Lung Transplantation
Patient Guide

BJH13062 11/13
Lung Transplantation  Patient Guide

Phone and Fax Numbers:
Phone: 314-362-5378 or 800-321-4054
Fax: 314-362-9272

Please listen to the entire message when calling our office for the first time and follow the instructions given to you.

- During business hours
  - Please listen to the message and follow the prompts.
  - Please note that the office is closed for lunch daily from 11:30 a.m.-12:30 p.m.

- After hours
  - If there is an emergency, follow the prompts to reach the answering service operator who will page the on-call nurse transplant coordinator.
  - If you wish to leave a message and have your call returned on the next business day, press 2 and listen to the prompts.

We recommend you add the lung transplant office phone number to your cell phone contacts.

Transplant Office Hours:
Monday-Friday 8 a.m.-4 p.m.

Physical Address:
Barnes-Jewish Hospital
Transplant Administration
4901 Forest Park Ave.
Located on the 5th floor of the Center for Outpatient Health
St. Louis, MO 63108

Mailing Address:
Barnes-Jewish Hospital
Lung Transplant Office
Mailstop 90-75-549
4901 Forest Park Ave.
St. Louis, MO 63108

Office information:
The lung transplant office is closed in observance of the following holidays:
- January 1 (observed)
- Memorial Day
- July 4 (observed)
- Labor Day
- Thanksgiving and the Friday after Thanksgiving
- Christmas (observed)

Occasionally, the phones in the lung transplant office are sent to the Answering Service during regular office hours. If you call during office hours and you get the Answering Service, consider calling back later unless it is an emergency. If it is an emergency, give the information to the Answering Service, and your call will be returned as soon as possible.
Barnes-Jewish Hospital and Area Resources

BarnesCare Travelers’ Health Services
314-331-3050; barnescare.com

Barnes-Jewish Home Health
314-953-2000

Barnes Lodge
314-625-4319 or 800-551-3492

Chaplain, Charlie Dey
314-362-7525

Diabetic Center (through Top Docs)
314-867-3627 or 866-867-3627

Dietician, Kate Stockman
314-454-7152

Financial Coordinator, Cina Winfrey
314-362-5516

Guest and Patient Relations
314-362-5196

Laboratory Outpatient, Main Level South
(Guest Services)
314-362-1239

Lost and Found
314-362-7648 or 314-747-5678

Lung Center
To schedule clinic appointments and
Pulmonary Function Tests (PFTs)
314-454-8917 or 877-888-5864

Medical Record Requests, Inpatient
314-454-5934 or 314-362-3651 (fax)

Medical Record Request Washington
University, Out-patient
314-454-8659 (fax)

Mid America Transplant Services
314-735-8200; mts-stl.org

Minor Procedures Area 10th Floor CAM
314-362-2597

Parkway Hotel
314-256-7777 or 866-314-7700; parkwayhotel.com

Pharmacist, Lung Transplant
314-362-5378 or 800-321-4054

Pharmacy, Barnes-Jewish Hospital Out-Patient,
Center for Advanced Medicine (CAM) 3rd Floor
314-454-7666 or 877-882-1687

Pre-Registration: Radiology, Bronchoscopy,
& Minor Procedure Area
314-362-1173 or 800-292-3648

Pulmonary Rehab
314-362-4157

Radiology 2nd Floor for Chest X-Ray, South
314-362-7112

The Rehab Institute of St. Louis
314-658-3800

Social Worker, Rebecca Bathon
314-362-6127

Top Docs Referral Service
314-867-3627 or 866-867-3627

Vision Center
(South) 314-362-6123 (North) 314-747-9454

Barnes-Jewish Hospital Security

Emergency on Campus
314-362-0911, in-house phone 20911

Non-emergency
314-362-0750, in-house phone 20750

Parking
314-362-0732

Shuttle Service
314-362-0750
Map of the Lung Transplant Medical Center

Lung transplant office: 5th floor

Clinic visits & PFTs: 8th floor

Bronchoscopy: 10th floor

56 ICU: 5th floor of Southwest Tower

Chest x-rays: 2nd floor

Where to report for lung transplant: Queeny Tower 7th floor to 7100

Pulmonary Rehab: street level

Lab Work: main level

Directions to the Medical Center on back
Directions to the Medical Center

Barnes-Jewish Hospital is conveniently located in St. Louis, Missouri, one block north of the I-64/US40 and Kingshighway Boulevard intersection. Our medical center campus is located in the Central West End neighborhood, across from Forest Park.

From the North
Take I-70 to I-170 South, then
I-170 South to I-64/40 East
I-64/40 East to Kingshighway, exit north
The hospital is immediately north of the exit, on the right.

From the South
Take I-55 North to I-44 West
I-44 West to Vandeventer/Kingshighway exit
Go straight at stoplight at end of exit ramp.
Continue straight until next stoplight, this is
Kingshighway. At Kingshighway, turn right; go about one mile north on Kingshighway, crossing over I-64/40 to the stoplight. The hospital is immediately north of the exit, on the right.

From the East
Take I-64 West to I-64/40 West; I-64/40 West to Kingshighway, exit north
The hospital is immediately north of the exit, on the right.

From the West
Take I-64/40 East to Kingshighway, exit north
The hospital is immediately north of the exit, on the right
-OR-
Take I-44 East to Kingshighway, exit north
Go about 1 mile north on Kingshighway, crossing over I-64/40 to the stoplight. The hospital is immediately north of the exit, on the right.

Parking
Barnes-Jewish Hospital South: The entrance to the South Garage is on Barnes-Jewish Hospital Plaza, right/south of hospital. Valet parking is to the left of the main entrance of Queeny Tower.

Center for Advanced Medicine (CAM): Once off the highway, continue North on Kingshighway to Forest Park Avenue. Turn right onto Forest Park Avenue, and then turn right again at the 1st stop light, which is Euclid Avenue. The CAM is immediately on the right. The North Garage is on the left. Valet parking is available at the entrance to the CAM (on the right).

Assistance When You Arrive
The Guest Services team is here to make your visit pleasant and convenient. Call 314-362-5194 (or toll-free 800-451-4892) between 8 a.m. and 5 p.m. Please call before the day of your appointment to ensure that staff will be available to assist you. Upon arrival, someone will direct you to your appointment and help you with other special guest services.

Short-term Housing, Nearby Hotels and Restaurants
You should speak with the social worker for specific information about area housing and amenities. Guest Services also provides complimentary concierge services, and they can help you in finding area housing or with other special requests. Call 314-362-5194 or visit barnesjewish.org/patients-visitors/services for more details.
The Transplant Team

**Transplant Pulmonologists:** These doctors are lung specialists and will discuss lung transplantation with you. They will manage your lung disease before transplantation and your lung transplantation care afterwards.

**Transplant Surgeons:** These doctors perform the transplant operation and will explain the procedure to you. They will also follow your progress and manage any surgical care.

**Transplant Nurse Coordinator:** One registered nurse will be your main contact person on the transplant team and will coordinate your care. The coordinator will discuss transplantation and help manage your care before and after the transplantation. You will be assigned a pre-transplant coordinator who will assist you through the evaluation process and while you wait for a lung transplant. After transplantation, you will transition to a different, post-transplant coordinator who will assist you with medical care after surgery.

**Social Worker:** The social worker has access to community resources and can provide you with information on housing, transportation, medical equipment, employment, legal issues, and finances. The social worker can also provide you with individual or family counseling when your illness causes anxiety, depression, family conflict, stress, bereavement, or changes in physical or mental capabilities.

**Financial Coordinator:** The financial coordinator will work with you to plan the financial aspects of transplantation, including insurance and hospital bills related to the transplant process.

**Transplant Anesthesiologists:** These doctors are responsible for putting you to sleep during the surgery and may help with pain management after the surgery.

**Transplant Dietitian:** The dietitian will assess your nutritional status and help you select the necessary dietary changes or supplements to take before transplantation. The dietitian is also available after transplant for nutritional counseling.

**Transplant Clinical Pharmacist:** This pharmacist will teach you how to take your medications and will be a resource for questions and issues related to your medications.

**Pulmonary Rehabilitation Specialists:** These specialists will oversee your rehabilitation to help you increase your strength and endurance before and after transplantation.

**Chaplain:** A chaplain will provide you with spiritual and emotional support as needed.

**Transplant Secretaries:** The secretaries are instrumental in scheduling appointments, providing general information and getting you in touch with the appropriate person to answer questions.

Qualifications of the Pulmonologists and Surgeons

The pulmonologists and surgeons at the Transplant Center who will conduct your transplant surgery and provide ongoing care for you are highly educated and experienced in lung transplantation. For additional information about specific surgeon qualifications please visit BarnesJewish.org/lungteam.
How the Lungs Work

The cells that make up your body use oxygen from the air you breathe. When cells use oxygen, they produce carbon dioxide as a waste, which needs to be removed from the body. The lungs have the job of delivering oxygen to the body and removing the carbon dioxide. When you breathe in, oxygen from the air moves into the lungs and is transferred to the blood. The pulmonary veins transport the oxygen-rich blood to the heart, where it is then pumped throughout the body. When cells use the oxygen, waste carbon dioxide is transferred to the blood. This blood is transported back to the heart, and then back to the lungs through the pulmonary arteries. The lungs remove the carbon dioxide from the blood when you exhale. This gas exchange occurs thousands of times per day, each time you breathe in and breathe out.

Everyone has two lungs which are located in the chest cavity. They are protected and supported by the ribs, diaphragm and muscles in the chest and neck. Each lung is made up of smaller sections called lobes. The right lung consists of three lobes and the left lung consists of two lobes. Each lobe is made of millions of tiny sacs called alveoli. Alveoli are where the inhaled oxygen is transferred to the blood and where the carbon dioxide is transferred from the blood to the lungs. The alveoli are connected to small tubes called bronchi, which gradually join together into one main tube called the bronchus. Each lung is connected to the windpipe (or trachea) by one main bronchus tube. A layer of thin tissue (called pleura) surrounds each lung.

Lung Diseases That Lead to Transplant

A variety of lung diseases may progressively damage the lungs, impair the function of the lung and ultimately lead to death. Some of these diseases include:

- Idiopathic Pulmonary Fibrosis
- Chronic Obstructive Pulmonary Disease (COPD)
- Emphysema
- Alpha-1 Antitrypsin Deficiency
- Cystic Fibrosis
- Pulmonary Hypertension
- Bronchiectasis
- Bronchitis
- Eosinophilic Granulomatosis
- Lymphangioleiomyomatosis
- Sarcoidosis
- Others

When the lungs are functioning properly, you are hardly aware of it. Unhealthy or damaged lungs are unable to supply a sufficient amount of oxygen to the body or cannot expel carbon dioxide efficiently. This may result in a constant feeling of being out of breath or fatigued. A lung transplant may be necessary when your health diminishes significantly and there are no other treatments to help repair the lungs or improve lung function.
The Benefits of Having a Transplant

Transplantation is indicated when it would potentially improve life expectancy and quality of life, i.e., when you would be likely to live longer and better with a transplant than with your lung disease. It can be difficult and imprecise to compare your expected survival after lung transplantation and your projected survival with your lung disease. However, this is the basis for deciding the right time to proceed with transplantation. While lung transplantation is a serious and complicated process, the risks of the surgery and recovery may eventually outweigh the detrimental effects of your lung disease and may provide for improvements in quality of life and length of life.

Risks of Transplant

Risks of Getting a Disease from the Donor

There will always be a risk of contracting a disease or infection from the lung donor through transplantation. This risk is minimal, and donor lungs are inspected before transplantation. All donors are screened for HIV, Hepatitis B, Hepatitis C and cytomegalovirus (CMV).

Other Treatments You Could Get Instead of Transplant

Lung transplantation is usually sought as the final treatment option for patients who did not respond well to other treatments. Speak with your pulmonologist or transplant coordinator to see if there are other treatment options for you.

Your Right to Refuse a Transplant

Patients have the right to refuse transplant at any point PRIOR to receiving a transplant. Talk to your transplant coordinator about your decision. They may be able to help you explore your options if you decide not to pursue a transplant.

Transplant Costs

What Insurance Will and Won’t Pay For

During your evaluation, you will need to meet with the financial coordinator, who will assist you with questions you have about billing and insurance. Even though your health insurance may cover a large portion of the medical care for your transplant, it is likely that you will have to pay some part of this, as well as for a portion of your medications and post-transplant care.
When considering costs, you should keep in mind the following:

- You may need to take a large number of expensive medications after your transplant, and the co-pays alone for these could consume a large part of your budget.

- Your insurance may require pre-authorization for certain medications if they are to be covered by your health plan. Even after the pre-authorization, the medications may only be covered partially or not at all.

- You may need intravenous medications and supplies at home, and should know ahead of time if your insurance will cover this, and how much it will cover.

- If you live outside of the St. Louis area, other expenses may include travel to Barnes-Jewish Hospital for periodic testing, or for treatment of illnesses that require expertise in transplantation.

If your insurance coverage changes, you should make sure the coverage you select meets your needs.

**You should also notify the lung transplant office immediately regarding changes in your insurance.**

For any questions or concerns regarding your insurance or bills, please contact the financial coordinator. See Financial Aid Resources, pg. 56 for a detailed list of resources.

**Out-of-Pocket Expenses You May Have to Pay**

No matter what your health insurance plan is, it is likely that you will have to pay your full deductible for medical care, as well as copays for services and prescription medications. If you are not from the St. Louis area, you should know that your insurance may not cover your living expenses while you are recovering during the first 12 weeks after transplant. Patients frequently find that costs for transportation and lodging for pre- or post-transplant care are not covered. Finally, your insurance may not cover in-home intravenous medications or your home spirometer. You should speak with your financial coordinator and social worker to clarify what expenses you will have, as well as what resources may be available to help with the cost.
During your lung transplant evaluation, the transplant team will do a thorough exam to determine if you are a good candidate for lung transplantation. The exact components of the evaluation will vary depending on your illness. You will meet with many members of the transplant team, including the surgeons, pulmonologists, coordinators, social workers, financial coordinators and dietitians. Clinical tests and procedures may include blood tests, pulmonary function tests (PFTs), a ventilation perfusion (VQ) lung scan, an echocardiogram, a computed axial tomography (CT) scan, a heart catheterization and others depending on your individual circumstances. The checklist below should be helpful in tracking how close you are to completing your evaluation.

