- Increased blood sugar and cholesterol
- Trembling hands and voice
- Numbness and tingling of hands and feet
- Difficulty sleeping



Do NOT substitute Prograf® or Gengraf® with generic brands before discussing it with your coordinator.

CellCept® (Mycophenolate Mofetil)

CellCept® (Mycophenolate Mofetil) is a very potent anti-rejection medication usually prescribed instead of Imuran.® The usual dose of CellCept® is 1000 mg to 2000 mg twice a day. CellCept® comes in 250-500 mg tablets.

Special instructions:

- Must be taken every 12 hours.
- Must be taken on an empty stomach one hour before or two hours after a meal.
- Do not take at the same time as cyclosporine or Prograf®.
- Notify your pharmacy several days before discharge so that this drug can be ordered for you.

Potential side effects:

- Nausea, vomiting, diarrhea
- Constipation
- Leg cramps, weakness
- Headaches
- Increased frequency of urination

Prednisone (Deltasone®)

Prednisone (Deltasone®) is a steroid drug that helps prevent and treat rejection. The dose of this drug will be slowly decreased over time. Most of the side effects of prednisone are dose-related. As the dose is lowered, the side effects decrease. Prednisone comes in 1 mg, 5 mg, 10 mg, 20 mg and 50 mg tablets.

Special instructions:

- Take with food.
- Have an annual eye exam with your local eye doctor.
- Wait four to six months before changing your eyeglass prescription, because prednisone can change your vision.

Potential side effects:

- Stomach irritation
- Increased appetite, weight gain
- Fat deposits
- Water retention and round, puffy face
- Cataracts
- Weakening of the bones (osteoporosis)
- Acne
- Fragile skin with bruising and skin tears
- Muscle weakness
- Blurred vision
- Increase in blood sugar (diabetes)
- Mood swings
- Increased blood pressure (hypertension)

Gengraf® (Cyclosporine)

Gengraf® (Cyclosporine) is a potent anti-rejection drug used for patients having difficulty tolerating Prograf®. You will not be taking Gengraf® and Prograf® and at the same time. Gengraf® comes in 25 mg and 100 mg capsules, and the dose will vary depending on the blood levels of the medication.

Special instructions:

- Must be taken every 12 hours.
- If possible, take it first thing in the morning on an empty stomach an hour before breakfast. This allows your body to absorb the medicine better and in lower doses.
- Take Gengraf® at the same times each day and in the same relationship to other medication since they can alter how Gengraf® gets absorbed in your body.
- Must be taken one hour before eating or two hours after eating.
- Do not take with other medications.
- Do not consume grapefruit or grapefruit juice while you are on cyclosporine; the interaction can dangerously increase the medicine's level in your blood.
- Take each dose with a full glass of water.
- Do not store capsules out of foil wrappers.
- Do not store in refrigerator or leave in hot sun.
- The capsules have a funny smell. You may take your dose out of the foil and let the capsules stand for five to ten minutes if the smell offends you.

Potential side effects:

- Increased risk of infection
- Damage to kidneys
- Elevated blood pressure
- Headaches
- Trembling hands and voice
- Tingling of hands and feet
- Increased body hair
- Thickening of gums
- Anemia
- Irritation of the liver
- Ringing in the ears

Imuran® (Azathioprine)

Imuran® (Azathioprine) is an anti-rejection drug that reduces the number of white blood cells that attempt to reject an organ. Imuran® is given by vein initially and later taken once a day in pill form. The dose varies based on blood counts. Imuran® comes in 50 mg tablets.

Potential side effects:

- Low blood counts
- Increased risk of infection
- Predisposition to mouth ulcers
- Irritation of the liver and pancreas
- Nausea, vomiting, diarrhea, upset stomach

Rapamune® (Sirolimus)

Rapamune® (Sirolimus) is an anti-rejection medication often prescribed when there is evidence of kidney injury. It is usually added in combination with a steroid medicine (i.e. prednisone) and Prograf® or Gengraf®. Rapamune® comes in 1 mg tablets. The dose will vary depending on the blood levels of the medication.

