



TRANSPLANTATION

Lung Transplantation

Transplant Reference Guide

FOR PATIENTS

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Table of Contents

Introduction

History	3
Evaluation	3
Transplant Team Members	5
Role of the Family	6
Psychosocial Support	6
Organ Donation	7
When a Donor Becomes Available	8

Anatomy and Physiology

Lung Function	
Transplant Procedure	
Physiology of the Transplant Organs	

After Surgery: What to Expect Upon Awakening	10
--	----

The Immune System and Rejection	12
---	----

General Guidelines

Medications After Transplant	13
Exercise	15
Sun Exposure	17
Nutrition	17
Smoking	18
Sexual Activity	18
Home Routine	18
Outpatient Visits	18
Things to Remember	19

Glossary	21
--------------------	----

Appendix A	22
----------------------	----

Appendix B	31
----------------------	----

INTRODUCTION

The Lung Transplant Program at the Tampa General Hospital (TGH) provides this manual for you to learn and understand the transplant process. The goal of the transplant team members is to ensure that you receive the best possible care throughout your stay. As a lung transplant patient, you will have many questions and much to learn regarding the transplant process.

The purpose of this manual is to inform you about preparing and waiting for the transplant, the team members you will meet, what to expect while in the hospital, and general information for after you leave the hospital. The booklet will also inform you of some basic facts about anatomy, physiology, and the immune system. It will also help you prepare for taking care of your body after your transplant.

We are committed to helping you understand this process in which you are the most important and active member. This booklet has been developed to serve as a guide for you and your family. Please feel free to ask questions or seek more information from any team member. A thorough understanding of the transplant process and taking an active role in the process is necessary to achieve our common goal of a successful transplant.

History of Lung Transplantation

The first reports of successful lung transplant experiments on animals appeared almost simultaneously from French and U.S. researchers in the early 1950's. Despite this initial technical success, there were no reliable anti-rejection drugs and all of the transplants eventually failed. However, these early attempts proved that a single functioning lung transplant was sufficient to sustain life.

In 1963, Dr. Hardy's transplant team at the University of Alabama performed the first lung transplant; this attempt and approximately 40 others over the next 17 years failed. Despite the early failures, several groups remained convinced that lung transplantation was destined to become a clinical reality. Their persistence led to advances in lung preservation, tracheobronchial healing, and immunosuppression.

In 1981, the first successful human combined heart-lung transplant was performed by Dr. Reitz and his colleagues at Stanford. Soon afterwards, Dr. Cooper and his associates at the University of Toronto reported a successful single lung transplant. As technology has improved, many disorders formerly thought to be only treatable with combined heart-lung transplant can now be treated with either a single lung transplant or bilateral lung transplant. Advances in lung transplantation have been very dramatic.

Evaluation

As you begin your transplant evaluation at TGH, you will meet various members of the Lung Transplant Team. Team members include physicians, nurses, transplant coordinators, physical therapists, respiratory therapists, social workers, and hospital administrators. Each of the team members will work with you and your family to determine the severity of your illness and suitability of various treatments including transplantation. Specific medical guidelines can determine whether or not you can safely receive a transplant. Also, we will be evaluating you and your family

to ascertain if each of you have the strong commitment and support necessary to adhere to the required medication regimen and to come to the follow-up appointments. While we are teaching you and your family about transplantation, we also welcome your questions.

The evaluation process serves two purposes. First, the physicians can evaluate the extent and severity of your disease and its impact on other systems of your body. Secondly, we need to assess the potential impact of organ transplantation and the effects of lifelong anti-rejection therapy on your body, your family, and your financial resources.

A portion of the transplant evaluation includes an assessment of dental disease. This can be performed by your family dentist. To lower the risk of infection following your transplantation, you should complete all major restorative work, dental extractions, and treatment of periodontal disease prior to transplantation. If you have seen your dentist within the past six to twelve months, please bring a letter from your dentist stating that all necessary work has been completed. The letter should be given to the transplant coordinator or the transplant physician.

Even if you meet all the qualifications for a transplant, other factors may influence the timing and success of your transplantation. The shortage of suitable donor organs is a major problem and can cause a significant delay in receiving your transplant.

The evaluation process gives the transplant team the necessary information to recommend transplantation. The following tests will be done for pre-lung transplant patients:

1. Blood work which includes assessment of your kidney function, liver function, blood type, and immunogenetic profile
2. Chest X-ray
3. Electrocardiogram (EKG)
4. Urinalysis and a 24 hour urine collection for creatinine clearance and total protein
5. Skin testing for Tuberculosis (T.B.)
6. Right heart catheterization to assess pressures in your heart
7. Pulmonary function tests
8. Appointment with the transplant surgeon and the transplant social worker

The pre-lung transplant patients will need to perform the following tests:

1. Exercise pulmonary function tests
2. Thin section CT scan of the chest
3. Nuclear wall motion study (to check how well your heart is pumping) and/or cardiac catheterization
4. Persantine thallium (or Dobutamine) study (to check how your heart functions under simulated exercise).

When the tests are completed and the results are compiled, your case is presented at the weekly lung transplant meeting. If you are accepted as a transplant candidate, you will be placed on the waiting list and will be given information about getting a beeper. The transplant coordinator will discuss this with you.

Transplant Team Members

Transplant Coordinator - The transplant coordinator is your main contact with the transplant team. The transplant coordinator arranges your admission, your tests, and activities throughout the entire pre-transplant evaluation and post-transplant care. The transplant coordinator also organizes the activities of the transplant team at the time of surgery.

Pulmonary Physicians - This is the first group of doctors with whom you will come in contact if you are a lung transplant candidate. They are the primary doctors responsible for all your pre-transplant care. They will also be closely involved in your post-transplant management and follow-up care.

Transplant Surgeons - The transplant surgeons will perform the transplant surgery and along with the other team members are responsible for your care post-operatively. They are also involved in your evaluation and follow-up care.

Social Workers - The social worker conducts a psychosocial assessment as part of your overall assessment for transplant. With the transplant coordinator, the social worker co-facilitates the support group for you and your support person and is available for additional support and counseling throughout your pre- and post- transplant process.

Financial Counselors - Our financial counselors will be in contact with your insurance company to determine whether transplantation is a covered benefit. The financial counselor can also inquire about other reimbursement alternatives.

Anesthesiologists - These doctors are responsible for putting you to sleep at the time of your transplant surgery. They also participate in your care post-operatively while you are in the CSU.

Cardiologists - These physicians will assist the pulmonologists with the care of the lung transplant patients.

Nurses - Intensive Cardiac Care (CSU) - You will go to the CSU immediately after your surgery.
8A - From the CSU, you will be transferred to the transplant surgical floor (8A) where you will remain until discharge. On rare occasions patients need to return to CSU for short periods of time. This is done to monitor your condition more closely for a day or two.

Physical Therapists - You will be working with the physical and respiratory therapists throughout the transplant process.

1. **Waiting period:** pulmonary rehabilitation for the lung transplant patients.
2. **CSU** - acute care - Exercises will be done in your room with the help of the respiratory and physical therapist.
3. **8A** - Exercises, along with the use of a stationary bicycle will be done both in your room and the therapist will start you on a walking program in the halls and on the stairs.

Respiratory Therapists - You will be working with the respiratory therapist when you are on 8A and are up walking in the halls and can tolerate a more vigorous activity program.

Psychiatrists - These doctors take part in the pre-transplant assessment and provides ongoing support/therapy, if necessary.

Transplant Pharmacist - This person will be working with you when you are on 8A to familiarize you with your post-transplant medications and develop a schedule for self-administration of your medications.

Role of the Family

The Transplant Team feels it is very important that each candidate has at least one support person available at each stage of the transplant process. This support person can be a family member or a very close friend who agrees to the long-term commitment of support. This support person will help you in many ways, such as being a patient advocate, morale booster, and assistant in managing your medicines, doctor appointments, and general good health.

Psychosocial Support

Psychosocial management of the transplant recipient and family is an integral part of the Transplant Team. Psychological care begins at the time of the initial assessment. Patients and their partners go through many stages before and after lung transplant:

- 1.** The first stage is usually facing the fact that life has become very limiting and that a transplant may be the only treatment left.
- 2.** The second stage often comes about when you make the decision to consider a transplant and decide to be evaluated.
- 3.** The third stage happens when you are accepted for a lung transplant by the TGH team and you need to decide whether you want to be placed on the waiting list.
- 4.** The fourth stage is the waiting. Once you have been accepted as a candidate, you can expect to wait as little as a couple of days or as much as several months. The waiting period will vary for each patient according to their specific body size, blood group, the number of other patients waiting, and the availability of organ donors.
- 5.** The fifth stage is the actual transplant surgery, recovery, and learning about the new medicines that you will be taking.
- 6.** The sixth stage can be phrased as “after the transplant, now what?”: beginning a new life, living with new medicines, regaining your physical strength, and returning to work or normal everyday activities.

