Lung Transplantation at Temple University Hospital

This booklet provides an in-depth guide through the lung transplant process. In it, you will find details related to all stages of the process, from the tests you will take during evaluation, to the surgery itself and through the post-transplant rehabilitation period, including a guide to your medications and follow-up testing.

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INTRODUCTION

WELCOME

Over the past two decades, organ transplantation has become an accepted medical treatment for end-stage organ disease. It can offer patients hope of returning to a better quality of life.

In this notebook, you will learn about each step in the process you’re about to face as a transplant candidate, and who to turn to when you have questions. We’re here to help you understand and manage your condition.

Temple University Hospital offers one of the most comprehensive medical and surgical pulmonary care programs in the country. With a multi-disciplinary team of over 20 specialists working with you, you can be confident you will receive the best care possible.

In recent years, lung transplantation has improved the lives of more and more patients. And Temple has played a leadership role, performing dozens of these lifesaving procedures.

HISTORY OF LUNG TRANSPLANTATION AT TEMPLE

Transplantation is a very complicated and demanding operation, and is really a last resort in most cases. Patients who need a lung transplant are in the end-stage of pulmonary (lung) disease, and therefore need drastic intervention. We will be working closely with you and your referring physician to evaluate your health and determine the best course of action for your specific condition. If there are intermediate steps we can try before transplantation, we will recommend them first.

There are two types of lung transplants: single and double. Single lung transplantation (one lung is replaced with a donor lung) is appropriate for emphysema, chronic obstructive pulmonary disease, and pulmonary fibrosis. Double lung transplantation (in one surgery, both lungs are replaced with both of a donor’s lungs) may be necessary for patients who have had repeated lung infections, patients with cystic fibrosis, or patients with severe pulmonary hypertension (elevated lung pressures).

The number of transplants performed over the past few decades has increased significantly. However, while the technology and the expertise are greater than ever, one- to five-year survival rates (how many patients live past the first, second, third, etc. years after their transplant) reflect the serious nature of the operation. Here are some statistics from the International Society of Heart Lung Transplantation, which you may find interesting.
From 1988 to 1995:

- Four hundred ninety (490) heart-lung transplantations, 1,264 double-lungs and 2,262 single-lung transplantations were performed.
- The mean (average) age of patients undergoing lung transplantation is about 47 years, equally divided between males and females.
- One-year survival rate is 70%, two and three year survival rate is about 65% and five-year survival rate is 50%.
- Infections of the transplanted lung were the major cause of death in the first months after transplantation.

THE TEMPLE UNIVERSITY HOSPITAL LUNG TRANSPLANT TEAM

These are the people who will be working closely with you to make your transplant as successful as possible. Each team member is an expert in a different area of transplantation:

Pulmonologist: Each potential candidate for lung transplantation will be evaluated by a pulmonary physician, a specialist who is skilled in the management of patients with advanced lung disease.

Your Pulmonologist is:

Cardiothoracic Surgeon: The transplant surgeon performs the operation and will meet with you to evaluate your specific needs, discuss the surgical procedure, and answer questions while you are in the hospital.

Your Cardiothoracic Surgeon is:

Transplant Nurse Coordinator: The transplant nurse coordinator coordinates your care with all members of the transplant team. This is the person who will meet with you in the pulmonary clinic both prior to and after transplant.

Your Transplant Nurse Coordinator is:

Cardiologist: A cardiologist will assess your heart function by reviewing your cardiac testing. The purpose of the tests is to rule out the presence of coronary artery disease.

Your Cardiologist is:

Psychologist: A clinical psychologist will meet with you and your family to examine and assess neuro-psychological function and to provide emotional support during this highly stressful time. This emotional and behavioral testing information helps us prepare and care for you during and after the transplant.

Your Psychologist is:
Outpatient Rehabilitation Team: Patients accepted as transplant candidates will be enrolled in a specialized exercise program designed to reduce shortness of breath and improve ability to perform daily activities until the transplant.

Your Outpatient Rehabilitation Team is:

Social Worker: A social worker will help you with your social and financial needs. The social worker will also provide emotional support and counseling throughout the transplantation process.

Your Social Worker is:

Financial Counselor: In addition to the social worker, a financial counselor is available to meet with you and your family with regard to insurance issues and other billing related concerns.

Your Financial Counselor is:

Dietitian: Your dietitian will review your eating habits and nutritional status. Good nutritional status has been proven to significantly enhance healing and outcome following surgery.

Your Dietitian is:

Anesthesiologist: The anesthesiologist not only administers the anesthesia at the onset of the operation, but also monitors your vital signs throughout your operation and, along with the surgeon and the pulmonologist, will direct your care in the Intensive Care Unit after surgery.

Dentist: A dentist (you are free to use your own) will be required to assess the health and hygiene of your teeth and gums, and write a letter to your transplant team, giving you medical clearance. An undetected oral hygiene problem could pose an infection risk after surgery and jeopardize your recovery.

Additional consultations not listed here might be requested depending on your individual condition and situation.
PRIOR TO TRANSPLANT

EVALUATION AND DETERMINING CANDIDACY

The first step in the process is an evaluation of your underlying lung disease, and your medical and surgical treatment options. The first person you’ll meet is the pulmonologist for a consultation. Your medical records (submitted by your referring physician), along with other data obtained as part of the transplant evaluation, will be reviewed. Your general health will also be evaluated for any other medical illnesses that would make a lung transplant inadvisable.