Special instructions:

- Do not consume grapefruit or grapefruit juice during treatment.
- Rapamune® is usually taken once a day. It is recommended that Rapamune® be taken four hours after taking Prograf® or Gengraf®.
- Rapamune® can be taken either with or without food, but it is very important to take every dose of Rapamune® in the same relation to food.

Potential side effects:

- Water retention or swelling
- Nausea, vomiting, diarrhea
- Increased blood pressure
- Increased cholesterol or triglyceride levels
- Fever
- Leg cramps, weakness
- Rash or acne

REJECTION TREATMENT IMMUNOSUPPRESSIVE DRUGS

Solu-Medrol® (Methylprednisolone)

Solu-Medrol® (Methylprednisolone) is used to treat acute rejection and is the IV equivalent of prednisone. A very large dose, usually 750 mg to 1000 mg is given once a day for three consecutive days. The side effects similar to prednisone, but because of the large doses its effects on blood sugar and mood may be more pronounced.

Thymoglobulin® (RATG)

Thymoglobulin® (RATG) are antisera raised in rabbits which treat recurrent or refractory rejection. They are given by IV once a day for consecutive 7-10 days. You will need to be hospitalized for the entire duration of treatment

Special instructions:

- Tylenol® and Benadryl® and other medications are given to relieve its side effects.

Potential side effects:

- Decreased blood counts
- Fever
- Shaking chills
- Increased risk of infection
- Joint swelling or pain
- Rash or itching

Infection Prophylaxis

ANTIBIOTICS

Bactrim® (Septra®, trimethoprim-sulfamethoxazole)

Bactrim® (Septra®, trimethoprim-sulfamethoxazole) is prescribed to prevent a life-threatening pneumonia called Pneumocystis pneumonia (PCP). It is taken as 1 double-strength or 1 single-strength tablet every Monday, Wednesday, and Friday.

Potential side effects:

- Nausea and vomiting
- Rash
- Lowered white blood cell count

ANTIVIRAL DRUGS

Valcyte® (Valganciclovir)

Valcyte® (Valganciclovir) is an antiviral drug that helps prevent reactivation and treat infections with cytomegalovirus (CMV). Tablets are supplied as 450 mg

Special instructions:

- Do not crush or split tablets.

Potential side effects:

- Decreased blood counts

ANTIFUNGAL DRUGS

VFEND® (Voriconazole)

VFEND® (Voriconazole) is another antifungal medication to prevent and treat Aspergillus. The usual dose of voriconazole is 200 mg twice a day and comes in 200 mg or 50 mg tablets.

Special instructions:

- Take voriconazole at least one hour before or after a meal.
- Take each dose with a full glass of water.

Potential side effects:

- Blurred vision, increased sensitivity to light, or other visual changes
- Rash or redness
- Sun sensitivity
- Hallucinations

ANTIFUNGAL DRUGS *continued*

Amphotericin B (ABELCET®)

Antifungal medication used to prevent serious fungal infections following lung transplant.

Special instructions:

- Delivered via a nebulizer

Potential side effects:

- When inhaled, amphotericin may cause some irritation to the lungs, or coughing. If these occur, tell your doctor or respiratory therapist promptly.

Nystatin (Mycostatin®)

Nystatin (Mycostatin®) is prescribed to help prevent and treat yeast infections of the mouth and throat.

Other Medications

- Magnesium is prescribed to replace this normal body salt that is wasted in your kidneys when you take Prograf® or Gengraf®.
- Calcium with Vitamin D is given to prevent and treat osteoporosis.
- Fosamax® (Alendronate), Actonel® (Risedronate), and Boniva® (Ibandronate) are all prescribed to prevent and treat osteoporosis, which is very common before and after lung transplantation. These are oral medications that will be taken for several years. The typical doses are: Fosamax® 70 mg weekly, Actonel® 150 mg monthly, and Boniva® 150 mg monthly.

You will be prescribed one of these medications depending on your drug prescription coverage.

