Emory Transplant Center
MAKING A DIFFERENCE IN THE LIVES OF OUR PATIENTS AND OUR COMMUNITY

Your Lung Transplant
AT Emory University Hospital
A Journey for Life
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The most important information you may ever read

Now that you are considering a lung transplant, your recovery may depend on your understanding of what to expect before, during and after your transplant. The purpose of this book is to provide you and your family with that information. Please read each section carefully. Feel free to jot down notes in the margins and ask questions about anything you don’t understand or concerns you might have.

At Emory University Hospital, we consider lung transplantation when conventional medication or surgery cannot improve the function of your failing lungs. Transplantation offers many people the chance not only to survive but to return to a more normal, productive lifestyle.

The Emory lung transplant team seeks to thoroughly educate every candidate about transplantation. Post-transplant management can be difficult and demanding. You and your family must completely understand the risks, limitations and benefits of transplantation before you can make an informed decision concerning this procedure.

It is important to understand that a lung transplant does not “cure” your lung disease. You will need daily medication and rigorous follow-up by the transplant team for the rest of your life.

The Emory lung transplant team is committed to helping you if you are committed to the demands and requirements of transplantation. Your attitude about surgery and recovery and your participation in your care will play a vital role in the ultimate success of your lung transplant.
Why You May Need a Lung Transplant

HEALTHY LUNGS
The lungs provide your entire body with oxygen and remove carbon dioxide. The lungs are elastic, cone-shaped organs, located in the chest within a protective cage of 12 pairs of ribs and the intercostal muscles between the ribs. The lungs also are supported by the neck muscles and by the diaphragm, the muscle that separates the chest cavity from the abdominal cavity. The right lung, which is larger than the left, is divided into three lobes: upper, middle and lower. The left lung, which is somewhat narrower than the right to accommodate the heart, is divided into two lobes: upper and lower. Each lung is surrounded by two protective layers of tissue called pleura, which seal the lungs in an airtight cavity.

The trachea, or windpipe, branches into two mainstem bronchi, resembling an inverted tree-like structure. The mainstem bronchi divides into five lobar bronchi, which further branch into the bronchioles, the alveolar ducts, and finally, the alveoli. Each branch becomes smaller and smaller as the branches spread out. The smallest branches end in about 300 million tiny sacs called alveoli, which are the basic unit of gas exchange.

Blood that is to be oxygenated in the lungs travels from the right ventricle of the heart into the pulmonary arteries, bringing blood to the alveoli. Gas exchange occurs between the alveoli and tiny blood vessels called capillaries. Oxygen passes from the alveoli into the blood and carbon dioxide, a waste product of metabolism, leaves that blood to enter the gas-filled alveoli and is thereby removed from the body. Freshly oxygenated blood returns through the pulmonary veins to the left atrium of the heart, where it is pumped to the body for distribution to all body tissues.

FAILING LUNGS
People need lung transplants when their lungs can no longer perform their vital function of exchanging oxygen and carbon dioxide. Lung transplant candidates have end-stage lung disease and are expected to live less than two years. They often require continuous oxygen and are extremely fatigued from the lack of oxygen. Their lungs are too diseased to be managed medically and no other kind of surgery will help them.

Several different diseases can lead to end-stage lung failure. Chronic obstructive pulmonary disease (COPD) can be caused by asthma, chronic bronchitis and emphysema. Alpha1-antitrypsin deficiency, a hereditary condition causing the lack of a protein
needed for healthy lungs, is responsible for some cases of emphysema. *Interstitial lung diseases* include idiopathic pulmonary fibrosis, sarcoidosis, eosinophilic granuloma, Goodpasture’s syndrome, idiopathic pulmonary hemosiderosis and Wegener’s granulomatosis. Two airway diseases that can lead to end-stage lung disease are bronchiectasis and cystic fibrosis. *Primary pulmonary hypertension* is a progressive disease causing high blood pressure of the pulmonary vessels in the lung and can be a life-threatening condition.

**TYPES OF LUNG TRANSPLANTS**

You may require either a single, double or heart-lung transplant. Your doctor will discuss which type of transplant is recommended for your condition.

**HISTORY OF LUNG TRANSPLANTATION**

Lung transplant is a treatment, not a cure, for end-stage lung disease. The first human lung transplant was performed by Dr. James Hardy at the University of Mississippi in 1963 for an isolated cancer of the lung. The patient lived for 18 days and died of kidney failure. Between 1963 and 1980, about 44 transplants were performed at medical centers around the world with no real success. Most of these transplants were performed on debilitated patients as “rescue” attempts after they became ventilator-dependent. Only two recipients lived longer than one month.

This disappointing start contributed to a halt in lung transplantation until cyclosporine was introduced in the early 1980s. Heart-lung transplantation was performed successfully in 1981 at Stanford University and became the only option for lung transplantation until lung transplantation became commonplace in the late 1980s.

The first lung transplant associated with prolonged postoperative survival was performed by Dr. Joel Cooper at the Toronto General Hospital in 1983. The patient received a right lung transplant for idiopathic pulmonary fibrosis and survived for over six and a half years before succumbing to renal failure. In 1986, Dr. Cooper performed the first successful double lung transplant. Results continue to improve because of better medications and treatment of infection and rejection. The main limiting factor is the small supply of donor organs.

In 1993, Emory established the only lung transplantation program in the state of Georgia, with the primary mission of serving those residents of Georgia suffering from otherwise untreatable complex lung diseases. Our patient survival rates are consistent with national averages.
Your transplant evaluation

Your primary doctor or pulmonologist may refer you for evaluation if your lung function is very low (determined by a pulmonary function test) and he or she thinks no other medical or surgical therapy will help you. Your medical records will be sent to us to review. If an evaluation is necessary, you will come for an outpatient visit with the transplant pulmonologist and nurse coordinator. During this visit, you will be interviewed, examined and counseled about what we think is the best plan for your care. This may or may not include full evaluation for lung transplantation. The realities of having and living with a lung transplant are explained and discussed. If it is decided to proceed with more evaluation, an additional 2-3 days of inpatient testing is needed. Occasionally, outpatient testing is appropriate.

TESTS
The evaluation consists of meeting many different people who will perform different tests. Tests may include:
- VQ scan (ventilation/perfusion lung scan)
- Chest X-ray (CXR)
- Chest CT (computed tomography)
- Six-minute walk
- EKG (electrocardiogram)
- Abdominal ultrasound
- Bone density scan
- Pulmonary function test (PFT)
- Echocardiogram
- Heart catheterization
- Blood work
- Urine collection
- Psychological evaluation

MEETING THE TEAM
It is important that you meet all the members of the lung transplant team during the patient evaluation. Each brings special knowledge that will help you during all phases of the transplant process. The transplant team reviews the results of your evaluation. A plan of care is presented to you for consideration. This may or may not include the next step towards transplantation – being placed on the waiting list for a donor lung or lungs.
Transplant Surgeon
The transplant surgeon will perform your lung transplant surgery and will be in charge of your care immediately following your surgery. The transplant surgeon will also follow your progress as needed after you are discharged from the hospital.

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

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

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

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

Financial Coordinator
The financial coordinator will help you understand the cost of transplantation and your insurance benefits. He or she can answer questions about insurance coverage and help you contact the appropriate personnel regarding these questions.
**Cardiologist**
Transplant cardiologists may meet with you to evaluate your cardiac function.

**Psychiatrist**
A psychiatrist will meet with you to obtain a general mental health history. He or she may recommend counseling to deal with emotional needs or issues, such as depression or alcohol, drugs or tobacco use, that might affect the outcome of the transplant. A psychiatrist will be available for any developing needs.

**Psychiatric Clinical Nurse Specialist**
The psychiatric clinical nurse specialist works with you and your family on issues such as stress, anxiety, depression and addiction. The psychiatric clinical nurse specialist will see you and your family during your initial evaluation, while you are in the hospital and as needed after you are discharged.

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

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

**Physical Therapist**
A physical therapist may help pre-transplant patients understand what exercises are prescribed by the transplant pulmonologist. He or she is specially trained to help you regain your strength after surgery and will refer you to a pulmonary rehabilitation program in the early weeks after transplant. Exercise is important to your recovery. It can reduce complications after transplant surgery, improve your endurance and help you maintain a healthy lifestyle.
Chaplain
Transplantation often poses many spiritual issues. A chaplain will visit with you while you are at Emory Hospital and is on call 24 hours a day. The chaplain can help you and your family deal with conflicting emotions and difficult spiritual questions that are often associated with transplantation.

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

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

BEFORE YOUR EVALUATION
Before you come to Emory for your evaluation, call your insurance company’s case manager to see if your insurance covers lung transplantation. (See sample questions to ask.) Get a copy of your benefits for lung transplantation including deductible and copayment amounts.

The Emory Financial Coordinator for Lung Transplantation will help you consider the financial arrangements you will need to make for transplantation.

Call the financial coordinator at 404-727-9864 before your evaluation if:
• you have any questions regarding your insurance
• you do not have insurance
• you do not have benefits for transplantation, or
• you are denied coverage for a transplant.

Contact the social worker for lung transplantation at 404-712-5524 if:
• you need help applying for disability
• you would like to discuss other financial assistance options.

FINANCIAL QUESTIONS?
Call the financial coordinator at 404-727-9864

DISABILITY QUESTIONS?
Call the social worker for lung transplantation at 404-712-5524.

REMEMBER:
Bring to your evaluation a copy of your benefits for lung transplantation, including deductible and copayment amounts.
DURING YOUR EVALUATION

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

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

You will meet with the social worker for lung transplantation during your evaluation to discuss social issues in detail. You will also meet with the financial coordinator to discuss financial issues during your evaluation.