These normal stages in transplantation are full of uncertainty. You and your family may go through many feelings such as disbelief, anger, anxiety and depression. You may worry that an organ may not be available fast enough, or you may be concerned about the actual surgery, recovery, and the medicines you will be taking.

We recognize that each phase of the program brings with it certain stresses which will be particular to each patient and family. The transplant team members are available to you for questions and support. All are committed to helping you and your family. A support group is available for you and your family to attend. The participants include those patients waiting for a transplant and those patients who have been transplanted.

Organ Donation

This section is dedicated to giving you a better understanding of the organ donation process. Once you have been accepted as a potential lung transplant recipient the wait for an appropriate organ donor begins. You will be “listed” on the national waiting list, through the United Network of Organ Sharing (UNOS) waiting list. Being “listed” means your name and pertinent information, such as type of organ needed, blood type, and size, is entered into a computer. All organ procurement agencies have access to this information, and utilize it if a donor becomes available.

It is VITAL that an organ be:

1. healthy
2. match the recipient (blood type and body size)

The organ donation system in Florida is through Lifelink of Florida. This network is in close communication with similar organ retrieval programs throughout Florida. (A list of all potential organ recipients is distributed throughout the network every Friday.)

Once a donor is identified in any center in Florida, Lifelink is notified. A transplant coordinator is available on a 24-hour basis to receive such calls. The information about the potential donor is then relayed to the Transplant Coordinator at TGH. In consultation with the surgeon responsible for your care, the coordinator has all the information needed to match you with an appropriate organ donor.

A multi-organ donor is usually a young person who has suffered a critical injury to the head which has resulted in death of the brain, yet normal function of all other organs of the body continues. The family of the critically injured person is approached once brain death has been diagnosed by two physicians, and given the option of organ donation. Should this wish have been expressed by the donor before death or if it is believed by the family that the giving of such a gift would comply with the wishes of the donor, organ donation is consented for by the family.

A “GIFT OF LIFE” has been given to you by the donor through the donor’s family members. At a time of grief for them, they have thought of others and given this gift to you freely and without personal or financial obligation.

A period of assessment occurs before accepting the donor organ. Most of the tests will have been completed before you are notified that a donor has been found. We must ensure that the lungs are healthy and that no previous surgical procedures or past illnesses have damaged the lung tissue.

Once it has been established that the donor lungs are healthy, a recipient is chosen who best suits the lung graft. Donor and recipient are matched according to blood group and body size. Should the rare occasion arise in which a donor can be matched equally with two recipients, the one most acutely ill at the time will receive the transplant. If both recipients present with the same level of need, the individual who has been waiting the longest will take priority.

A recipient can receive either a male or female lung(s) and the upper age limitation for lung donation is approximately 50 years. It must be stressed that our concern is more for the quality of the organ than for its age. A battery of tests is first done on the donor. The final decision is made when the donor surgeon actually sees the organ before removing it.

The shortage of suitable organ donors means that the procurement team may have to travel up to 1,000 miles to obtain the lungs. The procurement team (consisting of a surgeon and an organ donor technician) will leave the hospital in route to their destination about the same time as you are arriving in the hospital. The team is rapidly transported by ambulance, helicopter, and/or jet aircraft to and from the distant center so that no time is wasted once the procedures are underway. Continuous communication occurs between the transplant coordinator and the donor coordinator from Lifelink.

Should you wish to communicate with the family of your donor, you may do so through the transplant coordinator. Respect and confidentiality for both donor and recipient families are upheld at all times and no names are revealed.

If you would like further information on the organ donation, contact your transplant coordinator.

When A Donor Becomes Available

When Lifelink alerts us that there is a possible donor, the coordinator will telephone you at home or page you on your beeper. You will be expected to come directly to the hospital. The coordinator will give you all the information you need to know before coming to the hospital. You should not eat or drink anything unless further instructed. You will need to check in with an admissions clerk. Depending on the hour of the day that you arrive, you will check-in in admissions or in the emergency room reception. The transplant coordinator will tell you where you are to go. From Admissions you will go directly to the Transplant Unit (8A) to be prepared for surgery. There will be some time for you to spend with your family before the transplant operation. The surgery itself will take four to eight hours. After your surgery, you will be taken to the Cardiac Surgical Unit where you will stay for several days. After you arrive in the CSU, your family may visit for brief periods of time.

Lung Function

Your lungs' major function is to supply the oxygen which your body needs and to eliminate the waste product carbon dioxide, which is produced by your body's metabolism. This exchange process involves a complex interaction between your muscles, heart and lungs.

The normal lungs are soft and spongy and are made up of a type of tissue that allows them to stretch and recoil. The right lung has three lobes, the left has two. The right lung is larger than the left.

When you take in a breath (inspiration), your chest and lungs expand and air is sucked in. When you breathe out (exhalation), the lungs go back to their smaller size and the air is pushed out.

Muscles are used in breathing. The diaphragm is the large muscle between the chest and the stomach that is the main muscle used in regular breathing. It moves down (contracts) when we breathe in and moves up (relaxes) when we breathe out. Extra muscles are used when breathing becomes difficult.

Air enters your nose or mouth and flows through the trachea (your windpipe). The trachea divides into two main bronchial tubes, one going into each lung. The bronchial tubes continue to divide into smaller and smaller tubules, like a tree with many branches. These airways warm, moisten and filter the air we breathe in.

The airways are lined with special cells that secrete mucous. We call this the mucous blanket. It traps any irritating particles that we breathe into our lungs. Other cells have hair-like projections called cilia which help to move the mucous toward the throat so we can cough it out or swallow it.

At the end of the smallest tubules, there are elastic air sacs called alveoli. There are nearly 300 million alveoli. It is here that the inhaled oxygen is transferred into the blood. The blood will release this oxygen to your tissues and it will be used to produce energy. Carbon dioxide is a waste product formed during the energy producing process. It is returned to the lungs by the blood and blown out as you exhale.

The Transplant Procedure

Once a suitable donor is identified, a procurement team, consisting of a surgeon and a transplant technician, travel to the donor hospital to check the health of the donor organ. You will be contacted and asked to come to TGH as quickly as possible. Please make sure that you can be reached by beeper or phone, personally or through a reliable family member or friend, twenty four hours a day, seven days a week. We expect you to be at the hospital within two hours of contact. If this is likely to be a problem for you because of distance, special arrangements can be made beforehand through the transplant coordinator to find a way to get you here as quickly as possible.

As soon as you are admitted to the hospital, you will be prepared for surgery. When the procurement team is satisfied with the donor organ, you will be transferred to the operating room. Upon arrival there, a team of specially trained surgeons, anesthesiologists, and nurses will continue the preparations. You will be put to sleep, connected to various monitoring systems, and have intravenous lines started. Your breathing will be controlled by a machine called a ventilator.

Single Lung Transplant

After all the preparatory steps have been completed, you will be turned onto the appropriate side and an incision made between the ribs on the side of your chest. Once the donor lung has been brought back to TGH, your old lung will be removed. Sometimes, there is insufficient function in your remaining lung to keep you alive during this portion of the operation, and assistance with a heart-lung machine is required. If a heart-lung machine is necessary, a small incision will be made in your groin to connect your circulation to the machine.

The new lung is inserted in the place occupied by the old lung by reconnecting the bronchus, the pulmonary artery and left atrium from the donor lung to the corresponding structures in your body. After restoration of blood flow and ventilation to the transplanted lungs and completion of the heart-lung machine if necessary, the chest incisions are closed. You are then ready for transfer from the operating room to the intensive care unit.

Bilateral Lung Transplant

Patients who require bilateral lung transplantation undergo similar preparation as for a single lung transplant upon admission to the hospital. The incision in the chest, however, is on both sides of the front of your chest, just below the breast. The operation proceeds in stages, removing and replacing first one lung and then the other. The heart-lung machine may also be necessary. Once both lungs are in place and functioning satisfactorily, the incision is closed. You will then be transferred back to the intensive care unit.