Special instructions:

- Take at least 30 minutes before the first food or drink of the day other than water.
- Swallowed while in an upright position and with a full glass of plain water.
- Do not lie down for 30 minutes after taking the medication

Potential side effects:

- Chest pain
- Difficulty or pain when swallowing
- New or worsening heartburn
- Jaw, bone, or muscle pain

Heading Home from the Hospital

Going home with a new lung is very exciting. However, it can also be overwhelming because of the medications you must take and the risks involved with transplant. Before you go home, we will thoroughly review with you and your family what you need to do to keep your transplanted organ healthy.

The transplant coordinator, social worker, physical therapist, pharmacist and nurses will begin preparing you for discharge the day you transfer from the intensive care unit to the surgery floor. As noted earlier in the MEDICATIONS section, you will learn about your medications, how to take them, how to keep your own medications records, and where to purchase medications.

Daily Journal

Vital Signs

The transplant coordinator will provide you with a binder that will assist you in keeping your vital signs in an organized fashion. A thermometer and automatic blood pressure cuff will be ordered for you in the hospital. We ask that you check your temperature, heart rate and blood pressure every morning and every evening. The nurses will teach you how to check these vital signs so that you will feel confident doing this before you go home.

If there is a problem after discharge, the coordinator may ask you what your vital signs have been running for the past few days. Please have the journal available when you call the office.

Daily Weight

We ask that you weigh yourself every morning. Please try to do this in the morning after urinating and before eating breakfast and while wearing the same amount of underclothes. Write the weight in your journal every day. If you have gained more than two to three pounds in 24 hours or more than four or five pounds over two to three days, we ask that you call the transplant office. You may be retaining some fluid, more than likely due to a side effect of your medications and or/excessive salt intake.

Medic Alert Identification

We strongly suggest that you obtain a special medic alert bracelet or necklace. In case of a car accident or other type of emergency, this will alert health care professionals that you have had a transplant. The identification bracelet or necklace costs a nominal fee. To enroll, call 800-432-5378 or fill out the order form provided by the transplant coordinator.

Discharge from the Hospital

If you live in the Louisville area, you will be discharged to go home from the hospital. However, if you live more than 60 miles from Jewish Hospital, we ask that you stay in the area for 4-6 weeks to monitor your progress closely.



IMPORTANT PHONE NUMBERS

Lung Transplant Office: 502-587-4384 • 24 hours/day, 365 days/year

Hospital Operator: 502-587-4011

Regular office hours are Monday – Friday, 8:30 a.m. – 4:30 p.m.

After hours and weekends, the answering service will page the Coordinator on call for emergencies only.

Check-Ups

After your transplant, all appointments are scheduled at Trager Transplant Center Clinic, which is located on the third floor of the UofL Health – Frazier Rehab Institute building. You will start your appointment by reporting to the reception area to check in.

For the first few months, you will have many follow-up appointments. These visits may include lab work, chest X-rays, pulmonary function tests, chest CT, and bronchoscopies. They also include seeing the coordinator, who will review all of your medications and ask how you have been feeling. You will be asked specific questions about your vital signs, energy level, appetite, breathing, swelling of the feet, and rehab activities. This is a great opportunity for you to express any concerns or ask questions. After the coordinator sees you, the doctor will examine you.

Remember, do not take any medications except for blood pressure medication when having a bronchoscopy or lab work done. Please bring all of your morning medicines with you to the hospital so that you can take them after the bronchoscopy or lab work. Also, remember to bring your daily journal to all appointments for review.

Routine Blood Tests

We will check lab work with every clinic visit. Monitoring your blood through lab tests is one way that we can make sure that you are taking the right amount of medication. Do not take your morning medication (except for blood pressure medication) before coming for a scheduled visit because we will give you a special blood test to measure the your Prograf® or Gengraf® levels in your blood.

On occasion, we may ask you to have your blood checked either at Jewish Hospital or in your hometown. We have a special instruction form for laboratories outside Jewish Hospital, which includes mailing a small sample of blood to us for your Prograf® or Gengraf® level. It explains what blood work to draw and how to report the results.

If you have your lab work done in your hometown, we also ask that you always call our office on the day that your blood is drawn so that we can check on the results. Within five days after the labs are drawn, a coordinator will call you with any medication changes and let you know when to have your blood checked again. If you have not heard from a coordinator in five days, please call the office to check on your results.