LUNG TRANSPLANT COSTS

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

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

BILLING

Authorization by your insurance company for medical services provided by Emory does not guarantee full payment of all charges. You will be responsible for the following:

- All deductibles, copayments and noncovered services as outlined in your health plan.
- Any balance between charges and what your insurance carrier pays as “usual and customary charges.” Ask your insurer for a copy of its usual and customary charges and an explanation of how it derives them.

You will receive separate billing statements with separate billing account numbers for Emory Hospital (inpatient and outpatient hospital services) and The Emory Clinic (inpatient and outpatient hospital services).
doctors’ fees and medical services provided by The Emory Clinic). All Emory Clinic charges will be billed on one account.

However, you will have several different accounts with Emory Hospital. The first nine numbers on every hospital account will always be the same; only the last four (4) numbers will change. Your accounts will include:

- Inpatient admissions (different accounts for each admission)
- Specimen accounts (a separate account for lab specimens drawn outside of Emory University Hospital including those specimens drawn at The Emory Clinic buildings).
- Recurring accounts (outpatient follow-up visits). This account is referred to either as an outpatient recurring or transplant recurring account.

Recurring accounts will remain open for three to six months. Any outpatient hospital charges during that period will be placed on that account. On recurring accounts, the hospital bills your insurance company once a month.

**SAMPLE QUESTIONS TO ASK YOUR INSURANCE COMPANY:**

1. Do I have benefits for lung transplantation?

2. What is my transplant maximum benefit?

3. What is my lifetime maximum benefit? How much have I used toward that maximum?

4. What is my annual maximum benefit? How much have I used toward this maximum?

5. Is organ acquisition covered? If yes, is there any limitation on how much my insurance will pay?

6. Does my insurance plan have “Centers of Excellence” for transplant services? If yes, is Emory University Hospital an approved transplant center? If so, is there a different billing address than listed on my insurance card that transplant claims must be sent to? (Note: If there is a different address to submit claims to, please be sure that each time you come to Emory for transplant services, you tell the insurance registration representative the correct address.)
7. What are my deductibles, copayments and out-of-pocket expenses? How much have I paid this year toward my deductible and out-of-pocket expenses?

8. What are considered usual and customary charges? How much am I likely to pay?

9. Do I need to obtain authorization/precertification for outpatient office visits and medical services, such as pulmonary function studies or bronchoscopies?

10. Are outpatient prescription drugs covered? Specifically immunosuppressant medications, such as gengraf, Imuran®, CellCept®, Prograf® or Sporanox®? How much is my responsibility for paying for outpatient prescription drugs? Is there a mail-order pharmacy that I may use that provides a higher level of benefit?

11. Is there a specific nurse case manager who will coordinate my transplant care? If yes, what is his/her name and number?

12. Do I have any transportation or lodging benefits?

13. Are ambulance or air ambulance services covered at the time of transplantation?

14. Am I in a preexisting period of coverage so that treatment for my condition is not covered? If yes, what conditions need to be met to pass the pre-existing period?

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

THE WAITING LIST

If you and the transplant team agree that you are a suitable transplant candidate, the team will place your name on a waiting list for a donor lung. The United Network for Organ Sharing (UNOS) is the national agency that regulates organ transplantation. LifeLink of Georgia facilitates organ donation for the state of Georgia. UNOS, along with LifeLink of Georgia, puts your name on a national computerized transplant waiting list and helps locate donor organs. You may access information on UNOS via the Internet at www.unos.org.

Due to a critical shortage of donor organs, adults can wait up to two years or more before a suitable donor lung is available. Often patients can wait at home during this time.

While you are “waiting,” you will continue follow-up care with your referring physician. However, it is important that we are always aware of any illnesses that occur, so please inform your coordinator of any illness you may have. You should request that your physician fax us the office notes of all your visits. We would like to see you in our clinic at least annually.

Finally, if you plan to travel while you are waiting, please inform your coordinator of your travel plans in case there are additional phone numbers needed to contact you.

YOUR STATUS ON THE LIST

You will be listed as an active status patient on the lung transplant waiting list. When an organ becomes available, the patient with the greatest number of cumulative days spent waiting and with the proper blood group and body size will receive the donor lung.

The longer you are on the list, the more “points” (days on list) you accumulate. Moving closer to the top of the list makes it more likely that you will be transplanted if a donor lung becomes available. This system will likely change in 2005 to one incorporating mortalities while waiting vs survival following transplant by disease category.
FINDING A DONOR
Every effort will be made to find a donor quickly. The wait for a donor depends on your blood type and body size. To find a donor match for you, we look at two things:
• You and the donor must have compatible blood types.
• You and the donor must be height-compatible.
Many families often ask questions about the age of the donor and how the donor died. The transplant team cannot give out any information to you about the donor nor do we give any information about you or your family to the donor family. The donor family has been promised that this information will be kept confidential.
We do encourage you to write a letter to the donor family without revealing your identity. If you choose to write a letter, the transplant coordinator will send it to LifeLink of Georgia who will then forward it to the donor family.

YOUR BEEPER
Once you are listed for transplant, you will need to carry a beeper so that we will be able to get in touch with you immediately when a donor becomes available. We would like to have exclusive access to your beeper. Please pick a day of the week to test-page yourself and to have your transplant coordinator do a test-page to assure that your beeper is working properly. Also, you will want to change your batteries on a regular basis.

ANXIETY IS NORMAL
Everyone has a different experience with transplantation. You may encounter personal, physical, psychological, spiritual and financial stresses during each phase of lung transplantation.
During transplant evaluation, waiting for the transplant and after the transplant, you may feel discouraged, afraid, anxious, sad or depressed. It is normal to worry that you might die before an organ becomes available. Members of your family may also experience emotional distress related to your illness and worry about the risk of death before transplantation.
Post-transplant life can be a challenge too, even if you are highly motivated and well-adjusted. Minor complications are likely for most recipients and may require treatment and hospital stays that interfere with your daily life. As a transplant recipient, you will also be recovering from surgery and taking new medications that may cause extremes in your emotions. These feelings should go away in six to eight weeks after the transplant. If they do not, please let your transplant coordinator know.
DEALING WITH STRESS

Many transplant candidates report that keeping a positive attitude about the situation helps. Other helpful coping strategies during the waiting period include getting involved in activities and seeking support from others.

Simply talking with someone may help put your feelings into perspective and relieve stress and anxiety. Check with your social worker for the time and place of support group meetings in your area. There also are other organizations that can provide support including the Mentor Project, Second Wind (national and local chapters) and the Georgia Transplant Foundation (GTF). Please see the “Other Helpful Information” section of this book for more details.

While you can expect these brief periods of discouragement, they should not affect your usual daily activities. If these feelings occur frequently (for longer than a week or two) or begin to interfere with your daily activities, let your doctor and coordinator know.

Our goal as the transplant team is to help you openly explore and discuss your feelings at any time during the transplant process. Please do not hesitate to call us.

LUNG TRANSPLANT SUPPORT GROUP

Contact:
Judy Simpson
Social Worker
404-712-5524

Kathy McDonnell
Psychiatric Nurse
404-727-9345

ADDITIONAL SUPPORT GROUP INFO

Georgia Lung Transplant Support Group
Contact:
Bob Hudson
706-863-8172
Galungtx@aol.com
Going to the hospital

THE PHONE CALL
When a donor lung becomes available, a transplant coordinator will phone you at home first. If we cannot get in touch with you, then we will beep you. Please call us back within five to ten minutes.

We will tell you that we have a potential donor and then ask how you have been feeling. If you have a fever, vomiting or diarrhea, we may not be able to do the transplant. The most important thing you can do while waiting for a transplant is to seek treatment quickly if you become ill, so that you will be ready at any time should a donor lung become available.

The first call you get does not always mean the transplant will occur. We will tell you that we have a potential donor. The surgeon examines each donor organ and may find that the organ isn’t strong and healthy. If the donor organ is not functioning well, we will not do the transplant. This does not happen often, but it is a possibility.

LEAVING FOR THE HOSPITAL
You need to leave your house within 15-30 minutes of our call so that you can arrive at Emory as soon as possible. If you have difficulty driving to the hospital, please call the coordinator and we will try to help you get here safely. We would not want you to lose a chance for a new lung because your car broke down.

If you have arranged to fly here, you will need to contact the air ambulance service immediately for departure and arrival times and then tell your coordinator. With this information, we can anticipate when you will arrive at Emory.

ARRIVING AT THE HOSPITAL
When you arrive at Emory Hospital, please drive to the valet entrance on Clifton Road, then go directly to admissions located on the second floor of the hospital. They will direct you to your room where you will be quickly prepared for surgery. This time will be very hectic. We will take your vital signs, do a chest X-ray and EKG, weigh you and do blood tests. You will also receive some medication by mouth and through a vein before going to the operating room.

If all goes as planned, you will probably go to the operating room within two hours of arriving at the hospital. Single lung transplant surgery will last approximately four hours. Bilateral lung transplant surgery will last approximately six to eight hours.
Your family can wait in a special waiting room of the hospital while the surgery is taking place. This is also the place where an operating room nurse may talk with your family during surgery, most likely calling them by phone to tell them how things are going during the transplant. The surgeon will also look for your family in this waiting room after the surgery.

**THE LUNG TRANSPLANT SURGERY**

After arriving in the operating room, you will receive general anesthesia and be put to sleep. You may be placed on a heart-lung machine (cardiopulmonary bypass) that will handle the functions of your heart and lungs while the surgeon is working on both your old and new lungs. You will also have a breathing tube in your throat, called an endotracheal tube. This tube is connected to a machine called a ventilator, which will breathe for you during and after the operation.