Combined Heart-Lung Transplant

If you require a combined heart and lung transplantation, you will undergo similar preparation as for a single lung transplant prior to surgery. The chest incision, in this case, is in the middle of the breast bone (sternum) and the heart-lung machine is used always during the operation. Once the new heart and lungs are functioning satisfactorily, the heart-lung machine is discontinued and the incisions are closed. You will be transferred to the intensive care unit from the operating room for further monitoring and care.

Physiology of the Transplanted Organs

The transplanted organs will not have the same nerve attachment as your own organs. The effect of this is as follows:

Lung Transplant

Single Lung Transplant - Your own remaining lung will continue to send you messages about coughing and breathing, but your new lung will not. You may experience a sensation of breathlessness as a result of the remaining diseased lung.

Bilateral Lung Transplant - You will not feel irritation below the bronchial (windpipe) connection. Hence, you will not be stimulated to cough spontaneously by the presence of infection or secretions in your lungs. It is important that, if you feel mucous or fluid in the back of your throat, you make a conscious effort to cough and attempt to clear it. Notify your physician at the earliest sign of any unusual or persistent cough, shortness of breath and/or difficulty in breathing. The respiratory therapists, physical therapists, and nurses will be assisting you with a chest physiotherapy program immediately post-transplant and throughout your hospital stay. You will be taught various routines and techniques to help you maintain a clear airway at home. Pulmonary function tests will be performed at specific intervals to evaluate your transplanted lungs. Both groups will need to cough, deep breathe every hour while awake.

AFTER SURGERY: WHAT TO EXPECT AFTER AWAKING

You will go to the CSU straight from the Operating Room. You will not be awake, and will not remember the trip. When you awaken, you will find that several pieces of equipment, such as chest tubes and IV lines, have been attached to you while you were asleep. Most of this equipment is removed within a few days after surgery.

Cardiac Monitor - Three to five electrode pads will be placed on your chest and attached to a monitor on the wall above your head. This machine monitors your heart rate and rhythm and has an alarm that will sound should your heart rate speed up or slow down. It is so sensitive that it

will also sound if the nurse touches the electrode pads or if you move around in bed, so do not be too worried if you hear the alarm go off.

Ventilator - At the beginning of surgery, after you are asleep, the anesthesiologist will insert a tube through your mouth and into your trachea (windpipe). This tube is connected to a machine that breathes for you during surgery and assists you in breathing afterwards. The tube must be placed between your vocal cords and you will be unable to speak as long as it is in place. Writing materials will be available should you need to communicate. As soon as you are able to breathe on your own, the tube will be removed and you will be able to speak, although your throat may feel sore for a day or two.

Foley Catheter - This catheter drains urine from your bladder and will remain in your bladder for only a couple of days. Sometimes it gives the sensation that you need to urinate, but your nurse will remind you that the catheter is draining the urine. Let your nurse know if you feel as though your bladder is full.

Intravenous Lines - You will have several intravenous lines (IV's) in order to receive fluid, medications, and blood should you need it. One of these IV's, which is connected to the cardiac monitor above your head, measures your arterial and venous blood pressures. To take these measurements, the head of your bed will be flattened for a few minutes each hour.

Chest Tubes - You will have one or two tubes in your chest connected to a suction container at the side of your bed. These tubes drain blood and other fluids that accumulate in the chest cavity during surgery. The suction from this container makes a constant bubbling noise. The doctor usually removes these tubes within a few days after surgery.

There is no visiting in the CSU between 7 and 8:00 am and from 7 to 8:00 pm when the nurses are changing shift and giving report. Otherwise, short visits are recommended so that you have time to rest. The nurse caring for you makes the decision to limit or to extend any visit, depending on your needs or other activities in the CSU. Please have your family communicate with the CSU receptionist by means of the special telephone in the waiting room.

Only family is permitted to visit. Routine hospital visiting regulations will be observed unless your visitor is ill. Any visitor who has a cold, sore throat, cough, or flu symptoms should not visit. Your visitors must also wash their hands with a special soap when they come into your room.

You will remain in the CSU for approximately three to five days, depending on your post-operative course. You will then be transferred to the transplant floor for the rest of your hospitalization. There, the nursing staff, dietitian, respiratory therapists, and physical therapists will be working with you to speed your recovery. You will be very involved with a variety of activities during your post-operative recovery. You will be instructed on coughing and deep breathing in order to prevent fluid accumulation and infection in your lungs. You will be assisted in getting out of bed the day after surgery and will be instructed on daily exercises. You will also be taught about each of your medicines and how to take them.

After the CSU, you will be in a private room on 8A. You may have newspapers, magazines, and mail. However, you may not have plants or cut flowers in your hospital room, as different types of bacteria grow in the plant soil or the water in the flower vase. You must keep the windows in your room closed, but may have your door open.

THE IMMUNE SYSTEM AND REJECTION

The immune system is the body's defense mechanism which normally helps keep the body free from infection by attacking pathogens (invading micro-organisms or foreign material). However, your body sees your new organ as "foreign", and so your immune system will attempt to reject it. Your immune system is made up of many parts, but the T and B lymphocytes (which are types of white blood cells) are the most active against transplanted tissue. The immunosuppressive medicines you will be taking are prescribed and carefully adjusted to help your body tolerate your new organ. If you do not take your medicines, your immune system will destroy your transplanted organ. You will learn about your medicines after your transplant when you will be given another booklet explaining each of the medicines.

Rejection is the term used to describe the immune system's reaction to your new organ. It is rare to experience actual symptoms of rejection, although potential symptoms often mimic "the flu" (aching muscles, unexplained fatigue, and fever). The only definite way to detect rejection is by transbronchial biopsy. When a biopsy shows signs of rejection, or that your immune system is attacking your new organ, your immunosuppressive medicines will be altered. Sometimes a brief stay in the hospital may be required.

A **transbronchial biopsy** is the most reliable way to detect rejection in the lung. The first biopsy is usually done within the first 7-10 days after lung transplant surgery. Biopsies of your lung(s) will be performed periodically for the rest of your life. The procedure is done in radiology or the CCU procedure room and takes approximately 1 hour. Transbronchial biopsy is the standard way lung tissue is evaluated for many different types of lung problems other than rejection. It avoids surgery and is well tolerated by patients. After mild sedation is given and the throat is sprayed with numbing medicine to avoid gagging, a bronchoscope (a tube in which the physician can look through and take tissue specimens out of your lungs) is passed through the mouth and into your windpipe. The biopsy is taken with a thin instrument that slides through the bronchoscope and out into your lung tissue. The specimens are examined under the microscope for signs of rejection and infection. Results are usually available the next day.

While the immunosuppressive medicines help your body tolerate your new organ, the medicines also decrease your body's ability to fight **infection**. Therefore, it is very important that you attempt to prevent infection, recognize the symptoms of infection, and seek prompt medical attention if an infection develops. Ways to prevent infection are (a) washing your hands frequently and always before eating; (b) avoiding close contact with anyone who has a cold, the flu, or an infection; (c) good nutrition; and (d) maintaining a regular program of rest and exercise. You should **never** receive a vaccination against flu or any other infection without first checking with the transplant

team. Prior to any dental work, you will need to receive antibiotics to protect your heart from bacteria which can enter your blood stream through your mouth.

The lungs are the most common site for infection. Symptoms are cough, increased sputum production, fever, and shortness of breath. Pain or burning on urination are symptoms of a bladder infection. A cut or minor break in the skin can also be a potential site for infection. If you get a cut, wash and dry it well. Signs of infection are redness, swelling and drainage.

Contact the transplant coordinator should you develop any of the following:

- a.** a temperature of 100.5 degrees F or greater
- b.** blood pressure below 100/60 or above 170/100
- c.** an unexplained drop in systolic blood pressure by 20 mmHg or more
- d.** abrupt onset of weakness or fatigue
- e.** Spirometry (10% decrease from baseline)

GENERAL GUIDELINES

When you return home after your transplant, you will need to continue the routine you learned in the hospital and adjust it so that it fits into your normal life style. You will need to keep a daily record of your medications and your morning weight, morning and evening blood pressure, pulse, spirometry, and temperature. These records must be brought to every clinic visit for review.

Medications After Transplant

Immunosuppressive medications help to prevent and treat rejection. As you have been told, you will need to take these medications for the rest of your life or you will reject your new lung transplant. Immediately after surgery, the doses will be high since the chance of rejection is greatest at this time. Doses will be lowered quickly to smaller amounts if there is no sign of rejection. Other medications will be prescribed for you by the transplant team as needed.