Do NOT eat or drink ANYTHING after midnight except blood pressure medicine and water before having your blood drawn. Do NOT take Prograf® or Gengraf® the morning of your blood test.



Bronchoscopy

A bronchoscopy will be performed on a regular basis to check for lung rejection or infection. Generally, bronchoscopies are done according to the following schedule, but may be performed more frequently if you have been treated for rejection or if clinically indicated:

- At week one and two
- At month one, two and three
- At month six
- At 12 months

On the morning of your bronchoscopy, do not take any medications except for your blood pressure pills. You also should not eat for 8-12 hours before the procedure.

On the day of your bronchoscopy, you will need to go to the Endoscopy Lab on the first floor of the UofL Health – Outpatient Care Center (OCC). You will be given some medications to make you more comfortable during the procedure. Your doctor will pass a flexible fiber-optic tube (called a bronchoscope) through your mouth or nose down the windpipe to the lungs. At the same time, the doctor may take samples of lung tissue and cultures. All of these samples are useful in determining if there is rejection or infection present, even before you experience any symptoms or before a chest X-ray shows any abnormality. Problems that are detected early can be treated much more easily.

After the bronchoscopy, you will stay in a recovery area until you are fully awake and alert. You will not be allowed to drive home following the bronchoscopy, so please have a driver available. Do not plan any activity for the day you have a bronchoscopy.

Your doctor will tell you about symptoms to report, but it is not unusual to run a low-grade fever for 12-24 hours after a bronchoscopy. Call your transplant coordinator if you experience any of these symptoms after a bronchoscopy:

- Coughing up fresh blood (streaks of blood or flecks of clots mixed with phlegm is not unusual)
- Shortness of breath
- Temperature of 100.5° Fahrenheit or greater
- Chest pain especially with deep breathing

Biopsy results are usually available by early evening on the day after the procedure. Cultures may take up to 5 days before final results are available. After a physician has looked at the results of both the blood work and bronchoscopy, a coordinator will call you with your results. The coordinator will tell you what medications to change and when we will need for you to have more lab work.