If you are having a single lung transplant, you will have a thora
cotomy incision either on your right or your left side, depending on which lung is being replaced. After the donor lung arrives in the operating room, the surgeon will remove your diseased lung. You will be ventilated using your other lung. If your remaining lung is not able to exchange enough oxygen, the surgeon may place you on cardiopulmonary bypass. Your blood will be filtered through a machine outside your body which will put oxygen into your blood and remove carbon dioxide.

Three connections will be used to attach your new lung. These connections are called *anastomoses*. First, the main bronchus from the donor lung is attached to your bronchus. Then, the blood vessels are attached, first the pulmonary artery and then the pulmonary veins. Finally, the incision is closed and you will be taken to the intensive care unit, where you will be asleep for approximately 12-24 hours.

If both your lungs are transplanted (a bilateral transplant), the surgeon will make an incision below each breast, called an *anterior thoracotomy*, or an incision that goes from your right side to your left side at the base of your breasts. This is called a *transverse sternotomy* incision. In a bilateral lung transplant, each lung is replaced separately. The surgeon begins by removing the lung with the poorest function. You will be ventilated using your remaining lung unless partial cardiopulmonary bypass is needed. Once your first lung is removed, a donor lung will be attached using three connections — the donor bronchus is attached to your main bronchus, then the blood vessels are attached, first the pulmonary artery, then the pulmonary veins. Your second diseased lung is removed and the other new lung is attached just like the first one. Once the second lung is completely connected, blood flow is
restored. Finally, your incision is closed and you are taken to the intensive care unit (ICU).

With either incision, nerves can be cut resulting in various degrees of decreased sensation.

Various tubes and monitoring equipment will be used to monitor how well your lungs and body are recovering after surgery.

• IVs (intravenous tubes) will help you receive fluids and medications. A special IV called a pulmonary artery catheter (Swan Ganz catheter) in your neck vein will measure the pressures in your heart and lungs and tell the surgeon how well your new lungs are functioning.

• A heart monitor will record your heart rate and rhythm at all times.

• Tubes in your chest near the bottom of your incision and possibly on the sides of your chest will drain the blood and fluid that collect in your chest after the operation. They are usually removed several days after the surgery.

• A small tube, called a foley catheter, in your bladder will help us measure how well your kidneys are working. This tube will be taken out a couple of days after your surgery, and then you will urinate on your own.

• An epidural catheter may be placed to manage your pain. Later you will receive pain medication (through your IV tube) that you dose yourself through a special patient-controlled analgesia (PCA) device.

As you begin to recuperate and feel stronger, all the tubes and catheters will be removed.
WHAT HAPPENS AFTER SURGERY

After surgery, you will go to the cardiothoracic surgery intensive care unit (ICU) where a doctor and nurses are always very close by if you need anything. At first, you will be under the effects of anesthesia. You will have many IVs, special tubes and initially a breathing tube. Once you wake up and breathe on your own, the breathing tube will be removed.

When you first wake up, you may feel like you are not getting enough air. It is important to relax and let the ventilator breathe for you. You will not be able to talk while on the ventilator, but you can talk immediately after the ventilator is removed. The ventilator may be very uncomfortable, but the team will work very hard to remove it as soon as your heart and lungs are ready.

You also will hear many different noises. These are normal sounds made by the equipment around you and by people talking.

You will probably look different to your family. You will be pale, possibly swollen and will feel cool to their touch. This will improve after just a few hours in the intensive care unit. You will also still be sleepy and may not remember the first time your family visits.

A typical stay in the ICU is two to three days. You will then be transferred to the thoracic surgery floor where our nurses and physical therapists will help you regain your strength, teach you how to care for yourself when you go home, and prepare you for discharge from the hospital. If all goes well, you can expect to spend one to two weeks on the thoracic surgery floor.

DEEP BREATHING AND COUGHING

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

Since you will have a chest incision, coughing may be painful. The nurse will teach you how to splint (decrease the pain by holding a pillow or your hands over your incision). Ask the nurse for pain medicine so you can breathe deeply and cough more easily and effectively.

HOW TO USE THE INCENTIVE SPIROMETER:

1. Assume a comfortable relaxed sitting position.
2. Attach one end of the tubing to the unit and one end to the mouthpiece.
3. Slide the pointer to your target volume as instructed by the respiratory therapist or nurse.
4. Hold the unit in an upright position.
5. Exhale normally, then place your lips tightly on the mouthpiece.
6. Breathe in slowly to raise the piston to the target volume.
7. Avoid raising your shoulders as you inhale.
8. Remove the mouthpiece and hold your breath for about five seconds until the piston falls to the baseline.
9. Slowly exhale through your mouth.
10. After each breath, cough and breathe deeply. Do not just clear your throat.
11. Relax and pace yourself in order to avoid excessive fatigue or dizziness.
12. Repeat steps 5-9 at least ten times.
Possible complications after transplant

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

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

Some of the most common complications seen after lung transplant are: rejection, infection, bronchiolitis obliterans syndrome (BOS) and high blood pressure (please see definitions below).

ACUTE REJECTION

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

Acute rejection is a cellular reaction that takes place in the tissues of the lung and can be seen under a microscope. Almost all lung transplant patients will have at least one or two episodes of acute rejection in the first year. Usually acute rejection is treated by IV steroids.

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

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

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

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

**REJECTION WARNING SIGNS**

If you have any of these symptoms, call the transplant coordinator:

- Fever greater than 100.5 degrees Fahrenheit
- Feeling excessively tired or fatigued
- Shortness of breath
- Weight gain greater than 2-3 pounds in 24 hours or more than 4-5 pounds in 2-3 days.
- Loss of appetite, nausea, or vomiting
- Change in pulse rate or heart rhythm
INFECTION

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

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

BRONCHIOLITIS OBLITERANS SYNDROME (BOS)

The most common late complication of lung transplant is the development of bronchiolitis obliterans or obliterative bronchiolitis (OB). OB is an inflammatory disorder of the small airways, leading to obstruction and destruction of pulmonary bronchioles. The term bronchiolitis obliterans syndrome (BOS) refers to chronic lung rejection. BOS affects up to 50% of lung transplant patients within five years of the transplant and is perhaps the main impediment to prolonged survival.

A patient with BOS usually complains of dry or productive cough and progressive difficulty in breathing that is not helped by bronchodilators. The main functional abnormality is airflow obstruction, which is measured by a decline in the FEV₁. BOS is usually treated by increased doses of immunosuppression medications with improvement in some but not all patients. Patients are closely monitored for the development of infections that may be brought on by increased immunosuppresion.

HYPERTENSION / HIGH BLOOD PRESSURE

Many transplant recipients take medications to control hypertension or high blood pressure since prednisone and cyclosporine, two of the medications used to limit rejection, can raise blood pressure.

Blood pressure is recorded as a top (systolic) and bottom (diastolic) number. Normal blood pressures range from 100/70 to 130/80. After transplant you will take your own blood pressure regularly and keep a record in a daily diary we give you. We will also provide blood pressure guidelines and will expect you to call us if your blood pressure goes above or below the guidelines. Untreated high blood pressure can eventually damage your heart and other organs.
POST-TRANSPLANT DIABETES

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

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

CYTOMEGALOVIRUS (CMV)

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

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

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

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

**LEARNING ABOUT YOUR MEDICATIONS**

While you are in the hospital recovering from your surgery, our pharmacists and nurses will teach you and at least one family member about all your medications. We will review with you the purpose, dosage and possible side effects of each medicine. To help you feel more comfortable taking these medications, we will ask you to begin administering and keeping your own medication records in the hospital a few days before your discharge.

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

**WHERE TO GET YOUR MEDICATIONS**

Soon after your transplant surgery, the coordinator will ask you what pharmacy you will use to get your medications. You may use a pharmacy in your hometown or a mail-order pharmacy. Please try to plan ahead and make these arrangements before you get your transplant.

Prior to your discharge, a coordinator will either call your pharmacy with your medicines or provide you with written prescriptions. It is your responsibility to contact your pharmacy when you run low on medications or to contact our office when you need new prescriptions, so that you will always have all of your medicines. Your prescription usually will be for a month’s supply along with five refills. We recommend that you keep a one or two week supply on hand.

If you are interested in a mail-order pharmacy, please let the coordinator know. She can give you phone numbers to call. If you decide to use a mail-order pharmacy, it is your responsibility to call and initially set up the service, and then the coordinator will call in the prescriptions. Mail-order pharmacies will get medicine to you in a few days after you call them or can ship it to you routinely every month. After you contact them with your new medication dosages, the pharmacy asks us to verify the changed prescription. Mail-order pharmacies usually bill your insurance company directly.

**PLAN AHEAD:**

Before you have your transplant, arrange for your medications with the pharmacy of your choice.

My home pharmacy is

Their phone number is

My Atlanta area pharmacy is

Their phone number is

**IMPORTANT:**

Please bring your medications in their bottles with you to your first follow-up visit.
When you are discharged from the hospital, we will give you a three-day supply of travel medicines just in case there is a delay in receiving the medications from your pharmacy.

If you experience difficulty with the cost of your medications, please do not hesitate to let your coordinator know. We will work together to seek assistance.

**FREQUENTLY USED MEDICATIONS**

**Anti-rejection Medications (Immunosuppressants)**

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

**Cyclosporine (Gengraf®)**

Cyclosporine is a potent anti-rejection drug. It is given by vein initially and later taken in pill form. Cyclosporine comes in 25 mg and 100 mg capsules.

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

*Potential side effects:*
- Increased risk of infection
- Damage to kidneys
- Elevated blood pressure
- Headaches

**IMPORTANT:**

Do NOT eat or drink ANYTHING after midnight except blood pressure medicine and water before having your blood drawn. Do NOT take cyclosporine or Prograf the morning before your blood draw.