**A list of the medications is provided in Appendix A.

After you leave the CSU, you will be taught about each of your medications and how to take them. You **must** become responsible for your own medications. As soon as you are able, an individualized self-medication program will be set up for you. This self-medication program is designed to help you learn about the medications you are taking, what they look like, why they are used, and what the side effects are. A medication schedule will be tailored to fit your lifestyle and routines. It is important that you be consistent regarding the times you take your pills and how you take them (e.g. with meals or on an empty stomach).

Your medicines and manual with medication sheets will be at your bedside. You will be taught how to set up your medications and record your doses. After each time you have set up your medica-

tions **the nurse or pharmacist must check your pills before you take them.** Any time you are in the hospital you will be on a self-medication program.

All medications have side effects. Some of the effects are very general, and they may be due to conditions other than your medications. Most people experience side effects at the beginning when doses are high. Inform the transplant team of any side effects you experience.

Never stop or change any medication prescribed by the transplant team without contacting them first. Take your medicines only as directed and as outlined on your medication sheet. Keep your medication sheet up to date. Bring your medication sheet along with your vitals sheet each time you come to the clinic or hospital. Make sure your transplant doctor knows all of the medications you are taking, including those prescribed by other doctors.

Do not start to take any medications including medications prescribed by other doctors or over-the-counter (non prescription) medications without first checking with the transplant team. Do this before you buy the medication. Inform all your other health care providers that you are taking immunosuppressive medications.

Record your doses on your medication sheet. If you accidentally forget to take a single dose. Follow these recommendations:

- If you only take this medication once a day, then take this dose as soon as you remember that a dose has been missed.
- If you take this medication twice a day and it is less than 12 hours before your next scheduled dose time, **DO NOT** take the missed dose. Take your next dose at its scheduled time.
- If you take this medication four times a day, **DO NOT** take the missed dose or doses, take the next dose at its scheduled time.
- If you forget to take a daily scheduled dose or take more than your scheduled dose, call the transplant coordinator for instructions.

NEVER double up on your medication to make up for a missed dose. Some of your medications, if taken in a larger dose at one time, can irritate your liver and/or kidneys. If you have questions about whether you should take a missed dose or not, call your transplant coordinator.

Always have enough medication on hand. Get refills from your pharmacy before you run out. Contact the transplant coordinator if you need to have prescriptions written.

Your medications could be lethal if accidentally taken by a small child. Keep your medications out of the reach of children. Store your medications away from heat and direct light. Do not store them in damp places such as the bathroom or near the kitchen sink. Always check to make sure your medications is not outdated. Do not keep outdated medicine or medicine you no longer need. Be sure that any discarded medicine is out of the reach of children.

If you have any questions or concerns contact the transplant coordinator.

Exercise

Now that you've had your transplant, you can expect some significant changes in your lifestyle. Some will be pleasant, and therefore easy to accept; others will be bothersome or uncomfortable for a while.

You will have an incision across your chest which will take 6-8 weeks to heal. During the first 6-8 weeks following your surgery, you should NOT lift, push, or pull anything that weighs more than 10 pounds. The physical therapist will teach you the proper way to get into and out of bed or a chair, so that the least amount of strain is placed on your incision. Use of both arms together with overhead activities instead of one at a time, will decrease the stress on your incision. You may use your arms as much as you like within your pain-free range of motion.

Shortly following your surgery, you and the physical therapist will start your exercise program. Your program may begin with assisted arm and leg exercises while you are still confined to the bed, but it will soon progress to balance and stretching exercises in the standing position. When you are able to do the standing exercises, a stationary bicycle will be provided (while you are in the hospital) for additional exercise. At some point after surgery, you'll begin to walk in the hallway as part of your exercise program and eventually you'll begin to climb stairs.

Because your heart rate does not respond immediately to changes in your activity level, it is not the best indicator of how hard you are working. Therefore, the respiratory therapist will teach you a method for monitoring how much you are breathing as a means of assessing your response to exercise. Keeping track of the number of breaths you need to take is a convenient method for determining how hard you are working. Just as an automobile uses fuel and produces exhaust, so does your body. As you increase your level of activity, you produce more exhaust and you breathe faster and deeper. By counting the number of breaths needed in a specific time period, you can gauge how hard you are working. This is called the Dyspnea Index, and will be used during your hospital phase of rehabilitation.

Begin by inhaling normally, then count aloud to 15 (taking eight to ten seconds); take a breath when you need to, but not unless you need to. The number of additional breaths you must take to complete the counting sequence gives an indication of how hard you are working.

- Level 0 -** No shortness of breath, you can count to 15 without taking a breath in the sequence.
- Level 1 -** You can count to 15, but you must take one breath in the sequence; you should increase the intensity of the activity.
- Level 2 -** You need two breaths to count to 15; this is the desired level of intensity.
- Level 3 -** You must take three breaths to complete the sequence of counting to 15; this is an acceptable level of intensity.
- Level 4 -** You need to take 4 or more breaths to complete the counting sequence; you should stop the activity or, at least, decrease the intensity of your efforts.

Your respiratory therapist will provide you with a card that should help you remember how to determine your Dyspnea Index. As you progress in your endurance program, you will be given other ways to monitor how hard you are working.

You will gradually increase your exercise time and intensity. By the time you leave the hospital you should be gradually progressing with your walking. Your goal is to walk continuously for at least 45 minutes.

After you are discharged from the hospital, you will be given more specific instructions on how to continue and progress your activities. There are very few activities that are not recommended for you after your transplant. You should avoid any activity in which there is a risk of direct contact or sudden impact (i.e. football, boxing, bungee jumping). There are concerns about scuba diving, hang gliding, sky diving and flying in unpressurized cabins. Activities at high altitude will be difficult for you, since there is less oxygen, thus very high altitude (over 10,000 feet) activities such as mountain climbing are not recommended. You are encouraged to participate in physical activities that are enjoyable to you. Just be sure you have worked up to it, and have developed a good level of overall conditioning by walking or biking (or similar exercise). When starting a new activity, the general rule is to try the new activity for very short periods of time and assess how your body responds, then gradually increase your involvement.

IMPORTANT: There are times when exercise may not be the best thing to do, or when the intensity of exercise should be lowered (not such a hard push). The following are several situations of which you should be aware, and either exercise “easier” or not exercise at all.

When to Lower the intensity of exercise (i.e. slow down)

- If you are emotionally stressed
- If the weather is very hot and/or humid
- If you are at high altitude
- If your blood count (hematocrit) is low
- If you are lacking sleep and feel tired
- If you are starting back with exercise after a hospitalization or vacation, etc.
- If you are experiencing rejection

When not to exercise on a given day

- If you have a fever
- If your medical condition is not stable
- If any of the conditions above (when you should lower the intensity of exercise) are worsened by the exercise

When to Stop Exercise (and consult your physician)

- If you feel excessively fatigued (not from lack of sleep)
- If you are unusually short of breath during your exercise
- If you feel pains or pressure in your chest, neck, or jaw
- If you feel any discomfort in your chest or back which is new to you
- If you feel irregular or rapid heart beats which are new to you
- If you feel nauseated
- If you feel excessive pain in the back, legs, knees or hips
- If you become dizzy or lightheaded
- If you feel any unusual discomfort during exercise

Sun Exposure

It is very important to use a sunscreen when the weather conditions indicate. Patients on immunosuppression drugs are in a high risk group for skin cancers, therefore, plan ahead for time in the sun.

Nutrition

Nutrition will be an important part of your overall health care plan. A low-sodium (salt), low-fat, and reduced sugar diet will be prescribed. An additional dietary goal will be keeping to your ideal body weight. A nutritionist will work with you to increase your understanding and awareness of foods and their content, and help you to develop a diet plan.

Salt - Too much salt (sodium) in your diet can lead to high blood pressure. Since your medications may cause high blood pressure, it is important to follow a low-sodium diet. This is best accomplished by avoiding salt when cooking, and not adding it at the table. Read the labels on prepared foods to check for salt (or sodium) content and avoid processed foods. Certain non-prescription medications are high in sodium, (e.g. some laxatives and antacids) and should be avoided.

Fats - Transplant recipients are at increased risk of developing atherosclerosis. You can reduce this risk by following a low-fat diet, which will reduce the amount of cholesterol and other fatty substances in your blood. The following is a description of various types of fats that are common in our diets.

Saturated fats are fats which tend to raise blood cholesterol levels. Foods which are high in saturated fat are whole milk, butter, coconut oil, solid shortening, and cream cheese. These should be reduced or avoided in your diet.

Monosaturated fats are fats that have an uncertain effect on blood cholesterol levels, but may reduce cholesterol. An example of this type of fat is olive oil.

Polyunsaturated fats tend to decrease blood cholesterol. They are found in liquid oils, such as corn, cottonseed, safflower and soy oils.