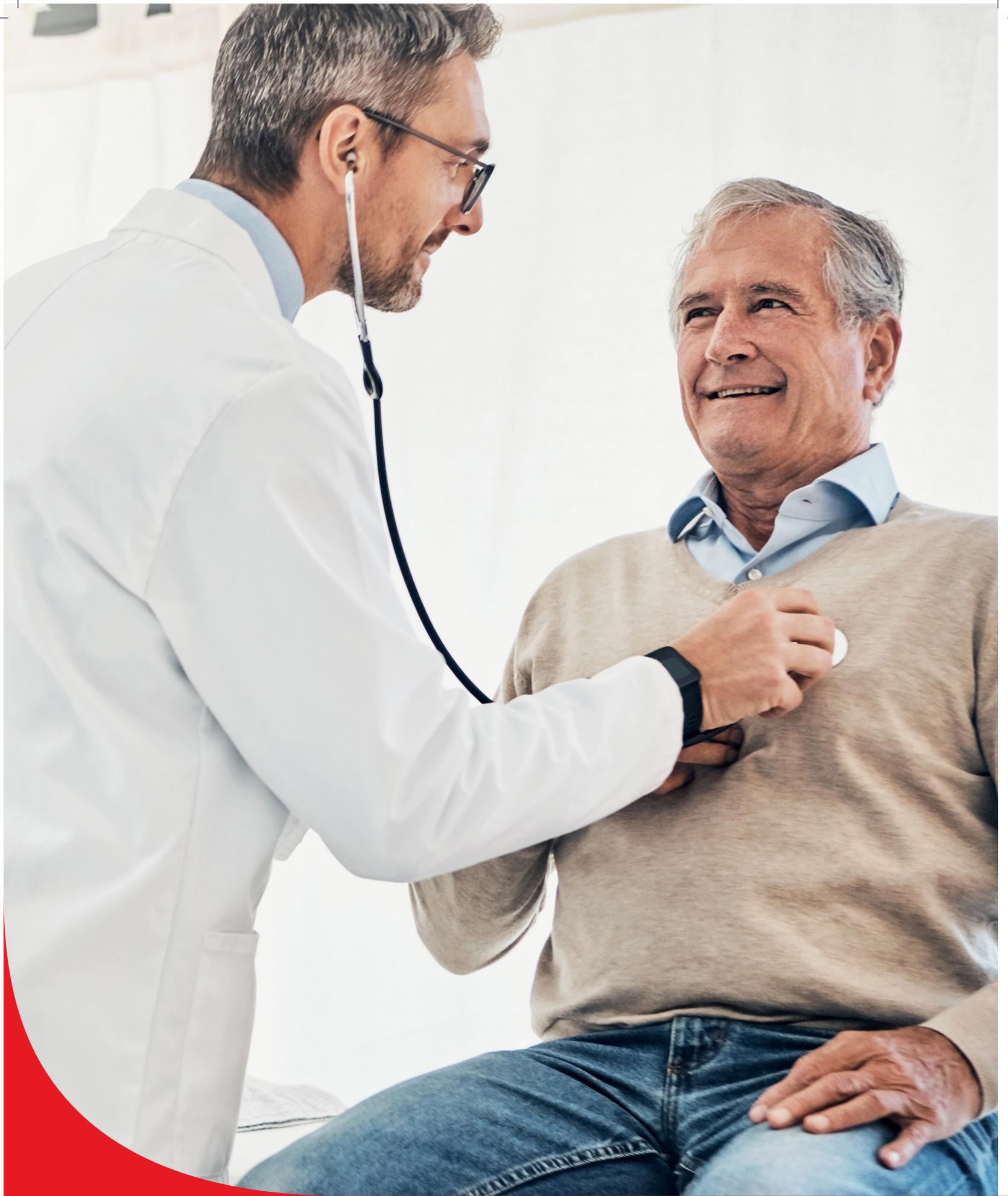
Do NOT eat or drink anything after midnight except for blood pressure medication on days when having a bronchoscopy.

Annual Exams

Every year, around the anniversary of your transplant, you will have your annual exam.

Annual visits include:

- Pulmonary function tests (PFTs)
- Chest x-ray (CXR) or Chest CT
- Urine collection
- Blood work
- Office visit
- Bronchoscopy



Staying Healthy

HELPFUL HINTS

- Keep all clinic appointments
- Never run out of medications
- Report changes in vital signs listed in section called “When To Call the Transplant Coordinator.”
- Also report any symptoms of illness to your transplant coordinator.
- Never take Prograf® or Gengraf® before having blood drawn.
- Never take over-the-counter drugs without checking with the transplant coordinator. They may interfere with your transplant medications.
- Never smoke and avoid smoke-filled areas. Ask family members not to smoke.
- Avoid lifting heavy objects and strenuous physical work for at least six weeks after transplant.
- No NSAIDS such ibuprofen, naproxen or Motrin®.

Your Daily Routine

Developing and adhering to a daily routine of checking vital signs and weight is the best way to detect post-transplant problems early.

- Home spirometry and taking your medications exactly as prescribed will help prevent post-transplant complications.
- Take your vital signs (temperature, blood pressure, heart rate) first thing in the morning while at rest. Record them in your daily journal.
- Weigh first thing in the morning and record your weight in your journal. Weigh around the same time and in the same amount of clothing. You may use bathroom scales.
- Do home spirometry twice a day for the first four to six weeks after surgery.
- If possible, take your Prograf® or Gengraf® first thing in the morning on an empty stomach an hour before breakfast. This allows your body to absorb the medicine better and in lower doses.
- Avoid grapefruit and grapefruit juice. Gengraf® or Prograf® as it can dangerously increase both medicines’ levels in your blood.
- Take your other medications with breakfast.
- Check vital signs again in the evening.
- Take your evening Prograf® or Gengraf® dose 12 hours after your morning dose and at least two hours after dinner.

Bathing

You may shower and bathe when the surgeon gives you permission. If you feel weak when standing in the shower, it may be a good idea to put a stool in the shower stall. Try not to use excessively hot water; it may dramatically lower your blood pressure and cause you to feel dizzy.