**TIPS FOR TAKING MEDICATIONS**

- Know the medicines that you are taking and their side effects.
- Tell the transplant coordinator if you experience any side effects.
- Keep a record of medicines you are taking, including the frequency and dose.
- Talk to the transplant coordinator before adding, stopping or changing any medicine, including those prescribed by other physicians such as your local doctor.
- Keep medicines in a dry place, away from heat or light, and out of the reach of children.
- If you miss a dose, DO NOT double the dose; take the next dose as directed.
- If you miss two doses, notify the transplant coordinator.
• Trembling hands and voice
• Tingling of hands and feet
• Increased body hair
• Thickening of gums
• Anemia
• Irritation of the liver
• Ringing in the ears

Tacrolimus (Prograf®)
Prograf® (formerly known as FK 506) is a very potent anti-rejection drug that comes in 1 mg and 5 mg capsules. It is used for patients having difficulty tolerating cyclosporine. You will not be taking cyclosporine and Prograf® at the same time.

Special instructions:
• Must be taken every 12 hours.
• Must be taken one hour before eating or two hours after eating.
• Do not take with other medications.
• Notify your pharmacy several days before discharge so that this drug can be ordered for you.

Potential side effects:
• Increased risk of infection
• Damage to kidneys
• Increased potassium
• Increased blood pressure
• Increased blood sugar
• Nausea, vomiting, and poor appetite
• Trembling hands and voice
• Headache
• Difficulty sleeping
• Constipation

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

Special instructions:
• Watch for increased bruising or bleeding and report to the transplant team.

Potential side effects:
• Increased risk of infection
• May lower your white blood cell or platelet count
• Predisposition to mouth ulcers
• Irritation of the liver

• Bring a list of your medications including their frequency and doses each time you see a health care professional.

• Never take over-the-counter medications or herbal remedies unless you check first with the transplant coordinator to prevent possible dangerous interactions.

• Do NOT take aspirin unless approved by the transplant coordinator as it affects blood-clotting rates.

Use other medications such as Tylenol.
• Anemia
• Nightmares
• Nausea, vomiting, diarrhea, upset stomach

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

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

*Potential side effects:*
• Nausea, vomiting, diarrhea
• Constipation
• Leg cramps, weakness
• Headaches
• Increased frequency of urination

**Rapamune (Sirolimus®)**
Rapamune (Sirolimus®) is an anti-rejection medication often prescribed in combination with a steroid medicine (i.e. prednisone) and cyclosporine (i.e. Neoral®, Sandimmune®). The usual dose is 1-3 mg per day. Rapamune comes in 1 mg tablets.

*Special instructions:*
• Do not consume grapefruit or grapefruit juice during treatment.
• Rapamune is usually taken once a day. It is recommended that Rapamune be taken four hours after taking cyclosporine (Neoral®, Sandimmune®), but always follow your doctor’s instructions.
• Rapamune can be taken either with or without food, but it is very important to take every dose of Rapamune in the same relation to food.

*Potential side effects:*
• Nausea, vomiting, diarrhea
• Constipation
• Headaches
• Increased blood pressure
• Increased cholesterol or triglyceride levels
• Water retention or swelling
• Leg cramps, weakness
• Rash or acne
• Fever
Prednisone (Deltasone®)
Prednisone is a steroid drug that helps prevent and treat rejection. The dose of this drug will be slowly decreased over time. Most of the side effects of prednisone are dose-related. As the dose is lowered, the side effects decrease. Prednisone comes in 1 mg, 5 mg, 10 mg, 20 mg and 50 mg tablets.

Special instructions:
• Take with food.
• Monitor your weight and report gains of 2-3 lbs. in 24 hours or more than 4-5 lbs. in 2-3 days.
• Have an annual eye exam with your local eye doctor.
• Wait four to six months before changing your eyeglass prescription, because prednisone can change your vision.

Potential side effects:
• Stomach irritation
• Fat deposits
• Cataracts
• Acne
• Muscle weakness
• Blurred vision
• Mood swings
• Sun sensitivity
• Increased appetite, weight gain
• Water retention and round, puffy face
• Weakening of the bones (osteoporosis)
• Fragile skin with bruising and skin tears
• Night sweats and trouble sleeping
• Increase in blood sugar (diabetes)
• Increased blood pressure (hypertension)

REJECTION TREATMENT IMMUNOSUPPRESSIVE DRUGS

Methylprednisolone (Solu-Medrol®)
Solu-Medrol®, available in IV only, treats acute rejection and has side effects similar to prednisone.

Antithymocyte Globulin Sera (ATGAM®)
ATGAM® is an antiserum raised in horses which treats recurrent or refractory rejection. It is given by IV and, once used, can only be repeated with great caution. Tylenol®, Benadryl®, and other medications are given to relieve its side effects.

Potential side effects:
• Decreased white blood cells and platelets
• Rash and itching
• Fever
Thymoglobulin (RATG®)
RATG® is an antiserum raised in rabbits. It is also used to treat recurrent or refractory rejection and has side effects similar to ATGAM®.

Muromonab-CD3 (Orthoclone OKT3®)
OKT3® treats recurrent or refractory rejection. It is given by IV. Tylenol® Benadryl® and other medications are given to relieve its side effects.

*Potential side effects:*
- Chills and fever
- Diarrhea
- Headache
- Shortness of breath

INFECTION PROPHYLAXIS

**Antibiotics**
The antibiotic trimethoprim-sulfamethosazole (Bactrim®) is prescribed to prevent a life-threatening pneumonia called Pneumocystis carinii (PCP).

*Potential side effects:*
- Nausea and vomiting
- Rash
- Lowered white blood cell count

**Antiviral Drugs**
Antiviral drugs such as acyclovir (Zovirax®) are prescribed to help prevent and treat herpes-related infections such as fever blisters and shingles.

**Ganciclovir (Cytovene®)**
Ganciclovir (Cytovene®) is an antiviral drug that helps prevent and treat cytomegalovirus (CMV). It is given by IV. Ganciclovir is used to prevent CMV if lung transplant recipients are CMV positive by blood test or when a CMV positive graft is implanted into a CMV negative recipient.

*Special instructions:*
Ganciclovir is administered over one hour. Do not administer with other medications.

*Potential side effects:*
Decreased white blood cells and platelets
ANTIFUNGAL DRUGS

Antifungal drugs such as nystatin (Mycostatin®) are prescribed to help prevent and treat fungal infections of the mouth and throat.

Itraconazole (Sporanox®)
Itraconazole (Sporanox®) is an antifungal agent that helps prevent and treat the fungus Aspergillus. The usual dose of Sporanox® is 200 mg once a day. Sporanox® comes in 100 mg tablets. You will take this medication the first 3-6 months after transplant to prevent Aspergillus.

*Special instructions:*
For patients taking the capsule form: take with a meal or snack so that the medicine is fully absorbed in the body.

*Potential side effects:*
- Constipation
- Diarrhea
- Nausea or vomiting

Voriconazole (VFEND®)
Voriconazole (VFEND®) is a new medication just approved as a second-line antifungal agent to treat Aspergillus. The usual dose of voriconazole comes in 200 mg or 50 mg tablets; the oral form is just as effective as the IV form of the drug.

*Special instructions:*
- Take voriconazole at least one hour before or after a meal.
- Take each dose with a full glass of water.
- Take all of the voriconazole that your doctor prescribes for you even if you start to feel better.

*Potential side effects:*
Continue taking voriconazole and talk to your doctor if you experience:
- Blurred vision, increased sensitivity to light, or other visual changes
- Nausea or vomiting
- Diarrhea
- Swelling or water retention
OTHER MEDICATIONS

Anti-hypertensives
Anti-hypertensives are drugs that help control blood pressure. Among the more commonly prescribed are nifedipine (Procardia XL®), amlodipine (Norvasc®), and lisinopril.

Potential side effects:
• Low blood pressure
• Dizziness
• Weakness
• Fatigue
• Possible sexual dysfunction
• Fluid retention

Mineral-based Replacement Drugs
Magnesium is prescribed to replace this normal body salt that is wasted in your kidneys when you take certain immunosuppressive medications.
Going home from the hospital

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

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

DAILY JOURNAL

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

The coordinator will tell you acceptable ranges for the vital signs so that you will know when to call if a reading is abnormal. If there is a problem after your discharge, the coordinator may ask you what your vital signs have been running for the past few days. Please have the journal available when you call the office.

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

BRING HOME:
- Blood pressure cuff
- Pills
- Thermometer
- Incentive spirometer
MEDIC ALERT IDENTIFICATION
We request that you obtain a special medic alert bracelet or necklace. In case of a car accident or other type of emergency, this will alert health care professionals that you have had a transplant. The identification bracelet or necklace costs a nominal fee. To enroll, call 1-800-432-5378 or fill out the order form provided by the transplant coordinator.

DISCHARGE FROM THE HOSPITAL
You will be discharged to go home if you live in the Atlanta area. If you live more than 30 minutes from Emory, we will ask you to stay in Atlanta for four to six weeks so we can monitor your progress closely.

The Mason Guest House of Emory University offers private, low-cost lodging for organ transplant candidates, recipients and families. Individuals from out of town coming to a transplant evaluation or follow-up care visit may also stay at the Mason Guest House. (See section on Mason Guest House.) If you are receiving intravenous infusions by visiting nurses you will not be able to stay at the Mason Guest House. If home IV therapy is indicated, the social worker will try to assist you with housing.