**Clinical Tests and Procedures**
- Blood tests
- Six minute walk
- Pulmonary function tests (PFTs)
- Arterial blood gas (ABG)
- Ventilation perfusion scan
- Echocardiogram
- CT scan
- Cardiac catheterization
- Radionuclide ventriculogram (RVG)
- Bone densitometry (DXA)
- Other: ___________________________
- Other: ___________________________
- Other: ___________________________
- Other: ___________________________
- Other: ___________________________

**Meetings and Appointments with the Transplant Team (must be completed prior to listing)**
- Meet with pre-transplant coordinator
- Pulmonologist appointment
- Surgeon appointment
- Meet with social worker
- Meet with financial coordinator
- Meet with dietician
- Patient education class 1: pre transplant
- Patient education class 2: post transplant
- Other: ___________________________
- Other: ___________________________
- Other: ___________________________
- Other: ___________________________

**Other program requirements**
- Identify a support person
- Identify and establish local lodging
- Identify a local pharmacy and provide them with your insurance information

Speak with your pre-transplant coordinator if you have questions about which of the above items you may still need to complete. Either your pre-transplant coordinator or the transplant office secretary will tell you when your appointments are scheduled. The exceptions to this are the transplant patient education classes, which are scheduled at the same time each week. Contact your coordinator to schedule your education classes as classes are not available on a drop-in basis.
Tests Required for Evaluation

Medical Evaluation
In general, the medical tests you will undergo as part of your evaluation are important in helping the transplant team decide whether or not you are a good candidate for transplantation. The evaluation allows the team to assess your overall level of health, the severity of your lung disease, and evidence of infectious disease, cancer and problems with other organs. You will have several blood tests, and brief descriptions of some of the other tests are below:

- **The six minute walk** test measures how far you can walk in six minutes, and is used to determine your oxygen needs.

- **Pulmonary function tests** result in actual measurements of how well your lungs work. You will breathe into a machine that records lung volume and air flow. A blood test called an arterial blood gas (ABG) is typically done as part of this test.

- **The ventilation perfusion scan** is a two-part test that measures air and blood flow to each lung. During the ventilation scan, you will inhale a small amount of radioactive gas, and detectors that are sensitive to radioactivity measure where the air goes in your lungs. For the perfusion scan, radioactive chemicals are injected into a vein in your arm, and the same detectors are used to measure how blood travels to and from the lungs.

- **An echocardiogram** uses sound waves to create moving pictures of your heart. This test involves placing a device called a transducer on your chest. The device sends special sound waves, called ultrasound, through your chest wall to your heart. This test helps measure how well your heart functions.

- **A Computerized axial tomography (CAT) scan** is a special type of x-ray. It results in images that show the size, shape and position of your lungs and other structures in your chest or abdomen.

- **Cardiac catheterization** is used to diagnose some heart conditions. A long, thin, flexible tube called a catheter is put into a blood vessel in your groin and threaded to your heart. Through the catheter, your doctor can do diagnostic tests on your heart.

- **Radionuclide ventriculogram (RVG)** is a test that shows the pumping function of your heart.

- **Bone densitometry (DXA)** is a test (scan) that measures your bone density (thickness).

Psychosocial Evaluation
As part of the multidisciplinary approach to the lung transplant evaluation, social workers meet with patients and caregivers to complete a psychosocial assessment. This assessment addresses a patient’s biological, psychological, social and spiritual strengths.

Financial Evaluation
A financial coordinator will work with you and your family to coordinate the financial aspects of the transplant process. The financial specialist will:

- Verify benefits and eligibility for every patient for all insurances.

- Explain coverage with the patient and provide financial counseling.

- Communicate and collaborate with transplant team members in the listing meeting and on-going as needed.

- Communicate and collaborate with hospital personnel as well as Washington University School of Medicine billing departments, and Barnes-Jewish Hospital Managed Care regarding the patient’s coverage.

- Provide feedback and counsel post-transplant patients as needed (i.e. drug coverage, Medicare and or Medicaid eligibility, questions regarding adequate coverage).
- Manage all pre-certifications for transplant evaluation and all pre-determinations for transplant procedures.
- Obtain referrals from the patient’s primary care physician for authorization of evaluation.
- Facilitate approvals for all phases of transplant.
- Counsel patients in all phases regarding participating insurance plans for Barnes-Jewish Hospital and Washington University School of Medicine.

**When Your Evaluation is Complete**

Most patients will complete their evaluation within the same week that it is started. The transplant team has a meeting each week to review new patients. All patients are required to attend pulmonary rehabilitation. Patients may be required to lose weight or meet some other predetermined goal before the transplant team will add them to the waiting list. Speak with your pre-transplant coordinator or pulmonologist if you have questions about your evaluation. When you have completed your evaluation, you will receive a letter within 10 days informing you whether or not you have been added to the waiting list. See “Listing for Transplant” pg.15 for more details.
WAITING FOR A TRANSPLANT
waiting for a transplant

Checklist For Success: Staying Prepared While You Wait
(also found in the brochure placed in folder)

☐ Keep up with your basic health care: immunizations, annual physicals (including DEXA scan, dentist visits, etc.).

☐ Keep up with your exercise program and/or pulmonary rehabilitation.

☐ Arrange for a support person, and inform the lung transplant office of that person’s contact information.

☐ Arrange for local lodging, and inform the lung transplant office of the address.

☐ Plan how you will get to the hospital when a suitable donor is found.

☐ Arrange telephone service where you can be easily reached, and inform the transplant office of the number. Using your personal cell phone is fine.

☐ Identify a local pharmacy, and inform the lung transplant office of the name and phone number.

☐ Take a guided tour of the areas of the hospital where you will go for your transplant and where your medical appointments will be.

Listing for Transplant

Once you have obtained medical and surgical clearance for lung transplantation and insurance approval has been obtained you will be listed on the national waiting list with the United Network of Organ Sharing (UNOS). Within 10 days of being placed on the waiting list, you will receive a confirmation letter from the lung transplant program stating that you have been listed and on which date. If you do not receive a listing letter you should contact the lung transplant office to check on your status.

Expected Waiting Time

Your priority on the waiting list is determined by a measure known as the Lung Allocation Score (LAS). The basic information you should know about LAS is as follows:

- The method for calculating LAS is set by the United Network for Organ Sharing (UNOS), and is a mathematical model that, for each candidate, weighs the benefits of receiving a transplant against the risks of not receiving a transplant.

- The calculations for the benefits of receiving a transplant attempt to forecast how long you will live if you receive a transplant.

Update the Lung Transplant Office Every Year

Your demographic information (name, address, phone numbers, contact persons, pharmacy name and phone number) should be updated with our office any time there is a change. This should also include any physician changes, additions or deletions.
The calculations for the risks of not receiving a transplant attempt to forecast how long you will live if you do not receive a transplant.

Your diagnosis, age, body mass index and overall functional status are considered in the LAS.

The LAS also uses data collected as part of your evaluation, such as your six-minute walk, pulmonary function tests with Arterial blood gas (ABG), kidney function and a few other variables.

Possible values for the LAS range from 0 to 100, with 0 indicating low priority and 100 indicating high priority for a lung transplant.

Your time on the waiting list does not contribute to the Lung Allocation Score, but changes in your condition and lab values can be used to update your LAS after you are listed.

For more information on LAS, see the OPTN website: http://optn.transplant.hrsa.gov/resources/allocation calculators.asp?index=86

Your priority on the waitlist and how long you might have to wait for a transplant are complex issues. No matter what your Lung Allocation Score is, it is important to understand that your transplant team has no control over when donor organs will be available. Additionally, when donor lungs are available, other factors must be considered, including blood type, size, human leukocyte antibodies (HLA), your decision regarding whether or not to accept a high risk donor, and others. This can be a frustrating and frightening time for patients, and we recognize that the uncertainty about how long you will be on the waitlist is a contributing factor.

Staying Listed for Transplant Each Year

After you are listed, you will have a Tuesday afternoon clinic appointment with a pulmonologist every 4-6 weeks to check your condition and update your LAS, as needed. The pre-transplant clinic is located on the 8th floor of the Center for Advanced Medicine, Suite B. In order to maintain active status on the waiting list, key clinical measurements that are used in the LAS must be updated every six months. Transplant programs have the option of updating this information more often, and your regular clinic visits make this possible.
When a Donor Becomes Available

The United Network of Organ Sharing (UNOS) is the organization that oversees all organ allocation in the U.S. and has a computerized program that matches donors with recipients. The United Network of Organ Sharing coordinates the efforts of Organ Procurement Organizations (OPOs) for donor organ recovery with those of transplant centers, which perform transplants. When donor lungs are available through an OPO, they are first offered to transplant centers in the OPO local area according to blood type, and prioritized by LAS. Transplant centers then accept or reject the organ offer for individual candidates based on the size of the lungs, donor risk factors, HLA mismatches and other factors. If no local transplant center accepts the lungs from an OPO, the lungs are then offered to transplant centers up to 500, 1000, 1500 and 2500 or more miles away. The final decision regarding suitability of the lungs is made by the organ recovery surgeon in the operating room with the donor.

When the transplant program is notified about a potential lung donor, your transplant surgeon will be notified, and will decide whether or not to proceed. If the lungs are accepted, you will receive a call from a transplant coordinator and should plan on leaving immediately for the hospital. You must have a reliable method of being reached at all times when you are waiting for transplant. You will be instructed to not eat or drink anything. The transplant coordinator will also instruct you on where to report when you arrive at the hospital. In most cases, you will report to 7100 Cardiothoracic Nursing Division located on the 7th floor of Queeny Tower. There is a chance that you will be called into the hospital for a transplant, but the donor lungs will be deemed unsuitable for you and the surgery will be canceled. This is known as a dry run. If the surgery is canceled, you will be sent home without receiving a transplant. If this occurs, you will be responsible for arranging transportation back home, having current medications and having enough oxygen to get home. Some patients never have a dry run, and some patients may have more than one.

While Waiting for a Transplant

- You will have clinic appointments every 4-6 weeks at the Center for Advanced Medicine (CAM).
- You will need to participate in pulmonary rehabilitation, Monday through Friday before transplant. This may consist of walking on a treadmill, riding a stationary bicycle or working with some light weights, and lasts approximately 1 hour. You will be given a standing appointment. Contact the pulmonary rehabilitation office at 314-362-4157 if you will be late or cannot attend. If you are feeling too ill to attend pulmonary rehab, you must also call your transplant coordinator.
- If you are not living in St. Louis prior to your transplant, you must arrange for pulmonary rehabilitation near your home.
- You need to let your coordinator know if you become ill or are hospitalized.
- Aside from your clinic visits, you need to continue with some basic medical care:
  - Have immunizations as needed, such as annual influenza vaccines (flu shots), and vaccines for hepatitis A and B, tetanus and pneumonia
  - See your dentist every 6 months
  - If you are at risk for osteoporosis, have an annual bone density scan
  - Women should continue with annual gynecological exams and mammograms
  - Men over 50 should have annual prostate exams
  - Have a colon screening when indicated
Identify Your Support Person
You are required to have a support person with you during your pre-operative appointments and for 12 weeks after your transplant. This needs to be arranged before you are active on the waiting list. The support person will be with you in case of a medical emergency and will help with day-to-day activities as you recover. Your support person may need to be involved in your personal affairs as well as your health care, and needs to be reliable and trustworthy. The support person can be a family member, friend or hired helper. You can have more than one support person, but all of them should be familiar with this book. All support persons should attend the education sessions before transplantation and the pre-discharge session in the hospital after transplantation. See “Role of the Support Person” pg. 30 for more information.

Local Lodging
If you don’t live in the St. Louis area, you and your support person will need to move here for a minimum of 12 weeks after your transplant. When relocating, we request that you live within a 50-mile radius of the St. Louis metropolitan area. For the first 12 weeks after your transplant, you will need to be at the hospital Monday through Friday for tests and appointments.

Transportation Arrangements
You and your support person must be able to leave for the hospital immediately after being notified that a donor has been identified. You are responsible for making your own travel arrangements. If you are driving from outside of the area, you should have a plan that will allow you to quickly notify your family and leave for the hospital immediately. If you are flying to St. Louis, you must have a pre-arranged flight plan with a charter service. Details of this plan must be provided to your transplant coordinator prior to listing. Prior to departure the charter service must notify the transport coordinator with the following information:

- The tail number of your plane
- Your estimated time of arrival
- The airport where you will land

Transport from the airport to the hospital is usually done via ambulance and should be arranged prior to take off. Further details should be discussed with your coordinator.

Local Pharmacy
You must be able to get your medications on the day of discharge from the hospital after your transplant. Prior to your transplant, you need to identify the pharmacy where you will be getting these medications. You should go into the pharmacy in advance of your transplant with your prescription and insurance information to make sure there is not going to be a problem with your coverage. There is a list of some pharmacies in the resource section of this book that may be helpful. Most of the chain pharmacies can be used, as long as your insurance is accepted there. Please inform your transplant coordinator of the pharmacy name and phone number before your transplant. Please note, medications in the first 12 weeks can change frequently, and you need to be able to get them in a timely fashion. Because of this, mail order medication services cannot be used until your prescriptions are less likely to change.
Home Health Services
You may need intravenous medications after discharge from the hospital after transplant. If your insurance does not cover these services, you will have to pay out of pocket for the services.

Fundraising
Frequently, insurance does not pay all of the expenses for your care. This varies from one plan to another, but patients commonly find that they must pay out of pocket for their home spirometer (can be several hundreds of dollars) and any intravenous medications provided through a home health service. Some patients will need to raise money for these expenses. You should be aware of what your expenses will be, decide if raising funds to cover them is something you want or need to do, and plan accordingly. We recommend that you begin fundraising activities as early as possible to ensure that your financial needs are met prior to surgery.

Tour the Hospital
You need to be familiar with how you will enter the hospital when you arrive for your surgery, the 7100 Cardiothoracic Nursing unit in Queeny Tower, 56 Intensive Care Unit (ICU) and other important locations. You can arrange for a tour through the lung transplant social worker or the lung transplant office.