Driving

You will not be allowed to drive for at least eight weeks after your transplant. Your reaction time is decreased because of the surgery, anesthesia, medications and bed rest. It also takes about eight weeks for your incision to heal properly. You may ride in a car during this time, but you must always wear a seatbelt. The coordinator will tell you when you are allowed to drive.

Exercise

After your transplant, you will begin an exercise program in the hospital under the direction of the physical therapist. **After you are discharged, you must continue pulmonary rehabilitation.**

Exercise helps counteract the weakening effects of your pre-transplant illness and helps offset possible side effects of the immunosuppressive drugs you must take after transplant. Those side effects may include weight gain, water retention, high blood pressure, elevated cholesterol, high blood sugar and weakened bones. Regular activity also promotes confidence and a sense of wellbeing.

Five to ten minutes of warm-ups and cool-downs before exercise will allow time for the heart rate to adjust to your exercise intensity without causing excessive weakness or fatigue. Walking and stationary cycling are excellent warm-up and cool-down activities.

Stop the exercise if you become dizzy, short of breath, nauseated, extremely tired or if you are sweating excessively.

Avoid these activities during the first six weeks after transplantation:

- Lifting more than 10 pounds
- Forceful pushing or pulling
- Use of a regular bicycle
- Contact sports

Limit your activity level to the warm-up or cool-down intensity if you have an infection, rejection, fever or if your resting heart rate is more than 20 beats per minute higher than your usual resting heart rate. Contact your physical therapist if you have any questions about your exercise program.



My physical therapist is: _____

Phone number: _____

Sexual Activity

Sexual activity may be resumed after discharge from the hospital. This will not harm your new lung. For the first six weeks after surgery, we advise taking a passive position that will not put pressure on your chest. You should expect your sex life to be healthy and enjoyable. If problems develop, please consult the transplant team.

Pregnancy

Women: Please talk to the transplant team if you are thinking about becoming pregnant. We can discuss pregnancy and birth control with you. Since there is little current data on transplant patients and pregnancy, advice on whether or not to become pregnant must be made on an individual basis. In general, we advise against pregnancy.

Men: Please talk to the transplant team if you are thinking about fathering a baby.

Protecting Yourself from Infection

In the first month after transplant, you will be on the highest doses of your immunosuppressant medications. This is the time when you will be more likely to get an infection, but there are certain things you can do to protect yourself:

- Wash your hands carefully and frequently. This is the single most effective way to decrease the spread of germs and to prevent infection.
- During your first month after transplant, avoid large crowds of people in areas such as airports, movie theaters and malls. You may go to the grocery store or a restaurant during times when these places are less crowded.
- After returning home, you may go out in public and have visitors.
- Avoid anyone who has any kind of infection that might be contagious. Avoid friends or family who have a cold, the flu, a virus or any other illness until they are well.
- Keep cuts and scratches clean and dry. Inspect these areas regularly for any sign of infection and notify the transplant team if you see any of these signs: redness, swelling, tenderness or drainage.
- Simple sore throats and ear infections can turn into bigger problems in transplant patients because your immune system is suppressed. Please notify the transplant coordinator of any signs of infection such as fever, shortness of breath, cough, sore throat, fatigue, headache or flu-like symptoms.
- Aspergillus is a fungus that can cause disease which can be fatal to immunosuppressed patients if not treated early. This fungus is found in soil, leaves and hay, so caution with gardening is advised. Also avoid construction and demolition areas. Wear a mask if you must be near any of these places.
- Pets can be a source of infection, so you need to exercise extreme caution. Dogs and cats should be screened for disease and regularly de-wormed. Avoid scratches or being licked. Do not clean litter boxes, animal cages, and aquariums.
- Avoid eating raw or undercooked meat or fish.
- Exposure to fumes and particulate matter may not cause infection but can damage lung tissue. Avoid fumes from solvent, paint, cleaning compounds, insecticides, etc. Avoid smoke from cigarettes and fires. Avoid dust from heavy cleaning, woodworking, yard work, etc. A mask may help if you encounter dust.