WHEN TO CALL THE TRANSPLANT COORDINATOR
Call your transplant coordinator if you experience any of these symptoms:
• Temperature of 100.5° Fahrenheit or greater
• Blood pressure greater than 150/95 or less than 90/60
• Heart rate greater than 130 or less than 50 (or varying 10 beats per minute from your baseline heart rate)
• Weight gain of more than two to three pounds in 24 hours or more than four to five pounds in two to three days
• Irregular heart rate
• Cough, shortness of breath, sore throat, chills, breathing fast, mucous production or discolored sputum
• Nausea, stomach pain that lasts more than 24 hours or decreased appetite
• Diarrhea or vomiting
• Blood in the urine or bowel movements, painful urination
• Decrease in urine output
• Fatigue
• Persistent headaches or flu-like symptoms
• Any unexplained rash
• Excessive swelling of the lower extremities
• Dizziness or “blackout” spells

IMPORTANT PHONE NUMBERS

Lung Transplant Coordinator:
404-727-9869

Lung Transplant Office:
404-727-9650

After hours call:
404-778-5000 and ask for the lung transplant or pulmonary attending physician on call.

Transplant Outpatient Services (2D)
404-712-5676

Mason Guest House
404-712-5100
Going for check-ups

After your transplant, all appointments at Emory will be scheduled in Transplant Outpatient Services (2D), which is located on the second floor, D-wing of the hospital. You will usually start your appointment by reporting to the 2D reception area.

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

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

ROUTINE BLOOD TESTS

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

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

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

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

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

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

On the day of your bronchoscopy, you will need to go to the Respiratory Department on the 4th Floor of Emory Hospital. You will be given some medications to make you more comfortable during the procedure. Your doctor will pass a flexible fiber-optic tube (called a bronchoscope) through your nose down the trachea to the bronchi. The doctor will look at each lung separately by passing the bronchoscope down each bronchus and all its segments. At the same time, the doctor may take samples of lung tissue and cultures. All of these samples are useful in determining if there is rejection or infection present, even before you experience any symptoms and long before a chest X-ray shows anything abnormal. Problems that are detected early can be treated much more easily.

After the bronchoscopy, you will stay in a recovery area until you are fully awake and alert. Your doctor will tell you about symptoms to report, but it is not unusual to run a fever for 12-24 hours after a bronchoscopy. You will not be allowed to drive home following the bronchoscopy, so please have a driver available.

Bronchoscopy results are usually available by early evening on the day after the procedure. After a physician has looked at the results of both the blood work and bronchoscopy, a coordinator will call you with your results. The coordinator will tell you what, if any, medications to change and when we will need for you to have more lab work.

REMEMBER:
You must FAST TRACK each bronchoscopy.
Call (404) 686-5270 or 1-800-640-9293.
YOUR FOLLOW-UP SCHEDULE

This is your routine follow-up schedule after your transplant, or the minimal number of follow-up visits you may have. You may be required to make more frequent visits based upon lab values and symptoms. Our routine office day is Tuesday morning. Our routine bronchoscopy days are Wednesday and Thursday.

WEEK ONE (You probably still will be hospitalized.)

_____ Chest X-ray
_____ Lab work
_____ Bronchoscopy

WEEK TWO

_____ Chest X-ray
_____ Lab work
_____ Office visit
_____ Bronchoscopy with biopsy

WEEK THREE

_____ Chest X-ray
_____ Lab work
_____ Office visit
_____ Staple removal

ONE MONTH

_____ Chest X-ray
_____ Lab work
_____ Spirometry
_____ Office visit
_____ CT of chest
_____ Perfusion scan (single lung)
_____ Bronchoscopy with biopsy

WEEKS FIVE, SIX & SEVEN

(These may be done locally if arrangements are made.)

_____ Lab work
_____ Spirometry

TWO MONTH

_____ Chest X-ray
_____ Lab work
_____ Spirometry
_____ Office visit
_____ Bronchoscopy with biopsy
WEEKS NINE, TEN & ELEVEN
_____ Lab work
_____ Spirometry

THREE MONTH
_____ Chest X-ray
_____ Lab work
_____ Pulmonary Function Test (PFT)
_____ Office visit
_____ CT of chest
_____ Six-minute walk
_____ Bronchoscopy with biopsy

FOUR MONTH
_____ Chest X-ray
_____ Lab work
_____ Spirometry
_____ Office visit

FIVE MONTH
_____ Chest X-ray
_____ Lab work
_____ Spirometry
_____ Office visit

SIX MONTH
_____ Chest X-ray
_____ Lab work
_____ PFT
_____ Office visit
_____ CT of chest
_____ Six-minute walk
_____ Bronchoscopy with biopsy

MONTHS SEVEN & EIGHT
_____ Spirometry

NINE MONTH
_____ Chest X-ray
_____ Lab work
_____ PFT
_____ Office visit
_____ Six-minute walk
MONTHS 10 & 11
_____ Spirometry

ONE YEAR
_____ Chest X-ray
_____ Lab work including 24-hour urine
    (must obtain jug prior to visit)
_____ PFT
_____ Office visit
_____ CT of chest
_____ Six-minute walk
_____ Bone density
_____ Ultrasound of gall bladder
_____ Bronchoscopy with biopsy

MONTHS 13, 14 & 15
_____ Spirometry

MONTH 16
_____ Chest X-ray
_____ Lab work
_____ PFT
_____ Office visit

MONTHS 17, 18 & 19
_____ Spirometry

MONTH 20
_____ Chest X-ray
_____ Lab work
_____ PFT
_____ Office visit

MONTHS 21, 22 & 23
_____ Spirometry
<table>
<thead>
<tr>
<th>Two Year</th>
<th>Monthly Procedure</th>
<th>Description</th>
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<tbody>
<tr>
<td></td>
<td>Chest X-ray</td>
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<td></td>
<td>Lab work including 24-hour urine</td>
<td>(must obtain jug prior to visit)</td>
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<td>PFT</td>
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<td>Office visit</td>
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<td>CT of chest</td>
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<td>Six-minute walk</td>
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<td>Bone density</td>
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<td>Ultrasound of gall bladder</td>
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<td></td>
<td>Bronchoscopy with biopsy (optional after one year)</td>
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<td>PFT</td>
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<td>Chest X-ray</td>
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<td>Lab work including 24-hour urine</td>
<td>(must obtain jug prior to visit)</td>
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<td>Bone density</td>
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<td>Ultrasound of gall bladder</td>
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FOLLOW-UP CARE IN 2D OUTPATIENT CLINIC

Establishing an Account
Your care as an outpatient will continue in 2D. This area is located in the D wing of the second floor in Emory University Hospital. Your first step is to call FAST TRACK at 404-686-5270 or 1-800-640-9293. Please have your insurance information handy. Tell the Admissions representative that you are establishing an account for 2D Outpatient Transplant. This account is good for three months. You must call FAST TRACK every three months or prior to visits to avoid making a trip to Admissions on the day of your appointment.

Your Visit Day
On the day of your visit, most patients utilize Valet Parking. The charge currently is $7 per day, which is $3 more than Visitor Parking. From Valet Parking, you will enter the hospital on the first floor. If you are here by 7:30 a.m., you may want to have your chest X-ray (CXR) done first since that department is located on the first floor in the C Wing. You will need to wait for your film and bring it yourself to 2D.

After your CXR, go to 2D. Sign in at the front desk and then wait to be called for your lab work. Timing of lab work is important because we are looking at your drug levels. Do not take your immunosuppressants after your previous evening’s dose until after your labs are drawn. Your labs usually will be drawn between 8 a.m. and 9 a.m. On the evening before, please take your evening dose of medicines between 8 p.m. and 10 p.m.

After lab work, you will either be placed in a room for your office visit or continue on to your next scheduled test.

The Pulmonary Function Lab is on the 4th floor, F wing. Report here for PFTs and/or spirometry. You will need to bring a copy of your test results back to 2D for your appointment.
ANNUAL EXAMS

Every year, around the anniversary of your transplant, you will have your annual exam. Plan to be here two to three days for this examination. You will not need to spend the night in the hospital unless complications occur, but bring someone with you to drive you home.

Annual visits include:
- Pulmonary function tests (PFTs)
- Bone density test
- Chest x-ray (CXR)
- Chest CT
- Six-minute walk
- Gallbladder ultrasound
- 24-hour urine collection (collection and testing may be done locally before dates of your annual exam, or collection may be done at home and a sample brought in on your exam date)
- Blood work
- Office visit
- Bronchoscopy (if indicated)
- V/Q lung scan (ventilator/perfusion lung scan – for single lung transplant – if indicated)
- Echocardiogram (for heart-lung transplant)
- Heart catheterization (for heart-lung transplant)

GALL BLADDER ULTRASOUND

Cyclosporine can cause the formation of gallstones. We will periodically recommend a gallbladder ultrasound to look for gallstones. If you develop gallstones, we will recommend surgery to have the gallbladder removed. If your gallbladder is not removed, a stone could possibly be released from the gallbladder and cause it to rupture. Since your immune system is suppressed, this could lead to a life-threatening infection.
Staying healthy

Now that you have had your transplant, you can expect to have a healthy life ahead of you. We encourage you to resume your normal activities as much as possible and take good care of yourself. Here are some suggestions:

YOUR DAILY ROUTINE

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

Home spirometry and taking your medications exactly as prescribed will help prevent post-transplant complications.