Resources That are Available
There are multiple supportive services available that you may find helpful.
You will need to speak with the social worker about housing, transportation, medical equipment, employment, legal issues, finances or counseling for a variety of issues. The social worker can also help with the following:
- Guidance about fundraising for transplantation
- Assistance completing advance directives
- Information regarding returning to work and school after transplantation
- Assistance with writing the donor’s family
- Discharge planning from the hospital, including arrangements for rehabilitation or long-term care, home health care, supportive care and/or hospice

Barnes-Jewish Hospital offers a Transplant Mentor Program, which includes a group of patients and caregivers who have been through the lung transplant process and who have been trained in the mentor program. Mentors are available to offer support and share their experiences. If you are interested, please contact the social worker for the transplant team.

There is a Lung Transplant Support Group that meets the first Wednesday of each month. Pre- and post-transplant patients, as well as their families and support persons, come together to learn about selected topics of interest and to discuss their experiences. If you are interested, please contact the social worker for the transplant team.

For spiritual care and support, the lung transplant chaplain is available for you and your family. The chaplain is available for these (and other) needs:
- devotional needs
- sacramental needs
- prayer
- religious rituals
- contacting home clergy
- linking with a St. Louis congregation
Notes
surgery and recovery

Checklist for Success: Having a Successful Transplant
(also found in the brochure placed in folder)

☐ Keep up with your basic health care:
   immunizations, annual physicals, dentist
   visits and other care

☐ Arrange for a support person, and inform the
   lung transplant office of that person’s contact
   information

☐ Arrange for local lodging, and inform the lung
   transplant office of the address

☐ Plan how you will get to the hospital when a
   suitable donor is found

☐ Arrange telephone service where you can be
   easily reached, and inform the transplant office
   of the number

☐ Identify a local pharmacy, and inform the lung
   transplant office of the name and phone number

☐ Tour the areas of the hospital where you will
   go for your transplant and where your medical
   appointments will be

The Day of Your Surgery
The coordinator who contacts you regarding a donor
will instruct you on exactly where to go when you
arrive at the hospital. Upon arrival to the nursing
division, several tubes of blood will be drawn, and
you will have an EKG and a chest x-ray. Members
of the surgery team will examine you and ask you
questions prior to the surgery. You will be moved to a
preoperative holding area where the anesthesia team
will insert intravenous lines and make other

preparations for the surgery. Family and friends who
are with you will be directed to the 56 ICU waiting
area, on the 5th floor of the Southwest Tower of
the hospital. Occasionally, it may be necessary to
take you into the operating room and bypass the
holding area. In this case, all the preparations for
the surgery will be done in the operating room.

How Long You Should Expect to Be in the Hospital After Surgery
The average hospital stay is 10-14 days
for an uncomplicated transplant.

What Happens During Surgery
Your operation may take up to 5 hours or more. If
you are receiving two lungs, the transplant will be
performed through separate incisions beneath the
breasts on the front of the chest. Occasionally, it is
necessary to connect these two incisions by dividing
the breast bone as well. There are three connections
for each lung: the airway, the pulmonary artery and
the pulmonary vein. When all three connections have
been made, blood flow is restored to the donor lung.
This process is repeated for the other lung. You will
have up to 4 chest tubes inserted to help re-expand
your lungs and drain fluid from your chest. Your chest
will be closed back up with stitches, surgical glue and/
or staples, and you will be transferred to the ICU.
Recovery in the Intensive Care Unit

When the surgery is finished, you will be taken to the Cardiotoracic ICU (56 ICU). You will have many intravenous (IV) lines and tubes, and will be on a ventilator (breathing machine) to support your breathing. There will also be pumps for intravenous (IV) fluid and medications, monitors for your vital signs and other special equipment if needed. While you are on the ventilator, you will have a breathing tube (endotracheal tube) in your mouth and throat until you are able to breathe with your new lungs on your own. A nasogastric tube (NG tube) will be in your nose or mouth to remove stomach secretions and to deliver some medications. The nasogastric tube will be removed when you can swallow without difficulty. A catheter will be placed in your bladder until you are able to empty your bladder on your own. Chest tubes will be in your chest to drain fluid and air from the space around the new lung(s). When the lungs have expanded and no fluid or air is draining from the tubes, they will be removed.

Pain Management After Surgery

Every patient feels pain after a major operation, but no two people feel this pain in exactly the same way. You can expect to feel pain at your chest incision, and may also feel pain in your back, neck and arms because pain from the incision can radiate to these areas. The nursing staff will monitor you closely and give you medications to keep you comfortable. Due to these medications, patients often do not remember much about the first 12 to 24 hours after surgery. As you start physical therapy, the joints and muscles in your back and legs may be sore because you have not used them for a long time. You will probably feel aches and pains in other parts of your body as well.

The Transplant Team will prescribe pain medication when you are discharged from the hospital. We expect that you will only need this prescription pain medication for a short time after you leave the hospital. You may use either regular or extra strength acetaminophen (Tylenol™) to control your pain if the prescription pain medication seems too strong. Your prescription pain medication may contain acetaminophen as well, and you should avoid taking extra acetaminophen while taking these medications.

Keeping Your Lungs Clear

The nerves to the donor’s lungs are severed when the lungs are removed, and cannot be reattached during the transplant operation. As a result, your cough reflex will not feel the same after transplantation. However, you need to cough in order to remove secretions from your new lungs. You will be provided an incentive spirometer to help mobilize these secretions. You will also be provided a cough pillow to help splint the incisions when you cough. Pain medication should be used to decrease your pain so that you can cough adequately. An Acapella valve may be ordered for you also to help bring up secretions.

Transfer to Thoracic Stepdown Unit (7100)

Once you no longer require intensive care management, you will be transferred to 7100 for continued care and management until you are discharged from the hospital.
Visiting Hours

General visiting hours are 11 a.m.-9 p.m., except in the ICU, where visiting hours depend on each patient’s needs. To ensure the comfort and safety of all of our patients:

- Visitors should observe the visiting hours listed and should avoid lengthy stays
- No more than two visitors are permitted at one time
- Only immediate family members may visit on the day of surgery
- Staff may ask visitors to leave the room if treatment of the patient is required
- The hospital does not permit children under age 12 on patient floors or allow them to be left unattended in the hospital

For the protection of our patients, after 9 p.m. your visitors should check in with security at the information desk for a name tag. Security will also contact the nursing division to obtain after-hours clearance for visitors.

Potential Post-Operative Complications

Primary Graft Dysfunction

Injuries may not be detectable even though the donor lungs are carefully evaluated before transplantation. These types of injuries to the donor lungs are called primary graft dysfunction, which means that the lungs do not function optimally after transplantation. Some degree of primary graft dysfunction occurs in up to 50% of all lung transplant patients, but it is often mild. There is no specific treatment for primary graft dysfunction other than allowing time for the transplanted lungs to heal. Primary graft dysfunction can be severe, causing serious problems in 10-20% of transplant recipients, and can result in death.

Some patients will need to stay on the ventilator longer after surgery, and will have an extended stay in the intensive care unit. After recovering from severe primary graft dysfunction, patients are at an increased risk of developing chronic rejection.

The Risk of Infection

Your immunosuppressant medications will make you more susceptible to infections for the rest of your life. The level of immunosuppression is highest during the first year after transplantation. Therefore, the risk of infection is highest during this period. Bacteria, viruses and fungi can cause infections after lung transplantation. An infection in someone who is immunosuppressed can lead to serious complications. Notify your transplant coordinator or local physician as soon as possible if you experience any symptoms consistent with infection. These symptoms may include the following:

- Fever, chills
- Productive cough or shortness of breath
- Cuts or wounds that are red, warm, and/or have drainage
- Flu-like symptoms
- Nausea, vomiting or diarrhea lasting longer than 24 hours
- Increase in fatigue
- Burning during urination
- Decrease in FEV1 by 10%
- Colored sinus drainage (green, yellow, brown)

Cytomegalovirus (CMV) is a common virus; about 60% of adults have had a CMV infection sometime in their lives. In healthy people, the virus generally causes a flu-like illness similar to the stomach flu, but after it resolves, the virus remains inactive in the body. This virus will leave antibodies in the blood and can
be detected in a blood test. If you have had a CMV infection, or if your organ donor had a CMV infection, the inactive CMV virus can be reactivated after transplantation. In your immunosuppressed condition, this type of CMV infection can be serious and even life-threatening. The peak time for a CMV infection is two weeks to three months after transplantation.

A CMV infection can occur without noticeable symptoms. A weekly blood test for CMV will be performed during the first three months after transplantation. Treatment for CMV infections usually involves a course of additional medication. See “Valganciclovir (Valcyte®) OR Ganciclovir (Cytovene®)” pg. 50 for more information.

Common symptoms of a CMV infection can include the following:
- Fever
- Shortness of breath or decline in lung function
- Extreme fatigue
- Muscle and joint aches
- Decreased white blood cell count
- Abdominal discomfort, nausea or diarrhea

Increased Risk of Cancer
Immunosuppressive medications diminish the body’s overall immune defense system. It is important to be screened routinely for various types of cancer. You should also take additional precautions, such as regularly wearing sunscreen that is SPF 30+ and conducting routine breast-self exams (if applicable). See “Routine Health Maintenance” pg. 40 for more information about regular medical care and cancer screening.

Airway Problems
Airway problems after transplantation can occur at the surgical connection between the donor and the recipient airways. The airways in the lung receive their main blood supply from bronchial arteries, the main arteries that distribute blood from the heart to all parts of the body. However, when the lungs are removed from the donor, the bronchial arteries to the donor lungs are not preserved, and when the donor lungs are transplanted, the circulation to the airways is not restored. Thus, the airways in the transplanted lung depend on blood from the pulmonary arteries. In most cases this blood supply is adequate; however, it is initially deficient in some patients, and the surgical connection between the donor and recipient airways or the donor airways can be injured as a result. In most situations, the injury to the airway is relatively mild, and it heals slowly over the first few months after transplantation without any long-term consequences. More frequent bronchoscopies may be necessary to monitor the injury and to remove any damaged tissue or mucus that accumulates. If the injury is more severe, additional measures may be employed to keep the airway open.

Rejection
One of the most concerning complications after transplantation is rejection. The immune system recognizes that the transplanted lung is foreign to the body. This stimulates an immune reaction to the transplanted lung which is referred to as rejection.

Rejection can be divided into two categories: (1) cell-mediated rejection and (2) antibody-mediated rejection. Additionally, rejection is classified as either acute or chronic. Acute rejection primarily involves inflammation around the very small arteries (arterioles) and airways (bronchioles) in the lung. Acute rejection is not unusual; about 40% - 50% of recipients experience one episode during the first
year after transplantation. Recipients with acute rejection typically respond well to treatment or to adjustments in immunosuppressive medications. However, multiple episodes of acute rejection increase the risk of developing chronic rejection later.

The pathways for chronic rejection, also referred to as bronchiolitis obliterans syndrome (BOS), are poorly understood. Both cell-mediated and antibody-mediated mechanisms may contribute to the damage. Chronic rejection is manifested primarily by scarring and obliterating the small airways (bronchioles) in the lung. Unfortunately, some degree of chronic rejection develops in about 50% of recipients. Because scarring of the airways is permanent, the goal of treatment is to slow the process and prevent further decline in lung function.

It is important to recognize the symptoms of acute rejection, which include fever, shortness of breath and decrease in pulmonary function tests or spirometry measurements. However, rejection often occurs even when there are no obvious symptoms. For this reason, regular bronchoscopies will be performed to look for evidence of rejection in the first 12 months after transplant. Very low-grade (minimal) rejection may not require any treatment if you are doing well, but higher grades are usually treated with IV steroids. See “Prednisone OR Methylprednisolone (Solu-Medrol)” pg. 46 for more information. Maintenance immunosuppressive medications may also be adjusted. A follow-up bronchoscopy will be done after any indication of acute rejection to make sure the rejection is resolved. The diagnosis of antibody-mediated rejection can be detected by a blood test. Biopsies of the lung taken during bronchoscopy are sometimes used to determine antibody-mediated rejection. The most common therapy is an infusion of IV immune globulin once a month for six months. In some instances, a single IV dose of a medication called rituximab is given.

Chronic rejection is manifested primarily by a decline in lung function and is diagnosed by pulmonary function tests. A sustained decline in lung function greater than 10% may indicate chronic rejection if there are no other explanations for the decline. A bronchoscopy is useful to look for other possible causes of the decrease in lung function. In some cases, the biopsies that are taken during bronchoscopy will show a characteristic pattern that confirms the diagnosis of chronic rejection, but often the biopsies are negative or inconclusive. So, if there is a sustained decline in lung function of more than 10% below baseline without some alternative explanation, the default diagnosis is chronic rejection or BOS. In addition to regular immunosuppressive medications, treatments for chronic rejection can include azithromycin, an antilymphocyte globulin (Thymoglobulin or Atgam), photopheresis and Total Lymphoid Irradiation (TLI).

Preparing for Discharge From the Hospital After Transplant

When you are transferred to the 7100 nursing division, your support person needs to bring this book to the hospital. You and your support person(s) need to review the pertinent information, which includes everything from “Recovery After Transplant” pg. 26 through the end of the book. Your post-transplant coordinator and transplant pharmacist will arrange a teaching session with you before you are discharged from the hospital, and your support person(s) should attend it. The teaching sessions are scheduled during the day, Monday through Friday, and typically take 45-60 minutes. You will be expected to start your log sheet after the transplant coordinator reviews it with you.
The following list includes items that you will need as you leave the hospital. Most of these can be purchased at a local pharmacy or store:

- Hand sanitizer to carry in your purse or pocket
- Mild soap to wash incisions and chest tube sites
- Pillbox or another method to set up medications at home
- Athletic shoes and clothing for pulmonary rehab
- Thermometer to check your temperature
- Medical alert bracelet (see pg. 29 for details)
- Masks to wear in high exposure environments (see pg. 29 for details)
- Blood pressure cuff to monitor your blood pressure (optional)
- Scale to measure your weight (optional)

Recovery After Transplant

Life After Transplant

After your transplant, a post-transplant coordinator will be assigned to you. The post-transplant coordinator will meet with you and your support person in the hospital before discharge. Your support person should review both this book and the hospital discharge teaching to prepare for your care once you leave the hospital.