It's a good idea to carry a small bottle of hand sanitizer (like Purell®) with you and use it frequently, especially in public places.

Returning to Work

One of the goals after transplantation is to help patients return to work when they are physically and emotionally ready. Returning to work can be as easy as returning to a previous job. We ask that you not return to work with three months of your transplant. Unless there is a significant complication lung transplant is not considered a disability.

Travel Tips

If you choose to travel long distances for an extended period of time after your transplant, please notify the transplant coordinator. We can tell you the location of the transplant center nearest your destination in case any problems should arise. Air travel is discouraged during the first 12 months after your transplant due to high level of immunosuppression during the first year after transplant.

If you plan to travel overseas, alert the transplant team. Some required vaccinations may be harmful to transplant recipients. Always take your medications with you on the plane, in case your luggage is lost in flight. Also remember to bring extra medications in case you were to lose some of yours. We suggest that you wear a Medic Alert bracelet or necklace and carry an ID card that identifies you as a transplant recipient. This identification should have the contact number of the transplant team. In case of emergency, it is also a good idea to carry a list of your current medications.

Routine Medical Care

Routine medical care is important for early detection and treatment of disease. We recommend routine medical care not only because it makes good sense, but also because some of the medications transplant patients take can affect other body systems. All transplant patients will need to identify a primary care physician and should have periodic visits with them in addition to your visits with the transplant team.

Dental Exams

Some transplant patients experience problems with tender, swollen gums. To avoid tooth and gum problems, we recommend dental visits every six months and sometimes as often as every three months. If problems do arise, you may need to see a periodontist (a dentist specializing in gum problems). You may also be more prone to developing mouth sores and ulcers. Report any sores or white patches in your mouth to the transplant coordinator.

Generally, antibiotics are not needed before or after routine dental procedures, such as periodic exams and cleanings. In certain cases, antibiotics may be prescribed to protect your heart valves from becoming infected with bacteria from the mouth that gets into the blood stream. Contact the transplant coordinator prior to dental procedures to see if your situation requires antibiotics.

Eye Exams

We recommend routine eye examinations in addition to vision screening annually by an ophthalmologist. Prednisone and other medicines can cause changes in eyesight, including blurry vision, but also cataracts, glaucoma, or retinal problems. Tell your ophthalmologist that you had a transplant so he or she may specifically test for these conditions.

Skin Exams

One complication that is frequently seen in transplant recipients is skin lesions. The medications may make your skin sensitive, causing this condition. Because your immune system will be suppressed, you may also be more likely to develop skin cancers.

Skin cancer is the most common cancer in the United States. The cause of skin cancer is well known. Prolonged exposure to the sun, especially if it results in sunburn and blistering, plays a key role in beginning skin cancer. The majority of skin cancers occur on parts of the body not protected by clothing, such as the face, neck, forearms and back of hands. Therefore, we recommend always wearing a hat and using sunscreen (SPF 30 or greater) any time you are outside in the sun.

Even if you avoid the sun, it is not uncommon for you to develop skin lesions, growths and spots on various parts of your body. These skin problems may occur in places sunburned previously, even decades ago. Any such area should be reported to your physician promptly and watched closely for the warning signs of skin cancer. Most skin cancers are easily treatable if discovered early enough. For better detection, post-transplant patients should have a full body scan performed at least once a year by a skin cancer doctor. You will be seen much more quickly if you are an established patient.

FOR WOMEN ONLY:

Pap Smears

As a transplant patient, you may be more susceptible to cancer because of your altered immune system. Women taking transplant medications may be at increased risk of getting cervical cancer. Regular pap smears are an excellent method for early detection and treatment of cervical cancer. A Pap smear is the primary test for detecting cervical cancer, because there are usually no physical signs of this problem. Cervical cancer is 100 percent curable if it is detected early enough.

The transplant team follows the American Cancer Society recommendation of annual pap smears and pelvic exams for all women over the age of 18. Women who are or have been sexually active should have yearly exams regardless of age.