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

BATHING

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

HELPFUL HINTS

- Keep all clinic appointments.
- Never run out of medications.
- Report changes in vital signs listed in section called “When To Call the Transplant Coordinator.” Also report any symptoms of illness to your transplant coordinator.
- Never take cyclosporine before having blood drawn or before a biopsy.
- Never take over-the-counter drugs without checking with the transplant coordinator. They may interfere with your transplant medications.
- Never smoke.
- Avoid smoke-filled areas. Ask family members not to smoke.
- Avoid lifting heavy objects and strenuous physical work for at least six weeks after transplant.
DRIVING
You will not be allowed to drive for at least eight weeks after your transplant. Your reaction time is decreased because of the surgery, anesthesia, medications and bed rest. It also takes about eight weeks for your incision to heal properly. You may ride in a car during this time, but you must always wear a seatbelt. The coordinator will tell you when you are allowed to drive.

EXERCISE
After your transplant, you will begin an exercise program in the hospital under the direction of the physical therapist. After you are discharged, you must continue pulmonary rehabilitation. Exercise helps counteract the weakening effects of your pre-transplant illness and helps offset possible side effects of the immunosuppressive drugs you must take after transplant. Those side effects may include weight gain, water retention, high blood pressure, elevated cholesterol, high blood sugar and weakened bones. Regular activity also promotes confidence and a sense of well-being.

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

Stop the exercise if you become dizzy, short of breath, nauseated, extremely tired or if you are sweating excessively. Avoid these activities during the first six weeks after transplantation:
- lifting more than 10 pounds
- forceful pushing or pulling
- use of a regular bicycle
- contact sports

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

Contact your physical therapist if you have any questions about your exercise program.

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

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

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

SMOKING

Smoking is an ABSOLUTE contraindication to lung transplantation. You MUST be smoke-free for 12 months to be considered for a transplant. If you are smoke-free for six months and have three negative urine tests for nicotine, then we will have you come in for an outpatient evaluation. You must avoid smoke-filled areas and ask family members not to smoke. If you are exposed to secondhand smoke, you may have a positive urine nicotine test.

PROTECTING YOURSELF FROM INFECTION

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

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

**RETURNING TO WORK**

One of the goals after transplantation is to help patients return to work when they are physically and emotionally ready. Returning to work can be as easy as returning to a previous job.

However, you may not have worked for a long time, lack current job skills, or need to change occupations because of physical or other limitations. You may benefit from career counseling. The Georgia Transplant Foundation can assist you in a number of ways:
• career interest testing
• coaching for job search and interview techniques
• skill training
• resumé development
• career counseling
• social security and benefits counseling
• placement in a job that matches your interests, capabilities and functional limits.

When you are ready, the social worker will be happy to assist you with a referral to the Georgia Transplant Foundation for any of these services.

*The Georgia Transplant Foundation has JobLink, a “return to work” program to help transplant recipients. For more information, call 770-457-3796 or 1-866-GA TX 411*
TRAVEL TIPS

If you choose to travel long distances for an extended period of time after your transplant, please notify the transplant coordinator. We can tell you the location of the transplant center nearest your destination in case any problems should arise.

If you plan to travel overseas, alert the transplant team. Some required vaccinations may be harmful to transplant recipients.

Always take your medications with you on the plane, in case your luggage is lost in flight. Also remember to bring extra medications in case you were to lose some of yours.

We suggest that you wear a Medic Alert bracelet or necklace and carry an ID card that identifies you as a transplant recipient. This identification should have the contact number of the transplant team. In case of emergency, it is also a good idea to carry a list of your current medications.

ROUTINE MEDICAL CARE

Routine medical care is important for early detection and treatment of disease. We recommend routine medical care not only because it makes good sense, but also because some of the medications transplant patients take can affect other body systems. All transplant patients should have an annual check-up by their local physician, including a complete history and head-to-toe physical exam.

Dental Exams

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

Some patients will need to take one dose of antibiotics before and after any dental procedure, including cleanings, fillings or oral surgery. This is to protect your heart from endocarditis, an infection of the inner lining or valves of the heart caused when bacteria from the mouth gets into the bloodstream. Contact the transplant coordinator prior to dental procedures to see if you need antibiotics.

CHECK-UP SCHEDULE

Teeth: dental exam every six months

Ask the Transplant Team about antibiotics before having any dental exam.

Eyes: vision check every year, especially if you wear glasses or contacts.

Skin: see a dermatologist annually if you develop any unusual sores or lesions.
Vision Screening
We recommend regular vision screening annually. Prednisone and other medicines can cause changes in eyesight, including blurry vision, cataracts or glaucoma. Tell your ophthalmologist that you had a transplant so he or she may specifically test for these conditions.

Dermatology
One of the complications frequently seen in transplant recipients is skin lesions. You will be taking medications for the rest of your life and they will make your skin more sensitive. Because your immune system will be suppressed, you may also be more likely to develop skin cancers.

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

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

You may also be more prone to developing mouth sores and ulcers. Please let the transplant coordinator know if you notice any unusual lesions or ulcers on your skin or any sores or white patches in your mouth. Suspicious lesions should always be examined by a physician.
Immunizations
Transplant recipients should not receive live vaccinations, because they can actually cause the disease we are trying to prevent. This includes the measles, mumps and rubella (MMR), oral polio (OPV) and smallpox vaccinations.

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

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

All transplant candidates and recipients should receive a pneumococcal vaccine every five years to protect against pneumonia. We recommend that all transplant patients and their family members receive a yearly flu shot, and all patients should also receive a tetanus booster shot every 10 years.

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

The transplant team and the American Cancer Society recommend annual pap smears and pelvic exams for all women over the age of 18. This should include a rectal exam to check for blood in the stool. Women who are or have been sexually active should have yearly exams regardless of age. A urinalysis and complete blood count (CBC) also should be included in this yearly exam.

We also recommend good health practices such as prompt treatment of vaginal and cervical infections, limiting the number of sexual partners, and using condoms to avoid sexually transmitted diseases.
Breast Self Exam (BSE)
As many as 95 percent of breast cancers are accidentally discovered. All women should perform regular exams 7-10 days after each menstrual period as a routine good health habit. We join the American Cancer Society in recommending that all women over age 20 perform monthly breast self-examinations. Your local physician or gynecologist should be able to instruct you in this practice. We also recommend breast exams by a physician every three years if you are between 20 and 40 years old and annually for women over the age of 40.

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

FOR MEN ONLY:
Testicular Exams
Most testicular cancers are discovered by men themselves. We do not know how to prevent testicular cancer, but if treated early enough, there is an excellent chance for its cure. The American Cancer Society recommends that all males over the age of 15 perform testicular self-examinations monthly on a set date. Your local physician can instruct you on this practice.

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

Since some insurance plans pay only for one such test per year, you should ask to schedule this test as part of your annual exam at Emory.

| BREAST HEALTH SCHEDULE: |
| Self-exam: *every month* |
| Doctor’s exam: |
| *every three years (ages 20-40)* |
| *every year (over age 40)* |

| Mammogram: |
| *every two years (ages 35-40)* |
| *every year (ages 50-75)* |

| TESTICULE/PROSTATE HEALTH SCHEDULE: |
| Testicle self-exam: |
| *every month* |
| Rectal, stool and prostate: |
| *exam annually* |

| PSA exam (after age 50) |
NUTRITION AND DIET

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

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

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

After your transplant, you will continue to follow a strict diet as well as take many medications. Some of these medications may cause side effects, such as elevated blood sugar, elevated blood cholesterol, fluid retention and especially weight gain. You will enjoy food much more now that you feel better, but you must make a special effort to follow your diet.

Our dietitian will develop individual guidelines and menus to fit your specific needs. It helps if your family members take part and follow your healthy diet with you.

On the following pages are some good-for-you recipes from The Low Salt Cookbook, published by the American Heart Association.

Reduced-Calorie Ranch Dressing
Makes 1 1/2 cups; serves 24; 1 tablespoon per serving
1 cup low-fat buttermilk
1/2 cup plain low-fat yogurt
1 tablespoon Dijon mustard
2 tablespoons minced onion
1 tablespoon fresh dill
1 tablespoon chopped fresh parsley
1/2 teaspoon garlic powder
1/4 teaspoon freshly ground black pepper

In a jar with a tight-fitting lid, combine all ingredients. Shake well to blend. Refrigerate for at least 2 hours.
**Vegetable Soup**

*Serves 4; approximately 8 ounces per serving*

- 1 tablespoon olive oil
- 1/2 cup chopped onions
- 1/2 cup diced celery
- 1/2 cup sliced carrots
- 1/2 teaspoon oregano
- 1/2 teaspoon thyme
- 2 cloves garlic, minced
- 4 cups low-sodium beef broth
- Freshly ground black pepper to taste
- 1/2 cup cut fresh green beans
- 1/2 cup chopped fresh tomatoes

Place oil in a medium stockpot over medium heat. Add onions, celery, carrots, oregano, and thyme and sauté until soft, about 5 to 7 minutes. Add garlic and cook for another minute. Add beef broth, pepper and the rest of the vegetables. Simmer 30 to 45 minutes or until vegetables are soft.

**Potato Salad**

*Serves 6*

- 5 medium, red potatoes, cooked, peeled and diced
- 1/4 cup chopped celery with leaves
- 1/2 cup sliced radishes
- 2 green onions, diced
- 2 tablespoons mayonnaise (reduced fat, if possible)
- 2 tablespoons plain nonfat yogurt
- 1 teaspoon dry mustard powder
- 1 tablespoon sugar
- 1/4 teaspoon turmeric
- 1/2 teaspoon celery seed (optional)
- 2 1/2 tablespoons white vinegar
- 3 tablespoons skim milk

Combine potatoes, celery, radishes and onions. In a separate bowl, mix together mayonnaise, yogurt, mustard powder, sugar, pepper, turmeric and celery seed. Add vinegar and milk and stir until mixed. Combine with potato mixture and stir well. Chill before serving.
Oven-Fried Fish

Serves 4

Vegetable oil spray
2 tablespoons acceptable margarine, melted
1 tablespoon fresh lemon juice
1/4 teaspoon freshly ground black pepper
1/4 teaspoon paprika
1/4 teaspoon basil
1/8 teaspoon garlic powder
1 pound fillet of flounder or other fish
1/4 cup dry bread crumbs

Lightly spray a shallow baking dish with vegetable oil spray. Preheat oven to 475° F. Combine margarine, lemon juice, pepper, paprika, basil and garlic powder. Mix well. Dip fish in margarine-herb mixture and roll in bread crumbs. Arrange fish in a single layer in a baking dish. Spoon remaining margarine mixture over fish. Bake uncovered 15 minutes or until fish flakes easily with a fork. Do not overcook.