The lung transplant pharmacist will come to discuss new medications, their side effects, drug interactions and other important information. If you require insulin therapy upon discharge, a diabetic nurse educator will meet with you as well. Dietitians are available to speak with you about appropriate food choices.

How Often You Will Have to Return to the Transplant Center?

After discharge and through 12 weeks after your transplant, you will attend pulmonary rehabilitation five days a week. During this period, you will have three bronchoscopies. Other activities during this period are scheduled once or twice a week as outlined in the example schedule below, and detailed in the sections that describe each one.
After your 12-week evaluation, you may need to return to the Transplant Center for monthly follow-up visits, as well as formal evaluations at 6 months and each year. If you do not return to the Transplant Center for these activities, you will need to arrange for their completion through your local physician.

Physical Therapy and Pulmonary Rehabilitation
The goals of physical therapy and pulmonary rehabilitation are to optimize your endurance, strength and flexibility so that you can resume normal activity. Immediately after surgery, a physical therapist will begin working with you in the ICU to help rebuild your strength. You will be assisted to a chair and resistance exercises will be done to keep your muscles toned. After your medical condition stabilizes, you will move to the Observation Unit (OU) on 7100. There, you will begin to take short walks with the physical therapists. When you are able to walk about 1000 feet, you will begin using the treadmill in the thoracic surgery division each weekday. As you continue to progress, you will move to a regular room on 7100. The pulmonary rehabilitation staff will monitor your progress, and will report any problems to your transplant coordinator. When you are ready to be discharged from the hospital, you will be given an appointment time for pulmonary rehabilitation.

Occasionally you may need to miss pulmonary rehabilitation if a clinic appointment or a bronchoscopy conflicts with it; if this occurs, please notify pulmonary rehabilitation by calling 314-362-4157.

Caring For Your Incision and Chest Tube Sites
It is important to keep your incision and chest tube sites clean and dry after you go home from the hospital. Each day, use a wash cloth and mild soap (no dyes or perfumes) to gently wash along the incision and chest tube sites. Rinse and dry the area completely. Leaving the sites open to air is helpful in healing.

Schedule for care through 12 weeks after transplant.

<table>
<thead>
<tr>
<th>ACTIVITY</th>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
<th>Friday</th>
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</thead>
<tbody>
<tr>
<td>Pulmonary rehab</td>
<td>X</td>
<td>X</td>
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<td>X</td>
<td>X</td>
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<tr>
<td>Lab work</td>
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<tr>
<td>Chest x-ray</td>
<td>X</td>
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<tr>
<td>Clinic visit (once weekly)</td>
<td>X</td>
<td></td>
<td>X</td>
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<td></td>
</tr>
<tr>
<td>Pulmonary function tests (once weekly)</td>
<td>X</td>
<td></td>
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</tbody>
</table>
Avoid picking or pulling at the scabs, and do not apply anything to the sites unless the transplant team directs you to. If you observe any open areas in the incision, or any drainage, foul smell, increased redness, increased tenderness/soreness or new swelling, report this to your transplant team. Examine the sites every day, and have your support person help with this.

Women with large breasts will need a supportive bra to lift the breasts up and away from the incisions. This will allow for air circulation and prevent the breasts from pulling on the incision. A cotton sports bra may be worn, but may cause irritation if the band goes across the incision.

Do not shower or immerse yourself in a tub with water at or above the chest tube sites until the stitches and/or staples are removed. The transplant team will remove the stitches or staples about 3 weeks after transplant.

Home Oxygen
You should keep your home oxygen until after your first bronchoscopy as an outpatient. The Home Health Company will require a doctor’s order to discontinue the oxygen, so you will need to provide your coordinator with their phone and fax number.

Home Spirometer
The home spirometer will be ordered while you are still in the hospital. The home spirometer will be delivered to pulmonary rehab after your discharge from the hospital. If you do not receive the home spirometer within 2 weeks of being discharged from the hospital, let your transplant coordinator know. If your insurance does not cover a home spirometer, you will need to pay out of pocket for it. The device may cost several hundred dollars therefore, we recommend saving money or fundraising before transplant if your insurance does not cover it. Your coordinator can provide you with more information on obtaining a spirometer.

The home spirometer is a handheld device that measures lung function. Forced Vital Capacity (FVC) and Forced Expiratory Volume in one second (FEV1) are the most important measurements from the home spirometer. Some spirometer’s measure the FEV6 which is similar to the FVC. FVC is maximum volume of air (measured in liters) that can be exhaled after a full breath. FEV1 is the maximum volume of air that can be exhaled in the first second after a full breath. These two measurements also come from the pulmonary function tests (PFTs) you will do at the hospital on a regular basis.

You will need to use your home spirometer every day to track your lung function. The pulmonary rehabilitation staff will instruct you on using it, recording the measurements on the log sheet, caring for the machine and troubleshooting problems. Your lung function should improve over the first 6-12 months after your transplant, and your FVC and FEV1 measurements will eventually reach a stable level. When this stable level is reached, your home spirometer readings should be reproducible (within 5-8%) from day to day. Contact your coordinator if you observe a sustained drop of 10% or more below your typical measurements.

If you have a pneumothorax (partial collapse of your lung), the transplant team will advise you not to use the home spirometer and not to have PFTs. You will be instructed when to resume the home spirometer and PFTs after the lung has fully re-expanded.

The home spirometer and the equipment in the Pulmonary Function Laboratory are different. Your home spirometer readings will not be identical to the measurements from the PFTs. This difference is usually small and is not a problem.
Medical Alert Bracelet
If you need medical care and are unable to communicate, a medical alert bracelet (or necklace) will inform other health care providers that you are a transplant recipient. You should get a medical alert bracelet (or necklace) in the first month after being discharged from the hospital. Medical alert bracelets can be purchased online, at department stores or pharmacies. The information you place on the bracelet should include the following:

- Your name
- Immunosuppressed Lung or Heart/Lung Transplant Recipient (or other organs transplanted)
- 800-321-4054 (lung transplant office)
- Any other medical information that you feel is appropriate

Masks
Wearing a standard mask over your mouth and nose may help to prevent the inhalation of particles and germs in the air. Most pharmacies and medical supply companies sell standard masks. A mask becomes less effective after one hour of continuous use and should be changed hourly. While the overall effectiveness of these masks is often debated, consider wearing a mask in high exposure environments:

- In the hospital, including waiting rooms and the cafeteria
- During any type of public gathering during the cold or influenza season
- In airports and on airplanes

You do not need to wear a mask while at home or when you are outside (unless it is windy or dusty). If someone in your home is ill, he or she needs to wear a mask when they are around you. You should also wear a mask when working outdoors. Molds and fungi live in soil and you may be putting yourself at risk by inhaling dirt and dust. Use of a heavier mask may offer you more protection when gardening or mowing your lawn; these can be purchased at most hardware or home improvement stores. You should completely avoid being around mulch, compost piles, or raking or burning leaves. Additionally, avoid working outdoors on windy or dusty days.

Sleep
Sleep patterns can be disrupted after your transplant. Prednisone can cause sleep disturbances, and your sleep cycle may be disrupted in the hospital. Emotional stress or pain can also contribute to sleeplessness. Your sleep pattern should return to normal within 3–6 months. Please talk to the transplant team about your concerns. Here are some tips for better sleep:

- Go to bed at the same time every night
- Avoid caffeine
- Keep your bedroom as dark as possible
- Try relaxation techniques
- Do not exercise within an hour of going to bed
- Avoid watching television in bed.
- If nighttime urination interrupts your sleep, try to drink most of your fluids early in the day, and reduce your fluid intake after 5 p.m.

Travel
When planning your travel, you should keep in mind the following regarding your medications:

- Keep more than an enough of your medications with you. If you are traveling by airplane, never put your medications in your checked luggage.
- If you are traveling by airplane, you may need to get a letter from your physician about your medications.
Keep your pharmacy’s phone number with you in case you need to get a refill.

Be aware of what pharmacies are available in the area to which you are travelling.

Mail order pharmacies can ship your medicines to you if you are away from home for an extended period of time.

Check with your airline regarding requirements or documents needed for travel.

With regard to preventing infection while you are travelling:

- If you are outside of the United States, make sure the water you drink is purified. Use caution with ice outside of the United States, since the water used for ice cubes may not have been purified.
- Only eat fresh fruit and vegetables if you can wash them thoroughly. Otherwise, eat only well cooked foods.
- Protect yourself from disease carrying insects, like ticks and mosquitoes.

The Center for Disease Control and Prevention (CDC) has a Traveler’s Health website that can be consulted for travelling outside the United States: cdc.gov/travel.

If you need additional support, there is a travel service through BarnesCare called BarnesCare Travelers’ Health Service. This service offers a consultation for advice on travel precautions, including the necessary vaccines or preventative medications for your specific destination. There is a fee for this service, and the phone number is located in the resource section of this guide.

Role of the Support Person

You are required to have a support person with you for about 12 weeks after your transplant. The support person will be with you in case of a medical emergency and will help with day-to-day activities as you recover. Your support person may be responsible for assisting you with dressing or bathing, helping with wound care, preparing meals, shopping, and other activities. You will not be able to drive for 6 weeks after the transplant or longer if still taking narcotics and your support person must feel comfortable driving in the St. Louis area. You also may not lift anything heavier than 5 pounds for 6 weeks after the transplant.

Your support person is encouraged to come to clinic appointments with you and needs to drive you home after any outpatient procedure that requires sedation, such as a bronchoscopy. Your support person does not need to do everything for you. Light chores are acceptable, and you should balance your rehabilitation with rest and other activities you wish to do.

Lab Work

Once discharged from the hospital, you will have blood drawn for laboratory tests on Mondays and Thursdays at the Outpatient Lab (Guest Services) on the main level at the of the hospital’s south campus; the phone number is 314-362-1238. These tests are used to adjust your immunosuppressive medications, to watch for toxicities that can be associated with these and other medications and to monitor for cytomegalovirus infection. When planning your lab work, you need to know the following:

- Your labs must be drawn before your morning dose of immunosuppressant is taken (Cyclosporine, Prograf, or Cellcept/Myfortic).
- There will be standing orders at the lab, and you do not need an appointment.
The lab opens at 8 a.m., and you need to allow 30-45 minutes to get the labs and a chest x-ray done.

You will need to coordinate the time you have your labs drawn, your chest x-ray and when you take your immunosuppressants with your pulmonary rehab appointment.

As you progress in your recovery the frequency of lab draws may be adjusted.

When your laboratory tests are done at Barnes-Jewish Hospital, most of the results will be available later on the same day. There is usually a longer delay for tests done through laboratories outside the BJC HealthCare system. You will receive a call from your transplant coordinator with your results.

Chest X-Ray
During the first 12 weeks after transplant, you will also get a chest X-ray on Mondays and Thursdays. The chest x-ray is done on the 2nd floor of the Mallinckrodt Institute of Radiology. When planning your chest x-ray, you need to know the following:

- There will be standing orders for the chest x-ray, and no appointment is needed.
- You will need to pre-register for each chest x-ray. The radiology staff will direct you to do this when you arrive for your first visit. This pre-registration is a requirement of the insurance companies.
- As you progress in your recovery, the frequency of chest x-rays may be adjusted.

If there is a holiday during the week, you should move the day for your labs and chest x-ray to the next day. For example, if the department is closed on Monday, labs and chest x-ray are to be done Tuesday and Friday that week. The lab and radiology departments are always closed the Friday after Thanksgiving. During that week, labs and chest x-ray will only be done one time.

Clinic Appointments
You will be seen regularly by a pulmonologist in clinic after being discharged from the hospital. These appointments will be on Monday/Wednesday mornings or Tuesday afternoons in the Lung Center, 8th Floor, Suite D of the Center for Advanced Medicine building (CAM building). When planning your clinic visit, you need to know the following:

- You should bring a list of questions or problems that you want to discuss.
- Please bring your log sheets.
- You will be given a list of your medications from the lung transplant electronic record. Review the list and make corrections as necessary. One of the team members will review the list with you during your clinic appointment.
- Normally as you check out, you will make your next appointment. If you need to make other arrangements at a later date, call the lung center.

Pulmonary Function Tests (PFTs)
Lung function improves after transplantation, and the rate of improvement varies from patient to patient. It may improve for up to 6 – 12 months after transplantation, but will ultimately reach a stable baseline. After this new baseline is reached, a sustained drop in lung function of 10% or more may signal a complication such as rejection. This decline in lung function can occur without any noticeable symptoms. Regular PFTs and home microspirometry measurements can help detect changes in lung function.

You will have weekly PFTs after being discharged from the hospital and until your 12-week evaluation. These are done in the Pulmonary Function Laboratory on the 8th floor of the Center for Advanced Medicine. When planning your PFTs, you need to know the following:

- You are responsible for making those appointments by calling 314-454-8917.
You may schedule them anytime during the week, but the best time is before your clinic appointment.

After your 12-week evaluation, your PFTs will only be done once a month.

The home spirometer and the equipment in the Pulmonary Function Laboratory are different. Your home spirometer readings will not be identical to the measurements from the PFTs. This difference is usually small and is not a problem.

Employment and School
Returning to work or school, for most of us, is a very important source of self-esteem, social contacts and financial benefit. It is our goal for transplant recipients who have been employed to return to work. Most patients will be eligible to work or go to school 6 months after lung transplantation. Depending on your recovery and the type of work you do, you may be able to return to work sooner. If you are unable to return to your previous occupation, then vocational rehabilitation in your home state can assist you with returning to school, learning a trade or looking for a job. For additional information, you can contact the lung transplant social worker.

When you make an application for disability benefits, both the Social Security Administration and private disability insurance companies assign a date for review. This review allows the company to request medical records to determine if you continue to be disabled and unable to return to your previous job or to some other gainful employment. For the first 12 weeks after transplant, you will be attending a pulmonary rehab program every day and we will be monitoring you closely. Once you have recovered, the lung transplant physicians will not certify your disability. If you are no longer disabled and you are still collecting disability benefits, you can lose those benefits and you may have to repay what you have collected.

Sexuality and Pregnancy
Sexual activity may resume after your incision heals and you feel ready. Resuming sexual activity after transplantation should be done without fear or embarrassment. You may resume sexual activity when you feel ready. Please keep in mind that no weight or strain should be placed on the incision or breastbone area for 6 weeks after the surgery.