Cholesterol blood levels can be reduced by changing the kinds of fats eaten and avoiding cholesterol-rich foods. Foods high in cholesterol include eggs, all organ meats, shell fish, and whole fat dairy products.

Sugar - In general, a reduced sugar intake is recommended. Highly refined sugar foods, such as cookies and cakes, provide a quick source of energy but do not have any nutritional value. They also make you gain weight. Some of your medicines may also cause an increase in your blood sugar.

Alcohol - It is recommended to use alcohol only on special occasions. Alcohol can interact with your medications and should be limited as much as possible.

Prednisone tends to increase appetite - especially for high fat and high sweet foods. It is essential, therefore to be prepared with alternatives to these cravings. Upon discharge, it is important to develop habits that make access to these types of food difficult. For example:

- Have snacks such as fruits, vegetables, dried fruit chips, and the like easily accessible around the house and in the refrigerator. If there is high calorie food around the house, hide it (on the top shelf, in opaque containers) so it is difficult to access.
- Eat only in one spot and do not have serving dishes at the table to “finish off” after your first helpings.
- Drink plenty of fluids - especially before a meal so you feel full at the meal, and don't eat so much.

- Keep your hands busy so it is difficult to eat.
- Develop activities that are “incompatible” with eating, such as writing, exercise, gardening - do them when there is a craving to eat - the craving will go away if you busy yourself with other activities.
- Be creative, develop your own strategies to deal with this side effect of Prednisone.

Smoking

Smoking is **NOT ALLOWED** after you receive a transplant because of increased risk of redeveloping coronary artery disease as well as lung infection. We also strongly discourage you from being in a room of smokers due to the damage to your lungs from secondary smoke.

Sexual Activity

In general, there are no restrictions regarding sexual activity. However, the restrictions protecting your healing sternum must be applied for the first eight to ten weeks after surgery. Any activity or position that causes stress or strain across the surgical incision should be avoided. After ten weeks, no physical restrictions exist. For a young woman with a transplant, the birth control pill should not be taken. For questions about birth control, please ask your doctor or transplant coordinator.

Home Routine

1. **Take your temperature twice a day**, once in the morning and once in the early evening. Record your temperature on the chart in your binder. If your temperature is above 100.5 degrees F (38.0 degrees C), rest for one hour, do not drink hot or cold liquids, and retake your temperature. If it is still elevated, call the transplant coordinator. **DO NOT TAKE** over the counter medications like aspirin, Tylenol, etc., to lower your temperature unless instructed by your doctor. Fever may indicate the onset of infection or rejection.
2. **Spirometry readings** - Initially twice daily, and record FVC/FEV1. Any decrease by 10%, you need to call transplant coordinator.
3. **Take your pulse and blood pressure** twice a day at the same time as you take your temperature. Record your pulse and blood pressure on your chart. Call the transplant coordinator if your pulse is less than 60, your systolic blood pressure has dropped 20 mmHg or more, and/or your diastolic blood pressure is 100 mmHg or more.
4. **Weigh yourself daily** at approximately the same time of day, in the same clothing and on the same scale. Record your weight on the chart provided. If your weight has increased by two pounds overnight call the transplant coordinator.
5. You will be taking immunosuppressants (Prograf, CellCept, Prednisone) for the rest of your life to prevent rejection. **Take your medicines** as outlined on your medication sheet. **DO NOT TAKE** any other medications except those that are prescribed to you by the transplant team.
6. **Remember**, if you have any questions or concerns, it is better to call even if it turns out to be nothing. This is better than allowing something important to go untreated.

Outpatient Visits

Please bring your medication sheets, vital signs, and dosing schedule log book. The transplant physicians and lung transplant coordinator will see you. You will always have blood drawn on your appointment days. **DO NOT** take your morning dose of Prograf until after your blood has been drawn. Remember to remind your doctor if you need prescriptions for any of your medicines and

let the team know of complaints you may have. You will always be in close contact with the Transplant Coordinator.

After your lung transplant, you are required to have several tests at specified intervals.

These tests include:

1. Bronchoscopy with biopsy.
2. CT scan with thin section (to check if rejection will change your baseline CT scan).
3. Pulmonary Function Tests, both at rest and with exercise (to check how well your lung(s) are working).
4. 24 hour urine for creatinine clearance and protein (to check how well your kidneys are functioning).
5. Lipid panel (to check your cholesterol level).

These tests will be scheduled by the Transplant Coordinator. All tests are done on an outpatient basis. At the time these tests are scheduled, more complete information will be given to you.

A list of common lab tests and values are provided in Appendix B.

Things to Remember

1. Almost every patient who receives a transplant has at least one rejection episode. If you feel unusually tired, have fast heart rate, extra or skipped heart beats, have difficulty breathing, or have any other feeling that is not normal, do not hesitate to call us immediately. We would rather hear from you than overlook something that might be harmful to your health and transplanted organ. If you need to call us regarding a problem, we are available in the hospital or in the office from 8 am to 5:00 pm, Monday through Friday, and during off hours (nights, weekends, and holidays) through the answering service (800-505-7769).
2. If you are nauseated or have been vomiting and cannot take your medicines, please call us immediately so that we can arrange for you to receive them intravenously, if necessary.
3. Make sure that you have ordered a Medic-Alert tag and wear it at all times. It should include the following information:
 - Type of transplant
 - Immunosuppressant drugs
 - Name of doctor
 - Drug allergies
4. If you are going to have any dental work done, contact us before you have any drilling or gum work done. We will place you on antibiotics to prevent an infection from occurring. If you are just going to have a regular check-up, there is no need for antibiotics. However, if cleaning your teeth usually causes bleeding, you should have a short course of antibiotics.

5. If you have any trouble with constipation, contact us, and we can prescribe the appropriate medication for you. **DO NOT** give yourself an enema, as there is a risk of developing an infection in your intestinal tract.
6. You do not need to make major changes in your life style.
 - a. You do not have to keep yourself away from the general public. You may attend movies, go to restaurants, etc. However, avoid people with obvious contagious infections.
 - b. Dishes do not need to be sterilized.
 - c. Bed linen should be washed weekly.
 - d. If you have a cat, ask someone else to change the litter box, as an organism, Toxoplasmosis which can cause an infection, can be in cat feces.
 - e. It is not a good idea to keep birds as pets.
 - f. You may swim in clean pools or the ocean. Avoid swimming in lakes.
 - g. Always wear a sunblock when out in the sun for extended periods of time.
 - h. Do not eat raw fish or meats.
 - i. You may use a hot tub or spa as long as the water is clean. Tolerance to heat differs between individuals and may be different following transplant. Hot tubs and steam rooms tend to cause shunting of blood to the skin (to get rid of excess heat), and can result in significant lowering of blood pressure. The key is to start with the hot tub or steam room for a very short period of time and lower temperature and assess your responses. If there were no problems, gradually increase the time and the heat. This way you will develop your heat tolerance, and be able to evaluate your response to it.

GLOSSARY

Terms You Will Hear

Donor - The person who gives the transplant organ.

Recipient - The patient who receives a transplant organ.

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

Crossmatch - The blood test that will determine if the donor's organ is compatible with the recipient.

CBC - A blood test that checks your white cell count and red cell count.

BUN/Creatinine - Tests that check your kidney function.

Prograf level - The blood test that checks the amount of Prograf in your blood.

Immune system - The body's defense system, whose role it is to identify and destroy foreign tissues, bacteria, etc.

Rejection - A process that occurs when the body's immune system tries to attack the transplanted heart/lung(s).

Acute rejection - Rejection which can occur anytime from a few days to months after transplant. It is usually treatable.

Chronic rejection - Rejection which occurs slowly, over a long period of time. It is not treatable.

Immunosuppressive drugs - Medications such as Prednisone and Prograf, that are taken after transplant to control rejection.

APPENDIX A

Immunosuppressive Medications & Their Side Effects

PROGRAF (FK 506, Tacrolimus)

Prograf is an immunosuppressant medication that is used instead of Neoral to prevent transplant rejection. Prograf is similar to Neoral in that it is adjusted according to your weight, kidney function, and the amount of the drug measured in your blood stream.

The most common side effects of Prograf are:

- **Signs of kidney dysfunction** such as a decrease in urine output, fever, or swollen hands and feet.
- **High blood pressure**
- **Diabetes**
- **Headache**
- **Tremor** (a slight shaking of the hands).