Spaghetti with meat sauce

Serves 6

1 pound lean ground beef
1 medium onion, chopped
1 clove garlic, minced
5 medium fresh tomatoes, peeled and chopped, or one 28-ounce can no-salt-added tomatoes, chopped
1 6-ounce can no-salt-added tomato paste
1/2 cup dry red table wine
1/2 teaspoon oregano
1/2 teaspoon basil
1/2 teaspoon fennel seeds
1/8 teaspoon freshly ground black pepper
1 8-ounce package spaghetti

Brown ground beef in a large nonstick skillet. Pour off fat. Add remaining ingredients except spaghetti. Cover and simmer over low heat 1 1/2 hours, stirring occasionally. If sauce appears too thick, add water. Cook spaghetti according to package directions, omitting salt. Drain. Pour sauce over spaghetti and serve.
Hash-Brown Potatoes

Serves 6

1/4 cup acceptable vegetable oil
1/4 teaspoon freshly ground black pepper
1/8 teaspoon onion powder
1/8 teaspoon garlic powder
6 cups chopped or grated peeled potatoes
1/4 teaspoon paprika

Heat oil, pepper and onion and garlic powders in a large, nonstick skillet over medium-high heat. Add potatoes and paprika. Cook until potatoes are crisp and browned, stirring frequently. Drain on paper towels and serve immediately.

Vegetable Medley

Serves 4

1 tablespoon acceptable margarine
2 medium yellow summer squash, diced
1 medium zucchini, sliced
1 medium yellow onion, diced
3 medium fresh tomatoes, diced
1/2 cup frozen corn
1 clove garlic, minced
1/2 teaspoon oregano
1/2 teaspoon basil
1/4 teaspoon freshly ground black pepper

In a large pan over medium heat, melt margarine. Add squash, zucchini and onion. Sauté 3 to 4 minutes. Add tomatoes, corn, garlic and seasonings and cook another 2 to 3 minutes. Serve immediately.

Apple Crisp

Serves 8

Vegetable oil spray
1 1/2 pounds (5 medium) apples, cored and sliced, unpeeled
2 tablespoons fresh lemon juice
1/4 teaspoon ground cinnamon
2/3 cup all-purpose flour
1/2 cup firmly packed brown sugar
1/2 cup uncooked oatmeal
1/3 cup acceptable margarine

Preheat oven to 375° F. Lightly spray a 2-quart casserole dish with vegetable oil spray. Arrange apples in prepared dish. Sprinkle with lemon juice and cinnamon. In a medium bowl, combine flour, brown sugar and oatmeal. Cut in margarine with a fork or pastry blender until mixture is crumbly. Spread over fruit. Bake 40 minutes or until apples are tender.
Glossary

Alpha-1-antitrypsin deficiency: a hereditary condition causing the lack of a protein needed for healthy lungs. It is responsible for some cases of emphysema.

Alveoli: tiny sacs in the lungs where oxygen and carbon dioxide are exchanged.

Anastomoses: the connections used in lung transplant surgery to attach your new lungs.

Anesthesia: medicine given by injection or mouth that causes partial or complete loss of feeling for a period of time, usually during surgery.

Antirejection medicine: (See immunosuppressants.)

Antibiotics: drugs taken to prevent infections and kill bacteria.

Antihypertensive: medicine that prevents or controls high blood pressure.

Aspirin: pain reliever taken by mouth; also helps to prevent blood clot formation. Pre- and post-transplant patients should not take aspirin without consulting the team. Tylenol® is normally used instead.

Azathioprine: immunosuppressive drug used mainly to prevent the body from rejecting an organ or tissue transplant. (See Imuran®.)

Bilateral lung transplant: double lung transplant.

Biopsy: (short term for lung biopsy; see also bronchoscopy.)

Breast self exam (BSE): monthly check of the breasts for lumps or tumors that could be cancerous.

Bronchitis: inflammation of the bronchi – the tiny tubes in the lungs that carry oxygen and carbon dioxide.

Bronchoscopy: a procedure used regularly after lung transplant to check for infection or rejection.
**Bronchi:** tiny tubes in the lungs that carry oxygen and carbon dioxide.

**Cancer:** disease in which abnormal cells multiply out of control and disrupt normal cell or organ function.

**Capillaries:** tiny blood vessels.

**Cardiovascular:** relating to the heart and the blood vessels or to the circulation of blood.

**Cataract:** thickening of the eye lens in one or both eyes that impairs vision and often leads to blindness.

**Catheter:** tube, generally small and flexible, inserted into the body, to infuse medications, monitor organ function and drain fluid.

**Catheterization:** inserting a tube into the body.

**Cervical cancer:** cancer of the cervix.

**Chemotherapy:** the use of drugs to destroy cancer cells.

**Cholesterol:** fat substance found in animal meats, dairy products and produced by the liver; a high level of cholesterol in the blood is a risk factor for developing heart disease. Blood cholesterol can be elevated by cyclosporine.

**Chronic obstructive pulmonary disease (COPD):** a condition causing breathing difficulty because the air flow out of the bronchial tubes of the lungs is partially blocked.

**Clinical nutritionist:** specialist in selecting foods that repair or maintain the body.

**Congenital:** existing at birth.

**Coronary arteries:** blood vessels that supply oxygenated blood to the heart.

**Cyclosporine:** drug that helps keep the body from rejecting a transplanted organ. Neoral® and Sandimmune® are different types of cyclosporine and cannot be interchanged. Gengraf® is a generic brand of Neoral® which may not presently be available.
Cystic fibrosis: a hereditary chronic disease causing excess mucous production in the lungs.

Dermatology: study and treatment of skin.

Denervation: cutting or blocking the nerve supply.

Diabetes: the body’s inability to control the amount of insulin or blood sugar it produces for energy.

Diaphragm: the muscle separating the abdomen from the lungs that helps with breathing.

Diastolic blood pressure: bottom number of the blood pressure reading that shows the amount of resistance in the blood vessels that the heart has to overcome.

Donor: person who gives an organ to be used in another person.

Echocardiogram: laboratory test that uses reflected sound wave images to see the heart.

Edema: swelling of body tissue caused by fluid leaking from blood vessels.

Emphysema: an obstructive lung disease in which the alveoli (tiny air sacs in the lung) are stretched or distorted, making it difficult to breathe. Emphysema is most often caused by cigarette smoking.

Endocarditis: an infection of the inner lining or valves of the heart caused when bacteria get into the blood stream.

Endotracheal tube: long tube used to provide an airway into the lungs.

End-stage lung disease: a condition that leads to failure of the lungs.

Enzyme: protein that helps complete chemical reactions without being changed in the process.

FEV1: Forced Expiratory Volume in the 1st second. Usually reported as a percent of that of a healthy person of your height, age, gender and race.

Fluid retention: condition in which the body stores fluid.
**Foley catheter**: tube inserted into the bladder to drain urine.

**Gallbladder**: organ that stores bile.

**Gallstones**: stones that form when the bile has too much cholesterol.

**Glaucoma**: eye disease in which increased pressure on the eyeball damages the optic nerve and eventually can lead to blindness.

**Heart attack**: blockage of a vessel that feeds the heart muscle, causing sudden tissue death (myocardial infarction).

**Heart monitor**: A device that records and displays information about the heart, including condition and number beats.

**Idiopathic**: arising from an unknown or obscure cause.

**Immune system**: your body’s natural defense system against foreign invaders such as viruses, bacteria, some types of cancers, and sometimes transplanted organs.

**Immunization**: giving antibodies or other agents to protect against disease.

**Immunosuppressants**: drugs that help treat or prevent the immune system from rejecting an organ transplant.

**Immunosuppression**: process of preventing the body’s immune system from rejecting an organ transplant.

**Imuran®**: immunosuppressive drug used mainly to prevent the body from rejecting an organ transplant.

**Infection**: condition in which the body is invaded by a disease-causing micro-organism.

**Interstitial lung disease**: inflammatory condition of the lung parenchyma or framework resulting in progressive replacement of gas exchange units (alveoli or air sacs) by scar tissue.

**Intravenous (IV)**: a catheter (small tube) inserted into a vein so that fluid, blood or medicine can be received.

**Lab draw**: process of taking blood or urine for laboratory analysis.
Laboratory (lab): place where blood and specimens are studied and identified.

Laxative: food or chemical substance that acts as a stool softener.

Lesion: injury or wound to skin or tissue.

LifeLink: an independent nonprofit organ and tissue recovery organization.

Lipitor: drug that lowers cholesterol.

Magnesium oxide: white, odorless powder used after transplant to counteract cyclosporine’s tendency to lower magnesium levels in the blood; low magnesium can cause heart rhythm problems or muscle cramps.

Magnetic Resonance Imaging (MRI): a diagnostic technique which uses magnetic fields to make cross-sectional images of organs and structures inside the body.

Mammography: screening process for early detection of breast cancer.

Medic Alert: nonprofit organization that provides a bracelet or necklace with your personal medical information which can be used by medical personnel in case you have a car accident or other type of emergency.