Changes in sex drive can occur after transplantation such as erectile dysfunction and medications can be prescribed for this. Honest and open conversations with your partner may be helpful, and you should talk to your gynecologist, urologist or other physician about this as well.

Practice safe sex after transplantation. This means knowing if your partner has any infections and using barrier methods such as condoms. If you only have one partner and your partner is free of any sexual transmitted diseases, no condom is necessary. If your partner has an infection, you are still at risk, even when using a condom. Many diseases can be transmitted sexually including hepatitis B, hepatitis C, CMV, HIV/AIDS, genital herpes, genital warts, and fungal infections (yeast). There is no cure for many of these infections, and others may be difficult to treat effectively because you are immunosuppressed.
Pregnancy is a complex matter for a woman who has had a lung transplant. If you are considering pregnancy, your coordinator or one of the transplant physicians will discuss the potential issues with you.

Follow-up Care After the First 12 Weeks
About 12 weeks after your transplant, you will have a comprehensive medical evaluation and will meet with members of your transplant team to discuss the next phase of care. During the remainder of the first year after transplantation, your follow-up care will consist of blood tests, chest x-rays, pulmonary function tests and a clinic appointment on a monthly basis. You may be asked to mail or fax your log sheets once a month to your transplant coordinator. The pulmonary rehabilitation specialists will give you an exercise program to follow.

If you live in the St. Louis area, we want you to continue your monthly care at Barnes-Jewish. If you live outside the area and a monthly trip to St. Louis is manageable, you can continue your post-transplant care at the hospital. You can also return to your original local physician for your follow-up care. In this case, you will be responsible for making and keeping your physician appointments, you will be given written orders for your tests to give to your physicians, and you and your physician will be responsible for mailing or faxing the reports to your transplant coordinator. If you live outside the St. Louis area, you should see a local physician who is familiar with your medical condition, even if you continue your regular post-transplant care at Barnes-Jewish. Having a local physician is essential for health issues not related to your transplant and for emergency situations.

Your coordinator will call you about your lab work, or if there are concerns about your chest x-ray or PFTs. If you arrange your follow-up care through your local physician and do not get a call, the reports may not have been sent to your coordinator. In this case, you should call your physician’s office to check on the status.

Regular Evaluations
You will have evaluation testing at 3 months, 6 months and each year around the anniversary of your transplant. The 3-month, 6-month and 12-month evaluations include at least the following:

- Laboratory testing (blood work):
  - CBC
  - CMP
  - Medication levels
  - PT/INR
  - HgbA1C
  - Fasting Lipid Panel
  - Urine test
  - Thyroid tests (if on thyroid medications)
  - Vitamin levels
  - Infectious disease testing (HIV, hepatitis A, B, and C)
- Chest x-ray
- Electrocardiogram (EKG)
- RVG (radionuclide ventriculogram) or echocardiogram
- Pulmonary function test (possibly with a blood gas)
- Six minute walk
- Bronchoscopy
- Clinic visit
- Bone density test, on an annual basis
- VQ scan, if you received a single lung transplant
- Other tests as needed

Your transplant coordinator and one of the transplant physicians will review your results and discuss them with you. These results will also be forwarded to your local physicians. Please be sure that we have the names and addresses of the physicians who should receive the results.
Starting with the second anniversary of your transplant, you are not required to come to Barnes-Jewish Hospital for these evaluations, and the infectious disease testing and bronchoscopy are not included. The Transplant Center prefers that you come to Barnes-Jewish Hospital for these annual evaluations if possible. If you are having your evaluation at Barnes-Jewish, you will be contacted by a secretary from the lung transplant office to schedule your visit, and our office will send the results to your local physicians. If you'd prefer, the evaluation can be done through your local physician. The transplant secretary will send a list of the appropriate tests to your local physicians, and your physicians can send the results to your coordinator.

**Bronchoscopy**

Bronchoscopy is a procedure to visualize the airways of the lungs and to obtain biopsies or fluid specimens from the lung. In the transplant population, bronchoscopy is routinely done to assess for infection and rejection, as well as to monitor healing of the anastomoses (the surgical connections between your airways and the donor airways). You should expect to have 3 bronchoscopies in the first 12 weeks after transplantation (about 4 weeks apart), one at 6 months after transplantation, and one at 12 months after transplantation. Additional bronchoscopies may be needed depending on clinical circumstances.

For instance, if acute rejection is found, a follow-up bronchoscopy is normally done a few weeks later.

The bronchoscopies are done on the 10th floor of the Minor Procedures Area (MPA) in the Center for Advanced Medicine (CAM). When planning for a bronchoscopy, you need to know the following:

- When a bronchoscopy is scheduled, you will receive a letter with detailed instructions, including the date and time of the procedure.
- If you have not already signed a consent form for the bronchoscopy during a clinic appointment, you should come to the lung transplant office at least one business day before the bronchoscopy to sign the consent for the procedure.
- You must also pre-register by calling 314-362-1173 prior to each bronchoscopy. The pre-registration is separate from the scheduling of the procedure.
- You will be sedated for the procedure and must have a designated person to drive you back to your residence. Your bronchoscopy will need to be rescheduled if you do not have someone to drive for you.
- Intravenous (IV) access is necessary for the bronchoscopy. If you have an intravenous line already (like a PICC, port or Hohn), it can be used.
- You should not eat or drink anything after midnight before your bronchoscopy.
- You may take your morning dose of medications with small sips of water, but you cannot eat breakfast.
- If you are diabetic, take ½ the normal dose of your morning NPH insulin.
- If you take aspirin, it must be stopped 3 days (72 hours) before the bronchoscopy, and it can be resumed the day after the bronchoscopy.
- If you take Lovenox (injection), warfarin (Coumadin) or Plavix, speak with your transplant coordinator about what to do with those medications.

The aspirin, Lovenox, warfarin and Plavix are blood thinners. These medications will put you at an increased risk for bleeding during the bronchoscopy, and will need to be stopped in advance. Speak with your transplant coordinator about how far in advance to stop your taking these medications, and when you should resume taking them.

When you arrive at the MPA, you will be asked questions, fill out paperwork and have an IV started. This may take 1 ½ to 2 hours. Pre-procedure medications are given as an intramuscular injection in your arm or hip. These medications help dry up your
mouth and make you a little sleepy. In the bronchoscopy suite, you will be given some nebulized (aerosolized) lidocaine to anesthetize your throat and suppress your gag and cough reflexes. After this is finished, the doctors will briefly examine you and ask you a few questions.

The actual bronchoscopy takes about 20-30 minutes. It will usually include a complete visual inspection of the airways, a bronchoalveolar lavage (washing some sterile saline into a segment of the lung and then removing it), and biopsies of lung tissue. The bronchoalveolar lavage (BAL) fluid is screened for various types of infection. The biopsies are examined for both rejection and infection.

It will take about 2 hours to recover. After you are fully awake and are able to eat and drink safely, you will be released to go home. If you are living locally, it is okay to return home after the bronchoscopy. If you travel in from out of town for the procedure, you should stay in the St. Louis area overnight. This is a precaution in case you develop a complication after the procedure and need to come back to the medical center.

Some irritation after the bronchoscopy is not unexpected. Symptoms may last for a few days, including the following:

- hoarseness
- sore throat
- wheezing
- slight tightness in the chest
- slight temperature elevation
- productive cough of clear, white or blood tinged sputum (red to brown in color)
- feeling tired

You may take acetaminophen (Tylenol) for a temperature elevation. Do not use your home spirometer or have PFTs done for a few days after your bronchoscopy. Your lung function will decline slightly for several days after a bronchoscopy, and your home spirometer and PFT results will not be accurate until you have recovered from the procedure. Speak with your transplant coordinator about when you should resume regular spirometry.

If you develop shortness of breath, chest pain, high temperature, bleeding with coughing or sputum of color other than what is described above, you need to call the transplant office right away.

The preliminary results of the bronchoscopy will usually be available within 1-3 business days after the procedure. The cultures are monitored for a few weeks for infection. Some infections grow very slowly and may take a while to be identified. Your transplant coordinator will notify you of the biopsy results and tell you if any treatment is needed. If there is infection that needs to be treated, your transplant coordinator also will notify you of the treatment.

Although there are risks associated with bronchoscopy, the benefits of the information that can be obtained outweigh the risks of the procedure in most situations after lung transplantation. Possible complications (also outlined in the consent you must sign prior to the procedure) include the following:

- bleeding
- pneumonia
- bronchitis
- pneumothorax (collapsed lung)
- death

As frightening as these complications sound, the complication rate at Barnes-Jewish Hospital is 1.5% to 3%.

One of the complications is pneumothorax (collapsed lung). Biopsies must be taken to check for rejection, and sometimes one of the biopsies creates a small air leak in the lung. If this happens, air can escape from the lung and become trapped between the lung and the chest wall. The air leak may be self-
limited, and the pneumothorax may be small. In this case, the air outside the lung will be slowly reabsorbed, the lung will re-expand fully, and the pneumothorax will disappear on its own. A larger pneumothorax can cause shortness of breath and may not resolve on its own. In this case, a chest tube has to be inserted between the ribs to evacuate the pneumothorax and re-expand the lung. The tube would remain in place until the lung re-expands and the air leak has sealed itself. This tube would be similar to the chest tubes that were in place after your transplant operation, but it would be smaller.

When to Contact Your Transplant Coordinator and What To Do in Emergencies

Please call your primary coordinator during regular office hours with routine questions or issues. Your primary coordinator will have access to the lung transplant computerized database and other electronic medical information. Although this is not an exhaustive list, you should contact your coordinator if any of the following apply:

- You believe you are experiencing anything worse than mild side effects from your medications.
- You need to arrange for prescription medication refills. Call your pharmacy first for refills. You should typically allow up to 2 business days for this.
- You notice problems with your chest tubes, sites to chest tubes or surgical incisions.
- You observe a sustained drop of 10% or more in your lung function (FVC, FEV1) based on your home spirometer results.
- You are considering making any changes in your medications, especially if you receive a new prescription from a physician that is not on the transplant team.
- There are changes to your insurance plan or coverage.
- You become ill.
- You need to arrange for follow-up care through your local physician.
- You want more information about, or have questions about acute, chronic or antibody mediated rejection (AMR).
- You have an upcoming appointment for a bronchoscopy and are taking any blood thinners aspirin, or are on insulin.
- You have recently had a bronchoscopy and are experiencing any symptoms worse than mild throat and chest irritation or slightly elevated body temperature.

There is a transplant coordinator on-call after office hours, on weekends and holidays for emergencies. During these times, your phone call will be returned by the lung transplant nurse coordinator who is on call, but this nurse probably will not be your primary coordinator.

When you call the transplant office after hours, you will get a message. Listen carefully to the instructions. Also, keep in mind the following:

- If you need to be seen urgently, proceed to the nearest emergency room.
- If you are experiencing a life-threatening emergency, call 911 for emergency assistance.
- Our medical staff is available to talk with medical staff at other hospitals if needed.

Situations that we do not consider emergencies include:

- Laboratory test results: The on-call nurse does not have access to laboratory test results.
- Prescription refills: Refills are handled during office hours.
- Canceling or making appointments: This can only be done during office hours.
- When you are a patient in the hospital, it is not appropriate to call the lung transplant office about your care.
- The medical team caring for you needs to speak to a transplant physician.

If you are living outside of the St. Louis area, you need to contact your local physician for emergency situations. Make sure you know how to contact your local physician during office hours, after office hours, and what you need to do when the physician is not available (for instance, when they are on vacation). If the situation is life threatening, call 911. If your local physician has questions regarding your condition at the time of an emergency, the physician should call our office (800-321-4054) and speak to your nurse coordinator or one of the transplant physicians. If it is after office hours, call the same number to contact the on-call coordinator for assistance. In life threatening situations, standard emergency measures need to be followed, and the transplant office can be contacted when your condition has been stabilized.

If a situation arises in which you cannot take your immunosuppressants (by mouth) for greater than 24 hours (for instance, emergency surgery), the physician who is caring for you should notify your transplant coordinator or one of the transplant physicians. They can advise your physician on the management of your immunosuppression when you cannot take the medications by mouth. Information about contacting the lung transplant office should be shared with your family and/or friends so they can inform the physician who is caring for you if needed.

Guidelines for Success: Helping Your Transplant Last

Completing Your Log Sheet

Recording information on the log sheets is an important part of your follow up after transplantation. Please put your name at the top of every page to avoid any mix-up if you are asked to send your log sheets to your coordinator.

- Date: This is where the date is recorded.
- BP: This is your blood pressure, and it will be measured in Pulmonary Rehabilitation and at clinic visits.
- WT: This is your weight, and it will be measured in Pulmonary Rehabilitation and at your clinic visits.
- FVC and FEV1: These are measurements of lung function from your home spirometer. You may enter the results from your tests in the Pulmonary Function Laboratory as well, but please mark these so that they can be distinguished from the home spirometer readings.
- Immunosuppressant Doses: These are the doses of your immunosuppressant medications. Based on your lab results, you will be told if there are any changes in your immunosuppressants or other medications. Until you receive a phone call, continue the same dosages that you were already taking. You will record the current doses here, since your prescription bottles may no longer have the accurate dose information.
- Prednisone: Record your dose of prednisone here. Remember to taper the dose as directed and refer to the taper schedule that you received.

- CSA/Prograf: Record your dose of either Cyclosporine or Prograf here. Both medications are normally taken twice a day.

- Imuran/CellCept/Myfortic: Record your dose of either Imuran or CellCept/Myfortic here.

See below for an example of the Lung Transplant Log Sheet:

### Lung Transplant Log

<table>
<thead>
<tr>
<th>Name:</th>
<th>Medicine Dosages</th>
<th>Comments</th>
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<tbody>
<tr>
<td>Date</td>
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BP = blood pressure, WT = weight, FEV1 and FVC are measurements from home spirometry.
Preventing Infections
Following these guidelines at all times will help decrease the risk of infection.