NEORAL (Cyclosporine)

Neoral is a potent immunosuppressive drug used to prevent transplant rejection. Because of this drug, transplantation is now a therapeutic option for an increasing number of patients. In general, Neoral has given transplant recipients a new “lease on life” free from the restrictions of chronic, disabling disease and the serious side effects of high doses of Prednisone. The doses of Neoral are adjusted according to your weight, kidney function, and the amount of the drug measured in your blood stream.

As with any medication, you may experience some side effects while taking Neoral. Side effects are more common initially, when your dose is higher, and they usually subside as your dose is reduced over time. If you notice any side effects, do not be alarmed; simply report them to your physician but do not stop taking your Neoral without your transplant physician’s consent. Your blood will be tested frequently to monitor Neoral levels in order to minimize the risk of liver and kidney dysfunction.

The most common side effects of Neoral are:

- **Signs of kidney dysfunction** such as a decrease in urine output, fever, or swollen hands and feet.
- **Tremor** (a slight shaking of the hands).
- **Growth of excessive body hair** (thicker hairs).
- **High blood pressure**
- **Swollen or bleeding gums**
- **Headache.**

A small number of patients experience one or more of the following effects as well – stomach discomfort (cramps, nausea, and/or vomiting), diarrhea, acne, flushing, convulsions, decreased white blood count, breast enlargement in males, sinusitis, and a burning or tingling sensation on the skin, especially on the fingers and toes.

PREDNISONE/MEDROL

Prednisone is a corticosteroid, or steroid hormone, similar to one your body produces naturally. It is given with other medications to prevent rejection.

After transplant surgery, your Prednisone dose will be quickly reduced to approximately 20 mg daily. Then over the following months, the dose will be slowly decreased. The goal, when possible, is to be able to stop Prednisone therapy while keeping you free of rejection. During periods of rejection, the dosage may be increased for a few days and then gradually lowered. If rejection is severe, Prednisone may be given intravenously.

A usual maintenance dose is 5 to 10 mg twice a day. Prednisone is usually supplied as 5 mg, 10 mg, or 20 mg tablets that can be broken in half if necessary.

SIDE EFFECTS: The side effects of Prednisone are also related to the dose of the drug and may subside or decrease as your dosage is reduced. Again, you may or may not develop any or all of these side effects, but you should be aware that they can occur. Report any of these side effects to your physician:

- **Swelling of the face, hands, or ankles.** This will be noticeable by puffy cheeks or a “full” face. At first you may be alarmed at the difference in your appearance. This too will resolve as your dose is lowered.
- **Stomach irritation** That could lead to bleeding ulcers. You may be advised to take an antacid between meals and to take your dose with a meal, rather than on an empty stomach.
- **Weight gain** due to an increase in appetite or fluid retention.
- **Heightened risk of infection** due to suppression of the immune system. This risk is greatest in the early months after your transplant, when your dose is relatively high.
- **Diabetes** known as “steroid-induced diabetes”, may occur with high doses of Prednisone. If you have diabetes to begin with, your insulin requirements will be increased.
- **Skin changes** including slower healing, more delicate skin, rash or acne on the face, chest and back, increased hair growth, easy bruising, and stretch marks. In addition, your skin will be more sensitive to the sun. Use a strong (SPF 15) sunscreen.
- **Muscle Weakness**
- **Osteoporosis** a weakening of the bone which can lead to compression fractures of the vertebral column.
- **Fluid imbalance** including potassium loss. You may need to take oral potassium supplements.
- **Mood swings** that may make you feel fine one minute and blue the next.

Cataracts an eye condition that decreases clarity of vision. To help decrease your risk, regular visits to your eye doctor (ophthalmologist) are recommended.

NOTE: Because long-term use of Prednisone affects the functioning of your adrenal glands (which produce adrenaline). **NEVER** discontinue this medication abruptly. The Prednisone dosage must be gradually tapered over time. Also, because of the effect on the adrenal glands, you may need more Prednisone during stress. Your transplant physician will advise you about any dosage adjustments.

CELL-CEPT (Mycophenolate Mofetil)

This drug is an immunosuppressive drug. It comes in 250 mg and 500 mg capsules, and stops the inflammatory response that is a part of rejection. This drug is used in combination with Neoral and Prednisone. Take Cell-Cept as directed by your physician one hour before or two hours after a meal.

The **side effects** of Cell-Cept include increased risk of infection and diarrhea and stomach upset.

IMURAN (Azathioprine).

This drug is also an immunosuppressant. It comes in 50 mg tablets, which may be broken for smaller doses. Some transplant centers prescribe this drug along with Neoral and Prednisone. As with all medications, take Imuran as directed by your physician.

The **side effects** of Imuran include an increased risk of infection, nausea and vomiting, mild hair loss, decreased white blood cell count, as well as other blood abnormalities. There is also a possibility of liver dysfunction. Report any signs of jaundice (yellowing of the skin) to your transplant physician.

POLYCLONAL AND MONOCLONAL ANTIBODY (Orthoclone okt3)

This is a medication given intravenously for the treatment of severe rejection. It is used alone or with other medications. The medication is given over 10-14 days. The most common potential side effect of OKT 3 is a fever that occurs approximately 30-60 minutes after the drug is given.

Some other common medications you may be taking after your transplant.

ACYCLOVIR: Zovirax (brand name)

COMMON USES: Acyclovir is an antiviral drug that is often used after transplantation to prevent CMV (cytomegalovirus); or prevent or treat a herpes infection (cold sores or genital herpes); varicella zoster (shingles); and Epstein-Barr (mononucleosis). This medication cannot give total protection against these viruses, so should you have any symptoms of these viruses, let your transplant coordinator know immediately.

HOW TO USE THIS MEDICATION: Dosages can range from 200 to 3200 mg/day, but may be altered in individual cases. (The capsules come in 200 mg, 400 mg, and 800 mg strengths). Drink at least two quarts of liquid daily. To clear up your infection completely, continue taking this medicine for the full course of treatment even if you feel better in a few days. **IF YOU MISS A DOSE OF THIS MEDICATION**, take it as soon as possible. If it is almost time for your next dose, skip the missed dose and go back to your regular dosing schedule. Do **NOT** take two doses at once.

POSSIBLE SIDE EFFECTS: Most Common: dizziness, headaches; diarrhea, and nausea/vomiting. Less common: loss of appetite; and rash. Other: tiredness, joint pain; tenderness/swelling or bleeding of the gums.

CALL YOUR DOCTOR IF YOU EXPERIENCE: Joint pain; persistent or severe headache; dizziness; nausea; vomiting or diarrhea.

WARNING: General Warning: *This medication will NOT keep you from spreading herpes to others. Therefore, it is best to avoid any sexual activity if either you or your partner has symptoms of herpes.*

PREGNANCY/BREAST-FEEDING: While there is no information to indicate that acyclovir affects a developing fetus, you should avoid pregnancy.

* *Since acyclovir is excreted in human milk, nursing should be avoided.*

ITRACONAZOLE: Sporanox (brand name).

COMMON USES: Itraconazole is an anti-fungal agent. It is given to help prevent various fungal infections such as aspergillus and histoplasmosis.

HOW TO USE THIS MEDICATION: It comes in capsules of 100 mg. It is recommended that it be taken with food. **IF YOU MISS A DOSE OF THIS MEDICATION**, take it as soon as possible. If it is almost time for your next dose, skip the missed dose and go back to your regular schedule. **DO NOT** take two doses at once. To clear up the infection completely, continue taking this medicine for the full course of treatment even if you feel better. Since fungal infections clear slowly, you may have to take this medicine every day for several weeks or months. If you stop taking this medicine too soon, your symptoms may return.

POSSIBLE SIDE EFFECTS: Most Common: nausea; vomiting, mild skin rash or swelling. Less Common: loss of appetite, fatigue, headache; yellow discoloration of skin; and dark urine.

CALL YOUR DOCTOR IF YOU EXPERIENCE UNUSUAL FATIGUE; yellowing of the skin or eyes; nausea or vomiting; loss of appetite; or dark urine or pale stools.

WARNING: Drug Interactions: *Itraconazole may increase blood levels of Neoral, therefore, it is important to make sure that your Neoral levels are monitored while taking this medication.*

- * Sporanox is contraindicated with the antihistamine, Seldane (terfenadine), and Hismanol (astemizole); sedatives, or anti-anxiety drugs, triazolam (Halcion), and midazolam (Versed); and the gastrointestinal agent cisapride (Propulsid).
- * Antacids can reduce the amount of itraconazole in your blood, possibly interfering with its effectiveness. Do NOT take this medication with antacids, such as Zantac, Pepcid, Axid, or within two hours of taking an antacid.