We also recommend good health practices such as prompt treatment of vaginal and cervical infections, limiting the number of sexual partners, and using condoms to avoid sexually transmitted diseases.

Breast Self Exams

As many as 95 percent of breast cancers are accidentally discovered. All women should perform regular exams 7-10 days after each menstrual period as a routine good health habit. We join the American Cancer Society in recommending that all women over age 20 perform monthly breast self-examinations. Your local physician or gynecologist should be able to instruct you in this practice. We also recommend breast exams by a physician every three years if you are between 20 and 40 years old and annually for women over the age of 40.

Mammograms

A mammogram uses a very small, safe amount of radiation to detect masses or tumors in the breasts. The American Cancer Society recommends that all women have a baseline mammogram done between the ages of 35 and 39. Women should then have a mammogram every one or two years until age 50 and then every year until age 75.

FOR MEN ONLY:

Prostate Exams

All men over the age of 50 should have a rectal exam yearly. During this exam, the prostate is examined to see if it is enlarged or infected, and the stool is checked for blood. Men over 50 should also get a special blood test called a prostate-specific antigen (PSA) to screen for prostate cancer. This test will be part of your annual transplant exam at Jewish Hospital. If anyone in your family has ever had prostate cancer, start having this blood test at age 45.

Routine Check-up Schedule

- Dental: Every 6 months
- Eyes: Every year
- Skin: Every year
- Mammogram (women): Every year
- Pap smear (women): Every year
- Prostate (men): Every year
- Colonoscopy: Every 5 years

Immunizations

All transplant candidates and recipients should receive a pneumococcal vaccine to protect against one strain of pneumonia. Pneumococcal vaccination should be repeated if you are over the age of 65 and it has been more than five years since your previous one. We recommend that all transplant patients and their family members receive a yearly flu shot, and all patients should also receive the combination tetanus-diphtheria-pertussis booster shot every 10 years.



AVOID VACCINATION WITH LIVE VIRUSES such as FluMist®

Transplant recipients should not receive live vaccinations, because they can actually cause the disease we are trying to prevent. This includes the measles, mumps and rubella (MMR), oral polio (OPV), smallpox, and nasal influenza vaccinations.

Household contacts and siblings of immunosuppressed transplant patients should not receive either the oral polio vaccine (OPV) or smallpox vaccinations because they are easily transmitted. The inactivated polio vaccine may be given instead.

Household contacts may receive the MMR vaccine and children of transplant patients may safely receive the chicken pox vaccine because person-to-person transmission does not occur.



IMMUNIZATION SCHEDULE

- Influenza (injectable only) : Every October
- TDap: Every 10 years
- Pneumovax: Once, if over the age of 65 AND your last one was more than 5 years ago

Nutrition

Proper nutrition is necessary before and after your transplant. A balanced, low-fat diet will help you maintain a healthy body weight as well as reduce high blood cholesterol levels. A low-salt and limited-fluid diet will help reduce fluid retention. You also may need to reduce the amount of carbohydrates and sweets in your diet to help control high blood sugar.

Our clinical dietitian will meet with you and your family to evaluate your diet and teach you about the right foods to eat to meet your special needs. While waiting for an organ and after your transplant, the dietitian will adjust your diet as necessary. Our dietitian also is available to answer any questions you or your family may have and to help with meal planning at home.

Before your transplant, it will be important for you to reach and maintain a healthy body weight and to eat a balanced diet to keep your strength up while waiting for your transplant. We will ask you to reduce the table salt and sodium in your prepared food to prevent your body from retaining too much fluid or water. Some patients have poor appetites and need special attention to ensure good nutrition.

After your transplant, you will continue to follow a strict diet as well as take many medications. Some of these medications may cause side effects, such as elevated blood sugar, elevated blood cholesterol, fluid retention and especially weight gain. You must make a special effort to follow your diet, even though you will be enjoying your food again. Our dietitian will develop individual guidelines and menus to fit your specific needs and it will help if your family members follow a healthy diet with you.



For More Information

To learn more about UofL Health
– Trager Transplant Center and
our services or to be referred to a
physician, call 502-587-4384 or
visit UofLHealth.org/Transplant.

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