- Use good hand washing at all times, especially around children and pets. See additional tips in the section about pets.
- Since the mouth can be a major source of infection, it is important to take good care of your teeth and gums. Visit your dentist every 6 months. See additional information below.
- Carefully consider tattoos or body piercings due to the risk of hepatitis C infection. Practice safe sex, and use of condoms when appropriate. See additional information in the section about sexuality.
- Avoid contact with infants and others who have recently received live vaccines including: oral polio vaccine, MMR vaccine and varicella (chicken pox) vaccine. A general rule is to avoid contact with children for 2 weeks after these vaccinations. Also avoid small children when they are not feeling well.
- Use common sense, no sharing drinking glasses, eating utensils, toothbrushes, razors or towels.
- Stay away from people who are ill. This is very important in the cold and influenza season. If a family member is ill and cannot stay away from you, ask him or her to wear a mask when they are around you.
- Have someone change your furnace and air conditioning filters as recommended by the manufacturer.
- Avoid inhaling strong fumes from cleaning solutions, such as bleach.
- Do not handle or participate in the cleanup of household molds.
- Inform your local physician or your nurse coordinator if you have a cold sore that does not heal, a rash that does not go away, a white coating on your tongue, or a fungal or yeast infection.
- Inform your nurse coordinator or local physician if you are exposed to a contagious disease.
- Keep your tetanus vaccination up to date.
- Clean any cut or scrape and apply a clean, dry dressing on the wound.
- Thoroughly wash fruits and vegetables. Do not eat raw or undercooked eggs, meat or fish.
- No unpasteurized milk, cheese, juices or ciders.
- No spoiled food or food past its expiration date.
- Use mosquito and tick protection when appropriate.

Pets
Pets are acceptable, whether kept inside or outside your home. The pets must be healthy, their vaccinations should be kept up to date for your protection. Your pets should not sleep in your bed and preferably should not sleep in your bedroom. If you do not have a pet and are considering one, it is advisable to wait for about 12 months after transplantation before getting one. If you currently have a pet, the following will help keep you healthy:

- Good hand washing after handling the pet.
- Try to avoid cleaning kennels, litter boxes or other messes. If unavoidable, wear waterproof gloves and wash your hands immediately after you are done.
- Provide tick and flea prevention to any pet that goes outdoors. Promptly treat your pet for any infections.
- Birds, reptiles and exotic animals are not recommended.
Healthy Living

Nutrition/Diet

After transplant, it is important to adhere to a diet that promotes a healthy lifestyle. Some of the new medications can cause increased appetite, high blood pressure and high blood sugar. Dietitians are available for questions and counseling. Read food labels for sodium, cholesterol/fat and sugar content information in order to eat a balanced diet.

- **Reduce Salt Intake**
  Eating excess sodium or salt can contribute to fluid retention and to high blood pressure. Avoid adding salt to food, and limit the use of canned, processed and preserved foods that contain high amounts of sodium. Read food labels.

- **Reduce Fat and Cholesterol**
  Eating a diet low in fat and cholesterol will help to lower blood cholesterol levels and reduce the risk of heart and blood vessel disease. Vegetable oils can be used in the place of saturated fats whenever possible.

- **Limit Alcohol**
  Alcoholic beverages are high in calories and can be a big contributor to weight gain. In addition, excess alcohol does not react favorably with some of your medications. According to the USDA’s Dietary Guidelines, people should drink alcohol in moderation, which is defined as up to one drink a day for women and up to two drinks for men. Twelve ounces of regular beer, 5 fluid ounces of wine or 1.5 fluid ounces of 80-proof distilled spirits counts as one drink. Please discuss alcohol consumption with the transplant team.

- **Reduce Intake of Sweets**
  Prednisone and tacrolimus can increase blood sugar levels after the transplantation. Limit the amount of extra sweets especially if you have diabetes or if you are overweight.

Eye Care

Prednisone can cause vision changes, cataracts or worsen a current cataract. An annual eye examination is recommended. In the first 3-6 months after transplant, you may notice some vision changes that may require your prescription to be adjusted. This should be postponed until the prednisone dose is tapered down to prevent further prescription changes. Developing cataracts after transplantation is relatively common. Cataract surgery is safe and it can be done after you have recovered from the transplant. You can wear contact lenses after transplantation, but it may take some time to re-adjust to them. You must follow good hygiene practices with contact lens use.

Dental Care

Oral health is very important. Toothaches, infections and tooth decay can lead to serious infections that may be difficult to treat when you are immunosuppressed. The American Dental Association recommends dental check-ups and routine dental cleanings every 6 months. Because you are immunosuppressed, you will need preventative antibiotics before a dental cleaning or any invasive dental procedure as described in the American Heart Association (AHA) Endocarditis Prophylaxis Guidelines. The recommendation is Amoxicillin 2000 mg by mouth one hour before the cleaning/dental procedure. If you are allergic to Amoxicillin (penicillin), there are alternatives. Your dentist should be very familiar with this protocol and should prescribe the antibiotic for you before your appointment.

Routine Health Maintenance

In addition to your routine visits with the transplant team or your primary physician, it is important to have other routine screening tests done.
For Females:
- Self-Breast Exam every month
- Mammogram yearly after the age of 40 or as recommended by your gynecologist
- Pap smear and pelvic exam yearly or as recommended by your gynecologist.

For Males:
- Self-Testicular Exam every month
- Prostate specific antigen (PSA) blood test every year (over age 50) or if recommended by your doctor
- Rectal exam at age 40 and every year by internist or urologist

For Everyone:
- Colonoscopy at age 50 and then every 3-5 years thereafter or as recommended by your physician
- Annual exam of your skin by a dermatologist
- Bone density test every year to monitor for osteopenia and osteoporosis. If possible, the test should be done at the same radiology department every year so that results can be easily compared. Bone density testing can be done yearly because you are taking prednisone (steroids).
- Influenza vaccination (by injection) every year. Nasal vaccine (flu mist) is not safe after transplantation.
- Monitor blood pressure at every physician visit and more frequently if instructed to do so. You may have to purchase a blood pressure cuff and record the readings. Make sure you report the readings to your physician.
- Fasting Cholesterol Panel once a year
- Hemoglobin A1C (HBA1C) once a year to monitor for diabetes
- Thyroid function tests once a year (if taking thyroid medication)
- Eye examinations once a year
- Tetanus vaccination every 10 years; pneumonia vaccine every 5 years
- Dental visits every 6 months (with preventative antibiotics)

Vaccines
Vaccinations are generally avoided in the first six months after transplantation. The vaccine will not hurt you, but your immune system may not mount a response at this time, limiting the effect of the vaccine. After transplantation, you may receive vaccines that are derived from killed or attenuated viruses, but you may not receive vaccines that contain live viruses.

Vaccines that are recommended:
- **Influenza Vaccine**: Injection form only. Nasal mist contains live virus and should not be used in transplant patients.
- **Hepatitis A Vaccine**: Ideally, this vaccine should be completed before transplantation, if possible. It is a series of 2 vaccinations given 6 months apart. It can be given with the hepatitis B vaccine. If this vaccine is not completed before transplantation, the series should be completed 6 months after transplantation.
- **Hepatitis B Vaccine**: Ideally, this vaccine should be completed before transplantation, if possible. It is a series of 3 vaccinations. After the first vaccination, the second vaccination is one month later, and the third is 6 months after the first vaccination. If not completed before transplantation, the series should be completed 6 months after transplant.
- **Pneumovax or the Pneumococcal Vaccine**: After the initial vaccination, a booster is recommended every 5 years.
- **Tetanus Vaccine:** After the initial immunization, a booster is needed every 10 years. If you have an injury that puts you at risk for tetanus, then obtain the booster in 5 years.

**Vaccines that are permitted if needed:**
- Polio as an injectable vaccine only (Oral form contains live virus and should not be used in transplant patients.)
- Gardasil to prevent cervical cancer
- Typhoid vaccine (typhoid VI, killed virus), if you need this vaccine for travel purposes
- Rabies Vaccine
- Smallpox
- Japanese Encephalitis
- PPD or TB test and the Tine test to test for tuberculosis
- Immune Globulin to treat exposures for Hepatitis A and measles

**Vaccines you MAY NOT receive:**
- Flu Mist
- Measles, Mumps, Rubella combination (MMR) or each separate vaccine
- Varicella-Zoster (Chicken Pox)
- Oral typhoid, live virus
- Oral Polio, avoid person receiving this for 6 weeks
- BCG (given for bladder cancer)
- Yellow Fever
- Cholera
- Shingles vaccine

Some of these vaccines are routinely given to infants and children. You cannot be around children for a certain length of time due to the shedding of the live virus after the vaccine. Check with the MD/Pediatrician giving the vaccine to check on how long to avoid the vaccinated person. In general, it is about 2 weeks.

**Activities and Restrictions after Surgery:**

**Long Term**
No smoking or chewing tobacco.
Modest alcohol use is acceptable, but it should be avoided altogether while taking narcotics (see section about nutrition for more information).
medications

General Information
About Your Medications

Take your medicine correctly. Your health depends on it.

After the transplant surgery, you will take many medicines to keep you and your transplant healthy. Some prevent rejection (immunosuppressants), others prevent infection (anti-infectives) and the rest treat other medical conditions. You must take your medicines exactly as prescribed, or they will not be effective. If you do not take your anti-rejection drugs, you may develop rejection—and may not realize it until it is too late. If you do not take your other medicines correctly, you may get an infection or have other problems.

If your medicine schedule seems too hard to follow, talk to the Transplant Team. They can help you find the easiest way to take your medicines.

Why do I have to take so many medicines?
Anti-rejection drugs: One of the most common problems after transplantation is rejection. You will take three anti-rejection medicines for the rest of your life. Most patients take:
- Prednisone OR methylprednisolone (Solumedrol®)
- Tacrolimus (Prograf®) OR cyclosporine (Neoral®, Gengraf®)
- Mycophenolate mofetil (CellCept®) OR mycophenolic acid (Myfortic®) OR azathioprine (Imuran®)

Anti-infectives: Another common problem is infection. Anti-infective drugs help prevent infections. You will probably take some anti-infectives for the first three to six months after your transplant and others for the rest of your life. Most patients take three different types of anti-infectives:
- **Antibiotic to prevent PJP pneumonia:** Sulfamethoxazole/trimethoprim (Bactrim®) OR atovaquone (Mepron®) OR pentamidine (Nebupent®, Pentam®300)
- **Antiviral to prevent viral infection:** Acyclovir (Zovirax®) OR valganciclovir (Valcyte®) OR ganciclovir (Cytovene®)
- **Antifungal to prevent fungal infection:** Nystatin (Myamyc®, Nystop®) OR fluconazole (Diflucan®) OR itraconazole (Sporanox®) OR voriconazole (Vfend®) OR posaconazole (Noxafil®)

Other medicines: Many patients take medicines to treat other conditions. Examples include:
- Multivitamin, calcium and vitamin D supplements
- Stomach acid suppressing medicines
- Pain medicines
- Stool softeners or laxatives

How can I remember to take all these medicines?
Always use your medication list to set up your medicine. Do not rely on the instructions on your medicine bottles. Keep only the most up-to-date medicine list and throw away old lists. Keep your list up-to-date. Bring your medicine list with you whenever you come to the hospital or clinic.
It will be easier to remember your drug schedule if you know the name, purpose, dose and appearance of each medicine you take. Know your allergies, too.

Pharmacies sell medicine boxes that hold a seven-day supply of medicines. This might be helpful to remind you to take your medicine. Be careful, though—not all medicines can be put in these pillboxes, and you must remember to take those medicines too.

When should I take my medicines?
In the hospital, medicines are given at standard times, such as 8 a.m., 12 noon, 4 p.m. and 8 p.m. When you go home, you can fit your medicine into your own schedule—but be consistent. Take your medicines at the same times every day and in the same way in relation to meals (either with food every time or without food every time). Most people take their medicine at meal times to help them remember it and to prevent stomach upset. Morning and evening doses should be taken twelve hours apart.

What should I do if I miss a dose of medicine?
If you remember the missed dose within 3 hours, take it and continue on your regular schedule. However, if you don't remember until it's almost time for your next dose, skip the missed dose and continue on your regular schedule. Never take a double dose to make up for one that was missed earlier. If you are unsure of what to do, call the Transplant Office.

How do I store my medicine safely?
Keep all medicine out of the reach of children. Store them away from bright sunlight in a cool, dry place like a closet or bedroom. Do not store medicine in a bathroom or kitchen where it is warm and humid, and do not store it in the refrigerator unless you are told to do so. Do not store medicine in your car. Dispose of any medicine you are no longer using.

How and where do I get my medicines?
As stated previously, a local pharmacy is required in St. Louis for at least 12 weeks after your transplant. Medications in the first 12 weeks could be changed frequently and you need to be able to get them in a timely fashion; therefore, mail order medication services can only be used after you are on stable doses of medication. You must be able to get your medications on the day of discharge from the hospital. You should go into the pharmacy in ADVANCE of your transplant with your prescription insurance information to make sure there are not going to be problems with billing coverage. Please notify your transplant coordinator with the local pharmacy name and phone number before transplant. The resource section of this book lists local specialty pharmacies; these pharmacies are familiar with handling transplant insurance billing problems and will provide you with a care package including a medicine box, tablet cutter, blood pressure monitor and a thermometer. Most chain pharmacies can also be used, as long as your prescription insurance is accepted there.

We recommend that you use only one pharmacy. If the pharmacist has a complete record of all your medicines, he or she may be able to stock all the medicines you need and warn you of harmful drug interactions. Check your medicines when you receive them: look at your medicine and read the label. If anything appears different, talk to the pharmacist.

Refill early. Many pharmacies do not regularly stock transplant medicines, and they need time to order them. Try to keep a two-week supply of medicines on hand at all times. You need to be sure you never run out of your medicines. Always make sure you have a full supply of medicine when travelling.
How much will my medicines cost?
Medications are expensive and prescription drug coverage is strongly recommended. The medications may cost several thousand dollars per month both before, and even after, insurance coverage. Intravenous medications and supplies may not be covered by your insurance. You will be responsible for the costs not covered by insurance. Some medications have higher co-pays if you cannot have a generic or if there is not a generic available.

Can I use generic medicines?
It is okay to use generics. Most generic medicines are considered to be just as effective as the brand-name product, but this does not always apply. Some generics are not equivalent, and the pharmacist is not allowed to dispense these without contacting the physician.