PREGNANCY/BREAST-FEEDING: The effect of itraconazole on a developing fetus is not known; pregnancy is not recommended. Since itraconazole is excreted in human milk, nursing should be avoided.

CLOTRIMAZOLE: Mycelex Troche (brand name)

COMMON USES: Clotrimazole is used as a prophylactic anti-fungal agent. It offers protection against oral candidiasis or thrush.

HOW TO USE THIS MEDICATION: Let one lozenge dissolve slowly in your mouth after each meal and before bed. DO NOT chew or swallow whole. **IF YOU MISS A DOSE OF THIS MEDICATION**, take it as soon as possible. If it is almost time for your next dose, skip the missed dose and go back to your regular schedule. **DO NOT** take two doses at once. **DO NOT** eat or drink anything immediately after taking this medication.

POSSIBLE SIDE EFFECTS: Very rare: nausea/vomiting.

SULFAMETHOXAZOLE/TRIMETHOPRIM: Bactrim, Septra (brand names)

COMMON USES: This medication is used to treat or prevent infections. Specifically, it helps to prevent a pneumonia called pneumocystis carini pneumonia, which you are susceptible to because of your lowered immune system.

HOW TO USE THIS MEDICATION: This medication is best taken with a full glass of water to prevent the formation of crystals in the urine. Drink several additional glasses of water daily, unless otherwise directed by your physician. Drinking extra water will help to prevent unwanted side effects of sulfonamides. This medicine may be taken with food if it upsets your stomach. Dosage is usually one tablet twice a day. Dose may be reduced to one tablet three times a week. **IF YOU MISS A DOSE OF THIS MEDICATION**, take it as soon as possible. If it is almost time for your next dose, skip the missed dose and go back to your regular schedule. **DO NOT** take two doses at once.

POSSIBLE SIDE EFFECTS: Most Common: stomach upset; nausea/vomiting; loss of appetite. Less Common: sensitivity to sunlight; diarrhea; dizziness; headache; skin rash.

CALL YOUR DOCTOR IF YOU EXPERIENCE: rash; hives; swelling of the tongue; fever; sore throat; joint pain; cough; shortness of breath; vaginal irritation or discharge; paleness; unusual bruising or bleeding; or yellow discoloration of the skin or eyes.

WARNINGS: *General Warning: For many months after you stop taking this medicine you may experience more sensitivity to sunlight or sunlamps, so take proper precautions.*

DRUG INTERACTIONS: For people who are allergic to sulfa drugs, there are alternative medications that are given, such as Pentamidine and Cipro.

PREGNANCY/BREAST-FEEDING: Since sulfamethoxazole/trimethoprim is excreted in human milk, nursing should be avoided.

GANCICLOVIR: Cytovene (brand name)

COMMON USES: Oral Cytovene is usually given after ganciclovir IV is finished in order to provide protection against CMV infection, especially for transplant recipients of CMV positive donors. The indication for use in solid organ transplantation is relatively new, but so far it seems to be more effective than acyclovir in preventing CMV infections.

Following the directions for taking this medicine provided by your doctor. It is recommended that you take Cytovene with food (to increase bio-availability), and drink plenty of fluids. Cytovene comes in 250 mg capsules. The usual dose is 1 gram 3x/day. Cytovene capsules should not be opened or crushed. **IF YOU MISS A DOSE OF THIS MEDICATION**, take it as soon as possible. **IF YOU TAKE IT 3X/DAY** and it is almost time for your next dose, take one dose now and another in six hours, and then continue with your regular schedule. It is important to keep all doctor and laboratory appointments while taking this medication since it may lower your resistance to infection, and reduce the number of blood cells needed for clotting. To prevent bleeding, avoid situations where bruising or injury may occur.

POSSIBLE SIDE EFFECTS: Most Common: headache; nausea. Common: Fever, diarrhea; abdominal pain; lowered white blood cell count; unusual bleeding or bruising; anemia; decreased kidney function; decreased platelet count; numbness or pain in the hands, arms, legs, or feet; weakness.

CALL YOUR DOCTOR IF YOU EXPERIENCE: vomiting; fever, chills; cough; sore throat; unusual bleeding or bruising; rash; or confusion.

WARNINGS: *Drug Interactions. Do not take any over-the-counter medications without the approval of your transplant physician. This includes, but is not limited to, aspirin and other non-steroidal anti-inflammatory drugs such as Advil, Ibuprofen, Nuprin, and Aleve.*

- * Mixing ganciclovir with other drugs that can be damaging to the kidneys can increase the rate and extent of damage.
- * Mixing ganciclovir with other antiviral medication can increase the toxic effects of ganciclovir, and should be used together if absolutely necessary.

Pregnancy/Breast-Feeding: Pregnancy is not recommended while using Cytovene. Studies in animals have shown it has the potential to impair fetal development.

- * Use of birth control is recommended while taking this medicine. Males receiving this medicine should use a condom during sexual intercourse during treatment, and for 90 days after stopping treatment to avoid passing the drug on to their partner.
- * It is not known if ganciclovir passes into breast milk, but the possible toxic effects of this drug on a nursing infant should be kept in mind.

DIURETICS: Lasix, Bumex (brand names).

COMMON USES: A diuretic is a medication that helps your body get rid of excess fluid, which may be caused by steroids, by making more urine. Often, this causes the patient to urinate more frequently during the night. This, in turn, decreases the amount of fluid (blood) your heart needs to pump. You may have been taking one of these medications before your transplant. After your transplant, you may continue to require a diuretic.

Since the drugs act to increase urine flow, several common sense suggestions can make their use easier. The drug's effect may last from two to twelve hours, so plan your activities so that a bathroom is accessible. If an evening dose of a diuretic is required, take it in the early evening to prevent the inconvenience of excessive urination during sleep hours. Weigh yourself daily and keep a record. In general, large changes in body weight reflect fluid retention or fluid loss.

The following are directions for using these medications provided by your doctor:

- **IF YOU MISS A DOSE OF THIS MEDICATION,** take it as soon as possible.
- If it is almost time for your next dose, skip the missed dose and go back to your regular schedule.
- **DO NOT** take two doses at once. Usually, after your transplant you will **NOT** need to take any potassium supplements with the diuretic even though you may have needed them before.

POSSIBLE SIDE EFFECTS: Common: light-headedness; fatigue; indigestion; diarrhea; skin rash; hives. Less Common: vomiting; yellowing of the skin and eyes; dermatitis and other skin reactions; and anemia.

WARNINGS: *General Warnings: It is important to have your blood pressure and blood electrolyte levels checked frequently when you are taking diuretics. Electrolytes are necessary for the body to work properly. Symptoms such as dryness of the mouth; excessive thirst; muscle aches; nausea; headache; low blood pressure; and fatigue may indicate that electrolyte levels are abnormal.*

DRUG INTERACTIONS: Do not take any over-the-counter cough/cold, asthma, or diet medications without asking your transplant physician first.

* Diuretics may change the sugar metabolism in your body; patients who are diabetic may need to have their medication adjusted.

GASTROINTESTINAL: Zantac, Propulsid, Pepcid, Reglan, and Prilosec (brand names)

COMMON USES: These medications are used to treat heartburn, prevent and treat ulcers, treat gastrointestinal reflux, treat nausea and vomiting, as well as to act as an antacid to buffer the acid in your stomach. Prednisone causes increased acid in your stomach, which may cause an ulcer.

Use this medicine exactly as directed by your physician:

- **IF YOU MISS A DOSE OF THIS MEDICATION**, take it as soon as possible.
- If it is almost time for your next dose, skip the missed dose and go back to your regular schedule.
- **DO NOT** take two doses at once. Additional antacids may be used with these medications, but check with your transplant coordinator first.

POSSIBLE SIDE EFFECTS: nausea/vomiting; constipation/diarrhea; headache; dizziness; and drowsiness.

WARNINGS: *Drug Interactions: Antacids have the ability to interfere with the action of antibiotics. You should avoid taking antacids and antibiotics less than two hours apart.*

* Some antacid medications, such as Reglan and Propulsid, may cause drowsiness or dizziness. Do not drive or operate machinery while on these medications. Also, antacids may increase the effects of other depressants or alcohol.

**BLOOD PRESURE LOWERING MEDICATIONS:
Captopril, DynaCirc, Cardizem, Procardia, Vasotec (brand names)**

COMMON USES: These medications lower blood pressure and are often used in combination with other drugs. Remember high blood pressure is very common when taking cyclosporine and prednisone.