Mevacor®: drug that lowers cholesterol.

Mg: milligram.

Monopril®: drug that lowers blood pressure.

Mycelex® troche: anti-fungal agent which lowers the growth of yeast that can cause infection.

Mycostatin®: trade name for the drug nystatin. (See nystatin.)

Mylanta®: common over-the-counter drug used to relieve upset stomach.

Native lungs: your diseased lungs; the lungs you were born with.
Neoral®: (See cyclosporine.)

Norvasc®: drug used to prevent heart spasms and lower blood pressure.

Nystatin: antifungal agent used to prevent infections.

Ophthalmologist: physician who studies and treats the eye.

Pap smear: test in which cells from the vagina and cervix are collected then analyzed to detect cancer.

Pathologist: specialist who diagnoses abnormal changes in tissue removed during an operation.

Pleura: protective layers of tissue surrounding the lungs.

Pneumococcal: bacterial microorganism which causes pneumonia.

Pneumonia: infection of the lungs.

Post-transplant: after transplantation.

PRA (Panel Reactive Antibiotics): likelihood of already having antibodies against potential donors; if high likelihood pre-cross match tests are performed pre-transplant.

Prednisone: medication used to limit rejection of a transplanted organ or tissue.

Primary pulmonary hypertension: high blood pressure of the pulmonary vessels in the heart.

Prostate: gland around the neck of the bladder and urethra in males that secretes ejaculatory fluid.

Prostate-specific antigen (PSA): special blood test recommended for men over the age of 50 to screen for prostate cancer.

Psychiatric clinical nurse specialist: nurse specially trained to help you and your family deal with behavioral and mental issues such as stress, anxiety, depression and addiction.

Psychiatrist: physician who diagnoses and treats mental disorders.
**Pulmonary artery**: blood vessel that carries blood from the right ventricle of the heart to the lungs.

**Pulmonary artery catheter**: a long, flexible tube inserted through your neck vein into the pulmonary artery; used to measure pressures in your heart and lungs, and evaluate your heart function.

**Pulmonary fibrosis**: a progressive inflammation of the lung tissue that causes permanent scarring.

**Pulmonary hypertension**: a disorder of the lungs characterized by progressive high blood pressure in the blood vessels of the lungs and heart. Primary pulmonary hypertension does not have a known cause and onset may occur at any age, while secondary pulmonary hypertension has a definite cause (i.e. from liver diseases, SLE or other illness).

**Pulmonary valve**: structure between the right ventricle and pulmonary artery; regulates movement of fluid into the pulmonary artery.

**Pulmonologist**: doctor who studies and treats diseases of the lungs.

**Ranitidine**: (See Zantac®.)

**Rectal**: lower part of the colon or large intestine.

**Rejection**: condition in which recipient’s body rejects organ transferred from a donor.

**Renal**: pertaining to the kidneys.

**Riopan®**: medicine that reduces stomach acid.

**Sandimmune®**: trade name of cyclosporine. (See cyclosporine.)

**Sarcoidosis**: a chronic, progressive disease marked by inflammation of many organs, especially the lungs.

**Systemic lupus erythematosus (SLE)**: a disease of the immune system.

**Status**: patient’s current condition.

**Sternum**: narrow, flat bone that connects the ribs or the shoulder girdle or both; also referred to as the breastbone.
Swan-Ganz catheter: see pulmonary artery catheter.

**Systolic blood pressure**: amount of force used by the heart to eject blood out of the heart; the top number read as part of blood pressure.

**Testicular**: relating to the male reproductive glands that produce reproductive cells and the hormone testosterone.

**Tetanus**: infectious disease that causes painful muscle contractions; also known as lockjaw.

**Trachea**: the tube connecting the larynx and the bronchi.

**Transplant coordinator**: specially trained, registered nurse who coordinates care for patients before and after transplantation.

**Transplant surgeon**: cardiothoracic surgeon who performs the transplant operation.

**Transplantation**: transfer of living tissue or organs from one person to another.

**Transverse sternotomy**: a clam-shaped incision on the chest that extends from the right side to the left side just below the breast line.

**Ultrasound**: device that uses ultrasonic waves to outline the shape of various tissues and organs of the body.

**UNOS**: United Network for Organ Sharing, a national agency that maintains a national computerized transplant waiting list and matches donor organs and recipients.

**Vaccination**: injection that builds your body’s resistance to an infection.

**Ventilator**: mechanical device which controls and monitors flow of air to the lungs.

**Ventricle**: either of two lower chambers of the heart. The right chamber pumps blood to the lungs to be oxygenated, while the left ventricle is a powerful muscle that pumps the oxygenated blood throughout your body through your arteries.

**Vital signs**: temperature, pulse, respiration and blood pressure.

**Zantac**: drug used to treat stomach problems like peptic ulcers and heart burn.
Other Helpful Information

MAISON GUEST HOUSE
The Mason House is a private retreat that offers low cost housing for organ transplant candidates, recipients, living donors, and families. Guests who book one of the 15 bedrooms, each with a private bath, will find a comfortable bed-and-breakfast environment. In addition, a two bedroom suite is available with its own kitchen, living area and private entrance. Several bedrooms and bathrooms are wheelchair accessible. Continental breakfast is provided, but guests may cook their own meals. Other amenities include laundry facilities, TV’s in the gathering rooms, private phones, a VCR, stereo and a computer.

The Mason House is a home-away-from-home, created to make transplant candidates, recipients and their families feel far away from a hospital environment, yet close enough to feel secure should they need medical assistance. Please call 404-712-5110 for reservations.

THE MENTOR PROJECT

What is the Mentor Project?
The Mentor Project provides one-on-one contact between people living successfully with a transplant and people who are new to the world of transplantation. The project pairs a “veteran” organ transplant recipient, primary caregiver or living donor with someone who is waiting for a transplant, a recent transplant recipient, family members of a transplant recipient or a living kidney or liver donor. Through these connections, even the smallest questions get answered, experiences are shared, and support is provided to both patients and families.

Who are mentors?
Mentors are organ recipients, parents or other supporting family members and living donors who are at least six months out from their transplant date or the transplant date of their loved one. Mentors attend a full day of training to learn how to draw on their personal experiences to address the needs of others that they mentor. Mentors are updated periodically on services and assistance available to transplant families within the transplant community, and the mentor network is an excellent connection to these resources.
**How do I get a mentor?**

If you live in Georgia, you can be referred to the Mentor Project by your social worker, transplant coordinator, clinical nurse specialist or physician. A mentor is never assigned without the consent of the potential mentee. Georgia residents may also call the Mentor Project and request a mentor directly.

For more information about the Mentor Project contact the Georgia Transplant Foundation at 1-866-(GATX411) or 770-457-3796.

**JOBLINK**

*A career development and return-to-work program for transplant recipients in the state of Georgia*

JobLink is an assistance program that helps Georgia transplant recipients and candidates return to the work environment. JobLink offers needed information and training in order for the transplant recipient to reach career goals.

The objective of JobLink is to provide transplant recipients and candidates a quick and successful re-entry into the work force. Skilled placement specialists evaluate work needs and provide both necessary skills training and access to the appropriate vocational and rehabilitation services.

JobLink offers access to the state’s vocational rehabilitative services and provides a comprehensive return-to-work program — at no cost to you. The return-to-work program can be the link that completes the goal of transplantation in returning recipients to a productive lifestyle.

*Services include:*

- Career interest testing and development
- Assistance with Social Security issues
- Information on state vocational rehabilitation services
- Job skills training
- Resume development and interview techniques
- Job placement
- Early return-to-work programs
- Americans with Disabilities Act (ADA) awareness
- Post-placement intervention to ensure success
- Enrollment in Ticket to Work program

For more information, call 770-457-3796 or 1-866-428-9411. Your transplant social worker also will be happy to assist you with a referral.
### Helpful Websites for the Lung Transplant Patient

**Patient Information:**

- American Lung Association  
  http://www.lungusa.org/
- American Thoracic Society:  
  http://www.thoracic.org
- Coalition on Donation  
  http://www.donatelifenet
- Cystic Fibrosis Foundation  
  http://www.cff.org
- Emory Center for the Treatment and Study of Interstitial Lung Disease  
  http://www.emory.edu/WHSC/MED/PULM/ILD/clinical_diagnosis.html
- Emory Transplant Center  
  http://www.transplant.emory.edu
- Georgia Transplant Foundation  
  http://www.gatransplant.org
- International Society for Heart & Lung Transplantation  
  http://www.ishlt.org
- LifeLink of Georgia  
  http://www.lifelinkfound.org
- National Heart, Lung & Blood Institute  
  http://www.nhlbi.nih.gov
- Schleroderma Foundation  
  http://www.scleroderma.org
- Transplant Patient Data Source  
  http://www.ustransplant.org
- TransWeb: Transplantation and Donation  
  http://www.transweb.org
United Network of Organ Sharing
http://www.unos.org

*Patient Information/Support Groups:*

Second Wind Lung Transplant Association
http://www.2ndwind.org

Pulmonary Hypertension Association
http://www.phassociation.org

*Other Helpful Web sites:*

American Academy of Family Physicians
http://www.aafp.org/patientinfo

Infonet Johns Hopkins (support group links & 800 numbers)
http://www.infonet.welch.jhu.edu

Health Answers:
http://www.healthanswers.com

Healthfinder (U.S. government site):
http://www.healthtouch.com

IntelHealth (Johns Hopkins)
http://www.intelhealth.com

National Library of Medicine (Health Info for Consumers)

Wellness Web: The Patient’s Network
http://www.wellweb.com

SEARCH ENGINES:
http://www.healthatoz.com
http://www.hon.ch
http://www.achoo.com
http://www.webmd.com