- **Tacrolimus (Prograf®):** Generics are okay (except Dr. Reddy's), but with tacrolimus it is best to get the same generic with each refill. Tell your Transplant Team if you switch forms (manufacturers).

- **Cyclosporine (Neoral®, Gengraf®):** Not all brands of cyclosporine are considered equal. Consult the transplant office before you consider any change in cyclosporine product. Sandimmune is not permitted.

Can I take other medicines with my transplant medicines?
Many medications interact with your transplant medicines or can harm your transplant. Never take any new medicine—prescription or non-prescription—without the approval of the transplant team. Do not even take over-the-counter or health food supplements without getting approval first. If your local doctor or specialist prescribes a new medicine, check with the transplant team before you get the prescription filled to make sure it's okay to take.

Can I take over-the-counter (OTC, non-prescription) medicines?
For occasional headaches or minor aches and pains, you can take Tylenol® or its generic equivalent (acetaminophen), but do not exceed the recommended dose of 3,000 mg. Do not take aspirin, ibuprofen (Motrin®, Advil®), naproxen (Nuprin®, Aleve®) or Excedrin® without physician approval. They are irritating to the stomach, can hurt the kidneys and could increase your risk of bleeding. Many cough and cold products contain these medicines, so read the label or check with the pharmacist before you buy one. All herbal supplements should be avoided because very little is known about their effects on your body or transplant medicines.

What do I do if my medicine causes side effects?
Medicines can cause side effects. Some of these side effects are minor, others are more serious. Even if you are having bothersome side effects from one or more of your medicines, **do not stop taking medicines on your own.** Report any side effects to your transplant team. **It is important to be familiar with the common side effects of your medicines. Please report any perceived side effects to the transplant team.** It is important to keep all your appointments with the transplant team/local physician so this monitoring can be done.
Common Transplant Medications (Immunosuppressants)

The following section provides information about most of the medicines used after transplant. You will not be taking all of these medications at one time, but the information is being provided to you in the event that you switch or change medications in the future. Please be sure to only focus on the medications that you are currently taking. Your Transplant Team will give you a list of these medications.

Prednisone OR Methylprednisolone (Solu-Medrol®)

Purpose: Immunosuppression (oral prednisone) or treatment of rejection (intravenous Solu-medrol®).

Usual duration: Rest of your life

Dosage form: Prednisone comes in 5 mg, 10 mg and 20 mg tablets. You will usually need to cut tablets in half or combine multiple tablets to make up the dose that you need. Generics are okay. The intravenous form (Solumedrol®) is supplied by a home health agency.

Dose: Most patients take prednisone by mouth one time a day. It is best to take it in the morning with breakfast. You will be on a high dose at first, but the dose will gradually decrease (or taper) over the months following transplant. Before you leave the hospital, you will receive a taper schedule that tells you how the dose will decrease. Be careful to follow the taper schedule as directed.

Common side effects and what to do:
- **Mood changes, difficulty sleeping or vivid dreams:** Goes away with decreased dose.
- **Increased appetite, weight gain:** Eat a diet low in fat and calories.
- **Water retention and swelling:** Avoid salty foods. Use diuretic (water pill) for fluid retention if directed.
- **Stomach upset, bitter taste, heartburn and ulcers:** Take with breakfast.
- **Acne:** Wash area with an antibacterial soap two times a day. Goes away with decreased dose.
- **Thinning of skin, easy bruising:** Protect skin. Wash cuts with soap and water.
- **Muscle weakness and joint pain:** Goes away with decreased dose. Exercise in Pulmonary Rehabilitation will help build muscles. Report to transplant team.
- **Vision changes, glaucoma and cataracts:** Blurred vision will improve over time. Visit an eye doctor every year. You should wait to change prescriptions for your glasses or contacts until 6 to 12 months after transplant. Cataract removal is generally safe for our patients.
- **Increased blood pressure:** Avoid excessive weight gain and limit salt in your diet. Monitor your blood pressure at home as directed.
- **Increased blood sugar:** Avoid foods high in sugar. Monitor your blood sugar at home as directed.
- **Increased cholesterol:** Will be monitored with blood work.
- **Osteoporosis (bone loss):** Take calcium and vitamin D supplements. Exercise regularly. The transplant team will monitor your bone density.

Tacrolimus (Prograf®, Hecoria®)

Purpose: Immunosuppression

Usual duration: Rest of your life

Dosage form: Tacrolimus comes in 0.5 mg, 1 mg and 5 mg capsules. The capsule cannot be cut. You will usually need to combine capsules to make up the dose that you need. Generics are okay (except Dr. Reddy’s),
but with tacrolimus it is best to get the same generic with each refill. Tell your transplant team if you switch forms (manufacturers).

**Dose:** Most patients take tacrolimus by mouth two times a day, 12 hours apart. This drug can be taken with or without food, but the absorption can be decreased when taken with food. Because of this, be consistent with how you take the medication (for example, either always take it with food or always take it without food).

**Blood levels:** Your tacrolimus blood level is very important in helping the transplant team decide what dose is best for you. Always have your blood drawn 12 hours after your last dose, unless instructed otherwise. This means you should wait to take your morning tacrolimus until after your blood is drawn (bring your tacrolimus to the lab so you can take it immediately after your blood is drawn). If you take your tacrolimus before your blood is drawn, by mistake, do not have your tacrolimus level checked. Call your transplant team for instructions.

**Drug interactions:** Many medicines interfere with tacrolimus. They make it less effective or increase your risk of side effects. There are several fruits and fruit juices that should not be consumed including grapefruit, pomegranate and star fruit. The juices and fruits that are okay to use include grape, orange, apple, cranberry, tangerine and pineapple. Always check with the Transplant Team before starting or stopping any medicines.

**Common side effects and what to do:**

- **Hand tremors, shaking:** Goes away with decreased dose.
- **Nausea and vomiting:** Take with food if you need to, but be consistent with how you take it.
- **Flushing or hot flash:** Goes away with decreased dose.

- **Headache or migraines:** Goes away with decreased dose. Tell the transplant team if severe or persistent.
- **Increased blood pressure:** Avoid excessive weight gain and limit salt in your diet. Monitor your blood pressure at home as directed.
- **Increased blood sugar:** Avoid foods high in sugar. Monitor your blood sugar at home as directed.
- **Kidney damage:** The transplant team monitors for this in your lab work.
- **Hair loss/thinning:** Mild hair loss may occur.

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**Cyclosporine (Neoral®, Gengraf®)**

**Purpose:** Immunosuppression

**Usual duration:** Rest of your life

**Dosage form:** Cyclosporine comes in 25 mg and 100 mg capsules as well as a liquid form. The capsule cannot be cut. You will usually need to combine capsules to make up the dose that you need. Generics are okay, but with cyclosporine it is best to get the same generic with each refill. Sandimmune is NOT permitted.

**Dose:** Most patients take cyclosporine by mouth two times a day, 12 hours apart. This drug can be taken with or without food, but the absorption can be decreased when taken with food. Because of this, be consistent with how you take the medication (for example, either always take it with food or always take it without food). If you have cystic fibrosis, you will need to take your pancreatic enzymes with the doses to help your body absorb cyclosporine. Keep the capsules in their foil packet until you need to take them. Do not open the packets and store the capsules in a pill container - they have a strong odor and are sensitive to light.
**Blood levels:** Your cyclosporine blood level is very important in helping the Transplant Team decide what dose is best for you.

- Some patients have their blood drawn 12 hours after their last dose. This means you should wait to take your morning cyclosporine until after your blood is drawn (bring your cyclosporine to the lab so you can take it immediately after your blood is drawn). If you take your cyclosporine by mistake before your blood is drawn, do not have your cyclosporine level checked. Call your Transplant Team for instructions.

- Some patients have their blood drawn 2 hours after their morning dose of cyclosporine. This means you should take your cyclosporine and then get your blood drawn two hours later. Your blood should be drawn about 2 hours after you take your medicine. For example, it is okay to have your level checked from 1 hour and 45 minutes to 2 hours and 15 minutes after your cyclosporine dose.

**Drug interactions:** Many medicines interfere with cyclosporine. They make it less effective or increase your risk of side effects. There are several fruits and fruit juices that should not be consumed including grapefruit, pomegranate and star fruit. The following juices and fruits that are okay to use include grape, orange, apple, cranberry, tangerine and pineapple. Always check with the Transplant Team before starting or stopping any medicines.

**Common side effects and what to do:**

- **Hand tremors, shaking:** Goes away with decreased dose.
- **Nausea and vomiting:** Take with food if you need to, but be consistent with how you take it.
- **Flushing or hot flash:** Goes away with decreased dose.
- **Headache or migraines:** Goes away with decreased dose. Tell the Transplant Team if severe or persistent.

- **Increased blood pressure:** Avoid excessive weight gain and limit salt in your diet. Monitor your blood pressure at home as directed.
- **Increased blood sugar:** Avoid foods high in sugar. Monitor your blood sugar at home as directed.
- **Kidney damage:** The transplant team monitors for this in your lab work.
- **Unwanted hair growth:** You may use safe bleaching methods, hair removal creams or waxing. Avoid laser hair removal.
- **Mouth sores, gum swelling or bleeding:** Practice good oral hygiene by brushing teeth thoroughly after each meal and flossing regularly. Visit the dentist every six months. Report cyclosporine use to your dentist.

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**Mycophenolate Mofetil (CellCept®) OR Mycophenolic Acid (Myfortic®)**

**Purpose:** Immunosuppression

**Usual duration:** Rest of your life

**Mycophenolate mofetil (CellCept®) dosage forms:**
Mycophenolate mofetil comes in 250 mg capsules and 500 mg tablets. Generics are okay.

**Mycophenolic acid (Myfortic®) dosage forms:**
Mycophenolic acid comes in 180 mg and 360 mg tablets. They cannot be broken in half or crushed. There is no generic available.

**Dose:** Most patients take mycophenolate by mouth two times a day, 12 hours apart. This drug can be taken with or without food, but the absorption can be decreased when taken with food. Because of this, be consistent with how you take the medication (for example, either always take it with food or always take it without food).
Blood levels: Blood levels are not routinely measured. If a level is measured, have your blood drawn 12 hours after your last dose, unless instructed otherwise. This means you should wait to take your morning mycophenolate until after your blood is drawn (bring your mycophenolate to the lab so you can take it immediately after your blood is drawn). If you take your mycophenolate before your blood is drawn, do not have your mycophenolate level checked. Call your transplant team for instructions.

Drug interactions: Medicines that contain magnesium or aluminum (like Maalox®, Mylanta®, Amphojel® or magnesium supplements) should not be taken within 2 hours (before or after) mycophenolate. The absorption of mycophenolate is decreased with these medicines.

Common side effects and what to do:
- **Nausea, vomiting, diarrhea, abdominal cramps:** Decreases over time and with reduced dose. Take with food if you need to, but be consistent with how you take it.
- **Decreased white blood cell count/platelets:** Will be monitored with blood work.
- **Possible loss of pregnancy and higher risk of birth defects:** If you are a female and able to become pregnant, talk with your transplant team about effective birth control methods. If you are thinking about having a baby, tell your transplant team right away so they can discuss the best options for you.

Pregnancy complications:
May cause pregnancy complications or be harmful to your baby.
- If you are a female who can get pregnant and you are sexually active, talk to your transplant team about birth control options.
- If you are thinking about having a baby, talk to your transplant team so they can develop a plan that is best for you.
- If you get pregnant while you are taking mycophenolate (or within 6 weeks after you stop), tell your transplant team right away.

Azathioprine (Imuran®)

**Purpose:** Immunosuppression

**Usual duration:** Rest of your life

**Dosage form:** Azathioprine comes in 50 mg, 75 mg and 100 mg tablets. You will usually need to combine tablets to make up the dose that you need. Tablets can be broken in half if needed. Generics are okay.

**Dose:** Most patients take azathioprine by mouth one time a day. This medication can be taken with or without food.

**Drug interactions:** The anti-gout drug allopurinol (Zyloprim®) should be used only with extreme caution by inpatients taking Imuran®. Always check with the transplant team before starting or stopping any medicines.

**Common side effects and what to do:**
- **Nausea and vomiting:** Take with food.
- **Decreased white blood cell count/ platelet count:** Will be monitored with blood work.
- **Liver damage:** Will be monitored with blood work (rare).
- **Hair loss/thinning:** Mild hair loss may occur.
Common Anti-Infectives

Sulfamethoxazole-Trimethoprim (Bactrim DS® or Septra DS®)

**Purpose:** Antibiotic to prevent pneumocystis jiroveci pneumonia (PCP)

**Usual duration:** Rest of your life

**Dosage form:** Sulfamethoxazole-trimethoprim is available as both a tablet (that can be cut in half or crushed) and a liquid. Generic is okay.

**Dose:** Most patients take one double-strength tablet on Monday, Wednesday and Friday.

**Common side effects and what to do:**
- **Increased sensitivity to sunlight:** Avoid the sun when possible. Wear protective clothing and sunblock.
- **Rash:** Report to the transplant team.
- **Decreased white blood cell count:** Will be monitored with blood work.
- **Nausea, upset stomach:** Take with food.

Atovaquone (Mepron®)

**Purpose:** Antibiotic to prevent PCP pneumonia.

**Usual duration:** Rest of your life

**Dosage form:** Atovaquone is available as a liquid in a concentration of 750 mg per teaspoon.

**Dose:** Most patients take atovaquone 1500 mg (2 teaspoons) by mouth one time a day, with a meal.

**Common side effects and what to do:**
- **Rash:** Report rash to transplant team.
- **Headache:** Take acetaminophen (Tylenol®) as needed.
- **Diarrhea:** Report persistent diarrhea to the transplant team.

Pentamidine (NebuPent®, Pentam® 300)

**Purpose:** Antibiotic to prevent PCP pneumonia.

**Usual duration:** Rest of your life

**Dosage form:** Pentamidine comes as a solution to be inhaled through a nebulizer.

**Dose:** Most patients inhale 300 mg of pentamidine one time per month. It must be given in a controlled setting, like the hospital. An albuterol inhaler is given before the treatment to decrease coughing.

**Common side effects and what to do:**
- **Coughing:** Use albuterol inhaler before treatment.
- **Bad taste in mouth/burning in throat:** Goes away after treatment.