Medications can lower blood pressure in many ways. Some dilate the blood vessels. Others change the kidney's effect to control blood pressure. Still others block part of the nervous system that increases blood pressure.

Your physician will give you information on how to take this medication correctly:

- **IF YOU MISS A DOSE OF THIS MEDICATION**, take it as soon as possible. If it is almost time for your next dose, skip the missed dose and go back to your regular schedule.
- **DO NOT** take two doses at once.
- It is important that you check your blood pressure daily, and that you take any anti-hypertensive medications exactly as prescribed.

POSSIBLE SIDE EFFECTS: headaches; dizziness; fatigue; nausea; joint pains; rash.

CALL YOUR DOCTOR IF YOU EXPERIENCE tender, bleeding or swollen gums; irregular heart beat; dizziness; or swelling of the feet or hands.

WARNINGS: **Some of these medications can cause dizziness. Do not drive or operate machinery until you know how you react to this medication.*

ANTI-ANXIETY MEDICATIONS: Valium, Buspar, Librum, Atavan, Xanax (brand names)

COMMON USES: These medications are used to help control anxiety in transplant patients, which is often caused by the side effects of prednisone.

Your physician will give you information on how to take these medications when it is prescribed for you:

- **IF YOU MISS A DOSE OF THIS MEDICATION,** take it as soon as possible.
- If it is almost time for your next dose, skip the missed dose and go back to your regular schedule.
- **DO NOT** take two doses at once. It may take several weeks before the full effect of these medications is noticed.

POSSIBLE SIDE EFFECTS: drowsiness; dizziness.

WARNINGS: *Drug interactions: Do not take these medications with alcohol, which can induce drowsiness.*

* Do not take any over-the-counter cough/cold, allergy, sleep aid, or diet medications without asking your transplant physician.

Alcohol & Transplant Medications:

Some of the medications often used by transplant patients are listed here, along with potential interactions with alcohol. Always play it safe and check with your transplant team to learn exactly how your medications interact with alcohol. An occasional glass of wine or beer is usually not a problem.

APPENDIX B

Lab Tests and Normal Values	Purpose	Problems With Abnormal Results	Factors That Can Change Your Results
White Blood Count (WBC) (4500-11,000 cu/mm)	Tells how many infection fighting cells (white blood cells) are in the blood.	Low Level: can mean too few infection-fighting cells High level: means you may have an infection	Some medicines like Imuran and intravenous Acyclovir can lower your white blood cell count, while others like Prednisone can elevate it.
Hematocrit (HCT) (36.0-46.0%)	Tells how many oxygen carrying red blood cells are in the blood.	Low Level: can make you anemic, tired, and short of breath. High Level: can make your blood thicker and cause problems with clotting.	A lot of bleeding can make your hematocrit go down; blood transfusions make your hematocrit go up.
Platelets (Plt) (150,000-350,000/cu mm)	Tells how many cells that make your blood clot (platelets are in the blood).	Low Level: you may bleed more easily. High Level: can make your blood very thick and may require that you take a blood thinner.	Liver disease and some medications can cause problems with the platelet count.
Potassium (K+) (3.7-5.5 mEq/L)	Tells how much potassium is in the blood. Potassium helps the heart and other muscles work well.	Low Level: possible problems with the heart beat. High Level: possible problems with the heart beat and too much acid in the blood	Kidney failure can increase the level, high levels of acid in the blood can increase the level. Often seen with pancreas transplant. Sodium bicarbonate is used to lower this level; diuretics can cause low levels.
Carbon Dioxide (CO₂) 24-30 mEq/L	Reflects the acid balance in your blood.	Low CO ₂ means too much acid in your blood. Can make you feel tired and short of breath.	Kidney failure or pancreas transplants can decrease the level; sodium bicarbonate tablets can increase the level.
Blood Urea Nitrogen (BUN) (7-22 mg/dl) Creatinine (Cr) (0.5-1.2 mg/dl)	BUN and Creatinine indicate how well a kidney is functioning.	High Level: may mean that the kidney is not functioning properly.	High levels can result from kidney failure; high drug levels of Cyclosporin (Sandimmune, Neoral) and Tacrolimus (Prograf) in the blood, or organ rejection; a diet high in protein can increase the BUN.
Magnesium (Mg) (1.3-2.0 mEq/L)	Tells how much magnesium is in your blood. Your body needs magnesium to carry out many of its daily functions.	Low Level: can cause muscle weakness; sleepiness and problems with the heartbeat.	Medicines like Cyclosporine and Tacrolimus can cause your magnesium level to go down. Magnesium Oxide helps to keep the level normal; Cipro (antibiotic) can affect the absorption of magnesium, so it should be taken two hours before the magnesium.
Arterial Blood Gases (ABG) pH 7.35-7.45 pCO ₂ 35- 45 pO ₂ 80-100 O ₂ Sat 95-100	Tells how well you are getting oxygen and getting rid of carbon dioxide (by-product of metabolism) in your body. It is a measure of the acid-base balance.	There are certain levels that the body maintains as the result of how well your lungs are working and other buffer systems (your kidney) that help to maintain a normal balance.	If you don't get enough oxygen and don't eliminate CO ₂ , because your diseased lung is not capable of exchanging "good air with bad air", you will feel short of breath and anxious.

Lab Tests and Normal Values	Purpose	Problems With Abnormal Results	Factors That Can Change Your Results
Total and Direct Bilirubin (0.2-1.2 mg/dl) Total (0.0-0.4 mg/dl) Direct	Tells how well the liver is working	High Level: may mean that the liver is not working well.	Liver failure causes the levels to rise as the sick liver cannot remove the bilirubin, which is a waste product from the blood.
AST or SGOT (0-35 IU/L) ALT or SGPT (0-31 IU/L) Alk Phosp (30-120 IU/L) GGT (8-51 IU/L) LDH (0-220 IU/L)	Tells that there may be damage to the liver, heart, or bones	High Level: these enzymes are released into the blood if there is damage to the liver or bones. Damage can be a result of rejection or certain medicines.	Liver failure increase the levels; especially ALT or GGT; the bone disease that occurs with kidney failure can increase the alkaline phosphatase; certain medicines such as Imuran can cause AST an ALT to go up.
PT (11.2-13.6 sec) PT (20-31 sec)	Tests the clotting function of the blood.	High Level: may mean that your blood is not able to clot or stop bleeding well. Liver failure and medicines can cause this problem.	Liver failure can cause your blood to not clot well. Medicines like Coumadin and Heparin are used to make the blood thin and cause high levels.
Cyclosporine Level, Whole Blood HPLC (150-300 ng/ml) or Tacrolimus Level, Whole Blood TDX (6-15 ng/ml)	Tells how much Cyclosporine or Tacrolimus is in the blood. Both of these medicines prevent rejection.	Low Level: can increase the risk of rejection. High Level: can cause problems with other organs in the body like the kidneys and increase the chance of infections.	You should always have your blood drawn 12 hours after your last dose for the best results based on a twice-a-day dosing regimen. Any earlier might make the level high; later might make it low.
Glucose (blood sugar) Fasting (70-115 mg/dl)	Tells how controlled your diabetes is.	Low Level: can make you feel faint, cause sweating, nervousness, fast pulse, and a headache. High Level: can cause problems such as excessive thirst, fatigue, hunger, and weight loss, and can mean your transplanted pancreas is not working as well as it should.	Acute stress such as the surgery or infection, intravenous fluids with sugar, and steroids can all cause glucose to go up. Too much insulin can cause the glucose to be too low; exercise, severe cold, high fever, and a poor diet can lower the blood sugar level.
Cholesterol (fat-like substance) (<200 mg/dl)	Tells whether there is a problem with the liver. Tells whether you are higher risk for having a heart attack.	High Level: can cause narrowing or blockage of blood vessels which may lead to a heart attack. When the liver is not working well, the level may be low	Eating fatty foods up to 12 hours before the test may cause a high level. A fasting state is often required; certain diseases such as diabetes elevate the level; medicines such as prednisone and Cyclosporine may increase the level; diet and exercise will lower the level; bile tube problems such as blockage can cause a high cholesterol level.
Urine Culture	Tells if there is bacteria causing infection in your urine.	Infection in your urine can cause burning when you urinate; frequent urination; change in color and odor of your urine.	It is important to clean yourself well when obtaining urine samples to get an accurate result.

Thank you for your interest
in Tampa General Hospital's
Lung Transplant Program.

If you require more information
about our program or wish to speak
to a team physician or team member,
please do not hesitate to call us at:

1-800-505-7769 or 813-844-7137



TRANSPLANTATION