Valganciclovir (Valcyte®) OR Ganciclovir (Cytovene®)

**Purpose:** Antiviral to prevent or treat cytomegalovirus (CMV) and herpes simplex virus (HSV) infections.

**Usual duration:** Three to twelve months after transplant

**Dosage form:** Valganciclovir comes as a 450 mg tablet. It cannot be broken in half or crushed. There is no generic available. Ganciclovir is an intravenous (IV) formulation that will be provided by a home health agency.

**Dose:** Most patients take valganciclovir by mouth one to two times per day.

**Common side effects and what to do:**
- **Nausea and vomiting:** Take with food.
- **Decreased white blood cell count:** Will be monitored with blood work.
Acyclovir (Zovirax®)

**Purpose:** Antiviral to prevent herpes simplex virus (HSV) infections.

**Usual duration:** Rest of your life

**Dosage form:** Acyclovir comes in 200 mg capsules. Generic is okay.

**Dose:** Most patients take 200 mg of acyclovir by mouth two times a day.

**Common side effects and what to do:** Does not usually cause side effects.

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Nystatin Swish and Swallow (Myamyc®, Nystop®)

**Purpose:** Anti-fungal to prevent yeast infection in the mouth (thrush).

**Usual duration:** Three months after transplant

**Dosage form:** Nystatin comes as a liquid in a one-pint bottle.

**Dose:** Most patients take 1 teaspoon (5 mL) four times a day, after meals and at bedtime. Swish it around in your mouth, coating your tongue, gums, cheeks and roof of the mouth. After one minute, swallow it. It must be shaken well before use. Do not eat, drink or brush your teeth for 20 minutes afterwards.

**Common side effects and what to do:** Does not usually cause side effects.

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Fluconazole (Diflucan®)

**Purpose:** Antifungal to prevent or treat fungal infections.

**Usual duration:** Three months after transplant

**Dosage form:** Fluconazole comes in 100 mg, 150 mg and 200 mg tablets and an oral suspension. Generic is okay.

**Dose:** Most patients take 100 mg of fluconazole by mouth one time a day.

**Drug interactions:** Fluconazole may cause a small increase in tacrolimus or cyclosporine levels. The transplant team will monitor your drug levels.

**Common side effects and what to do:**
- **Nausea and vomiting:** Take with food.
- **Liver damage:** Will be monitored with blood work (rare).

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Voriconazole (Vfend®)

**Purpose:** Antifungal to prevent or treat fungal infections.

**Usual duration:** Three to twelve months

**Dosage form:** Voriconazole comes in 50 mg and 200 mg tablets and an oral suspension. The tablets are available in a generic form and are okay to use.

**Dose:** Most patients take 200 mg of voriconazole by mouth two times a day.

**Blood levels:** Your transplant team may check a voriconazole blood level to decide what dose is best for you. Always have your blood drawn 12 hours after your last dose, unless instructed otherwise. This means you should wait to take your morning voriconazole until after your blood is drawn. If you take your voriconazole by mistake before your blood is drawn, do not have your voriconazole level checked. Call the transplant team for instructions.

**Drug Interactions:** Voriconazole may increase your tacrolimus or cyclosporine levels. The transplant team will monitor your drug levels.
Common side effects and what to do:

- **Nausea and upset stomach:** Take with food.
- **Sensitivity to bright lights, blurred vision:**
  Goes away with time and with decreased dose.
  If any other vision changes occur, please contact
  the transplant team.
- **Liver damage:** Will be monitored with blood
  work (rare).
- **Increased sensitivity to sunlight:** Avoid the sun when possible. Wear protective clothing and sunblock.

Itraconazole (Sporanox®)

**Purpose:** Antifungal to prevent or treat fungal infections.

**Usual duration:** Three to twelve months

**Dosage form:** Itraconazole comes in 100 mg capsules or a liquid (50 mg per teaspoon). The liquid is not available as a generic, but is preferred if it is covered by your insurance.

**Dose:** Most patients take 200 mg (this means two capsules or four teaspoons) of itraconazole by mouth two times a day. The capsule must be taken with a full meal and carbonated beverage to be fully absorbed. The liquid solution can be taken with or without food.

**Blood levels:** Your transplant team may check an itraconazole blood level to decide what dose is best for you. Your itraconazole blood level can be drawn at any time in relation to your dose (i.e. you do not have to hold your morning dose on the day of the lab draw). Call your transplant team for instructions.

**Drug Interactions:** Itraconazole may increase your tacrolimus or cyclosporine levels. The transplant team will monitor your drug levels.

Posaconazole (Noxafil®)

**Purpose:** Antifungal to prevent or treat fungal infections.

**Usual duration:** Three to twelve months

**Dosage form:** Posaconazole comes as an oral suspension that is 200 mg per teaspoon.

**Dose:** Most patients take 200 mg (one teaspoon) of posaconazole by mouth four times a day. Some patients take 400 mg (two teaspoons) of posaconazole by mouth two times a day. Posaconazole must be taken with a full meal, nutritional supplement or a carbonated beverage.

**Blood levels:** Your transplant team may check a posaconazole blood level to decide what dose is best for you. Your posaconazole blood level can be drawn at any time in relation to your dose (i.e. you do not have to hold your morning dose on the day of the lab draw). Call your transplant team for instructions.

**Drug Interactions:** Posaconazole may cause an increase in tacrolimus or cyclosporine levels. If you are taking these medicines, the transplant team will monitor your drug levels. Antacids or acid suppression medicines can decrease the absorption of posaconazole and make it less effective. The transplant team may tell you to change your acid-suppression medicine.

Common side effects and what to do:

- **Nausea and vomiting:** Take with food.
- **Liver damage:** Will be monitored with blood work (rare).
Other Medications

Over-the-counter (non-prescription) medications

- **Multivitamins**: Take one tablet by mouth daily. Avoid herbal multivitamins. Cystic fibrosis patients may require Aquadek or ADEK instead of over the counter multivitamins.

- **Calcium**: Take one tablet by mouth three times per day with meals for calcium supplementation.

- **Vitamin D (cholecalciferol)**: Take 2,000 units by mouth daily for vitamin D supplementation.

- **Acetaminophen (Tylenol®)**: Take only if needed for pain, headache or fever. Take as directed on the label.

Stomach acid suppressing medications

**Purpose**: To decrease stomach acid, reduce the risk of ulcers, and reduce the risk of acid reflux into the lung.

**Usual duration**: Rest of your life

**Dosage form**: There are many medicines in this category. Options include omeprazole (Prilosec®), esomeprazole (Nexium®), lansoprazole (Prevacid®) and pantoprazole (Protonix®). Generic is okay.

**Dose**: Varies with each medicine. Most patients take it one or two times a day.

**Common side effects and what to do**: Side effects are not common. If you have persistent symptoms of heartburn, tell the transplant team.

Pain medications

**Purpose**: To decrease pain from surgical incision and possibly other pain after surgery.

**Usual duration**: Only for a couple of weeks (often less) until surgical pain goes away.

**Dosage form**: There are several options in this category, including acetaminophen (Tylenol®), oxycodone/acetaminophen (Percocet®) and hydrocodone/acetaminophen (Vicodin®, Norco®). Tell the transplant team if there are certain pain medicines that have worked well for you or that you had problems with in the past.
Dose: Varies depending upon medication prescribed. Generic is okay.

Common side effects and what to do:
- Nausea and vomiting: Take with food.
- Constipation: Use stool softener and laxatives as prescribed.
- Sedation/sleepiness: Avoid activities that require mental alertness; do not drive while taking.

Stool softeners and laxatives

Purpose: To help prevent and treat constipation, especially while on narcotic pain medications.

Usual duration: Some patients only require stool softeners while they are on pain medicines.

Dosage form: There are several options in this category. Examples include docusate sodium (Colace®), senna (Senokot®) docusate sodium with senna (Senokot-S®), polyethylene glycol (Miralax®), bisacodyl (Dulcolax®) or psyllium (Metamucil®). Many of these medicines are available over the counter and do not require a prescription. Generic is okay.

Dose: Varies with each medicine. Most patients take it one or two times a day. These medicines should be adjusted to ensure regular, daily, bowel movements (if you have diarrhea, decrease the dose; if you are constipated, increase the dose).

Common side effects and what to do:
If you have loose stools, diarrhea or abdominal cramping, stop medication and inform the transplant team.
Giving Back

If you are interested in writing to your donor family, the social worker can assist with this process and in reviewing the guidelines offered by MTS. The donor families often find comfort in hearing from the recipients. The correspondence is anonymous, and your identity will be kept confidential. You can state your first name, your age, and the organ that you received. When the letter is ready, you can give it to your social worker or nurse coordinator to review it to make sure that it does not reveal personal information. For more information, please talk with the social worker or transplant coordinator.

Ways to Support Organ Donation and Transplantation

Now that you are an organ transplant recipient, you, your family and your friends are more aware of the need for organ donors. You may wish to help spread the word for organ donation in your own family and community. You can be a voice to help educate others, and you may consider speaking to others about organ donation. Mid-America Transplant Services can help you with information to give to others; the MTS phone number is located in the Resource section.

National Resources

The internet is a useful resource with a variety of websites about transplant issues, but be cautious of your use of the internet. While much of the information it contains is valid, some of the information is inaccurate and misleading. Information obtained from the internet should support, not replace, information provided by your transplant team. The following websites may provide additional information, resources, and/or support to you relating to your transplantation and related health issues.

American Lung Association
Lung Helpline
800-227-2345  ■  lung.org

American Cancer Society
(for self-breast and testicular exam information)
800-227-2345  ■  cancer.org

Center for Disease Control & Prevention (CDC)
Travel information
800-232-4636  ■  cdc.gov/travel

US Department of Health and Human Services
Organ donation and transplantation
301-443-7577  ■  organdonor.gov

National Cancer Institute
800-422-6237  ■  cancer.gov

Organ Procurement and Transplantation Network
optntransplant.hrsa.gov

Second Wind Lung Transplant Institute
888-855-9463  ■  2ndwind.org

Second Wind of St. Louis
secondwindstl.org
Financial Aid Resources

The following organizations may be able to help you in a variety of ways. This is a sample list, and should not be interpreted as a comprehensive list or an endorsement.

National Foundation for Transplants
800-489-3863  transplants.org

The National Foundation for Transplants (NFT) can assist with fundraising efforts. Since 1983, NFT’s fundraising campaigns have generated nearly $60 million to assist patients during their transplant journey, and assists more than 2,500 patients annually.

Help Hope Live
(formerly the National Transplant Assistance Fund)
800-642-8399  helphopelive.org

HelpHOPELive is a fundraising resource for anyone dealing with the many challenges related to a transplant or catastrophic injury. They provide the consultation needed to raise funds to bridge the gap between what health insurance will pay and what is actually needed.

The Partnership for Prescription Assistance
888-477-2669  pparx.org

The Partnership for Prescription Assistance helps qualifying patients without prescription drug coverage get the medicines they need through the program that is right for them. They are sponsored by the Pharmaceutical Research and Manufacturers of America.

NeedyMeds
needymeds.org

NeedyMeds is a resource devoted to helping people in need find assistance programs to help them afford their medications and costs related to health care.

Air Care Alliance
888-260-9707  aircareall.org

The Air Care Alliance is a nationwide league of humanitarian flying organizations whose volunteer pilot members are dedicated to community service.

Children’s Organ Transplant Association
800-366-2682  cota.org

The Children’s Organ Transplant Association (COTA) works with patients who need a transplant due to a genetic disease such as Cystic Fibrosis by guiding the patients and their families and through all necessary fundraising steps.

Air Charity Network
877-621-7177  aircareall.org

Air Charity Network provides access for people in need seeking free air transportation to specialized health care facilities or distant destinations due to family, community or national crisis.

National Patient Travel
800-296-1217  patienttravel.org

The purpose of the National Patient Travel Center is to ensure that no patient in financial need is denied access to distant specialized medical evaluation, diagnosis or treatment for lack of a means of long-distance medical air transportation.

Medicare Hotline
800-633-4227  medicare.gov

Medicare.gov is a clearinghouse of information related to Medicare.
glossary

Donor - The person who gives the transplanted organ.

Recipient - The patient who receives a transplant organ.

Evaluation - A group of tests that you will have to take to help the medical staff determine if you are a good candidate for transplant.

Tissue typing - Blood tests that are performed in order to match organs for transplant.

Wait list - The list of candidates registered to receive organ transplants. When a donor organ becomes available, the matching system generates a new, more specific list of potential recipients based on the criteria defined in that organ’s allocation policy (e.g., organ type, geographic local and regional area, genetic compatibility measures, details about the condition of the organ, the candidate’s disease severity, time spent waiting, etc.).

Active candidate - A transplant candidate eligible to be considered for organ offers at a given point in time. Some transplant candidates are temporarily classified as “inactive” by their transplant center because they are medically unsuitable for transplantation or need to complete other eligibility requirements.

Lung Allocation Score (LAS) - The lung allocation score is used to prioritize waiting list candidates based on a combination of waitlist urgency and post-transplant survival. In this context, waitlist urgency is defined as what is expected to happen to a candidate, given his or her characteristics, in the next year if he or she doesn’t receive a transplant. Post-transplant survival is defined as what is expected to happen to a candidate, given his or her characteristics, in the first year after a transplant if he or she does receive the transplant.

Immune system - The immune system is the body’s defense; its role it is to identify and destroy foreign tissues, bacteria, etc. It protects the body from organisms that may cause infection or disease.

Rejection - A process in which the body’s immune system attacks the transplanted organ, usually resulting in damage to that organ.

Acute rejection - This type of rejection involves swelling around the very small arteries (arterioles) and airways (bronchioles) in the lung.

Chronic rejection - This type of rejection occurs when the small airways (bronchioles) in the lung become scarred and narrowed.

Anti-rejection drugs (Immunosuppressive drugs) - Medication that transplant recipients take that help decrease the body’s ability to reject the transplanted organ.
Please use this pocket to hold your education materials and discharge instructions.

Contact Information:

Lung Transplant Office
Mailstop 90-75-549
4901 Forest Park Ave.
St. Louis, MO 63108
314-362-5378
800-321-4054
Fax 314-362-9272
BarnesJewish.org/lungtransplant

Transplant Center

Lung Transplantation
Patient Guide

Transplant. A Lifesaving Option.