At this stage, if different treatments can be found that could make lung transplantation unnecessary, they will be discussed with you. For example, certain medications and respiratory treatments may be prescribed or modified to improve your pulmonary function.

Unless transplantation is completely ruled out at this point, the pulmonologist will then prescribe a series of tests, including several types of laboratory and diagnostic tests, some inpatient and some outpatient (see below).

You will also have consultations with the other members of the transplantation team, who will review your medical history, the progression of your lung disease, and your social support system. Remember, to be considered for a transplant, patients must be highly motivated, compliant with all phases of their medical care, and have a strong support system.

This process, from initial consultation to receiving test results, can take up to four weeks.

Testing

In addition to the tests we discussed in the General booklet (24-Hour Urine Test, Blood Test, Chest X-ray, Echocardiogram, Cardiac Catheterization, General Health), you will undergo the following examinations that are specifically related to the lung transplant.

MUGA Scan – The heart is scanned in order to determine the strength of your heart muscle. You will be given an intravenous injection at the start of this test.

Lung Scan – After receiving an intravenous (IV) injection, the lungs are scanned to determine the amount of air and blood moving through them.

Pulmonary Function Studies – You will be asked to breathe into a tube attached to a measuring device, which will show how well your lungs are working and determine your blood’s capacity to carry oxygen. A six-minute walk test, an arterial blood test, and an exercise test are included in this evaluation.
Sleep Study – For certain patients, it may be necessary to assess their oxygen needs during sleep. A sleep study requires one or two nights of sleeping in the Sleep Lab. This study is painless: a specially trained technologist will apply sensors to your head, face, chest, abdomen, and legs. State-of-the-art equipment will monitor brainwaves, eye movement, breathing, blood oxygen levels, heart rate, and muscle activity during sleep.

CAT Scan – A method of combining images from multiple x-rays to produce pictures of internal organs, which can be used to identify abnormalities. CAT scans of the chest tell us the extent of damage to your lung tissue.

DEXA Scan – Measures bone mineral density to check for possible bone loss. Bone loss is serious but treatable and early detection allows us to prescribe appropriate medication.

As you can see, these tests are extensive, and many HMO’s require referrals for each one. We will be happy to work with you and your insurance company to ensure that you have all the necessary clearances and approvals before we begin. You may still be responsible for a certain portion of the expenses, which your financial coordinator will help you figure out.

Note: Additional testing may be required, based on your current condition, the assessment of the pulmonologist, and/or your specific past medical history. Any extra testing should be explained to you when it is determined that such testing is needed. The pulmonologist may also have you see other physicians who specialize in treating other health problems (actual and suspected) that the team might identify during the evaluation phase.

Eligibility Consultation

Once all your testing is complete and the results are in, you’ll be asked to come back for a follow-up appointment at the Lung Transplant Clinic. This could be up to four weeks after you begin the process.

At this meeting, the transplant team will share the results of your tests, their decision concerning your eligibility for transplantation, the risks and benefits of transplantation, and whether you will need a single or a double lung transplant. You will need to bring your family to this meeting, so that everyone’s questions can be answered.

There will be a tremendous amount of information discussed at this meeting, and you will have much to think about concerning your health and what is best for you. Remember, even if the team decides that you are a candidate for transplantation, the final decision rests with you.
Be sure to ask as many questions as you need to, and do your own research on your condition to become well informed about your situation. Education about lung transplantation should begin with you and your family during the evaluation phase and continue until long after transplant.

THE WAITING PERIOD

Once you have decided to pursue a transplant, you begin the process of waiting for your lung(s). When a patient is selected, he or she must be available, healthy enough to undergo major surgery, and willing to be transplanted immediately. Therefore, as you are put on the national waiting list, you will be given a beeper, start Pulmonary Rehabilitation classes, and start a schedule of ongoing tests and appointments with your transplant team.

Listing and Matching of Candidates

At this time, you will be put on the national waiting list for donor organs. The United Network of Organ Sharing (UNOS) manages this list, and strictly ensures the fair and legal distribution of organs to recipients. This organization is responsible for working with your transplant team to match you with a donor.

The match is based on a ranking you will be assigned, which is based on information about your condition, including tissue type, blood type, length of time on the waiting list, immune status, degree of medical urgency, and the physical distance between you and the donor. Because this process is standardized, the Temple transplant team will have a general idea where you “stand” on the national waiting list. You can check in with them regularly to get updates.

Multiple Listing

Multiple listing means that you register on the waiting list at more than one transplant center. It is possible that multiple listing may increase your chances of getting an organ offer earlier.

Talk to your transplant team about this option. You should know that ultimately, it’s up to those subsequent transplant centers to decide whether or not to accept you for multiple listing, and it will most likely involve another full evaluation by their team. You may want to check with your insurance first to be sure that they will cover the additional testing.
Beepers/Cell Phones

When a donor lung becomes available, the physicians have a few precious hours to keep it healthy and get it to you. Because time is such a critical factor, we will help you obtain a beeper or cell phone so we can reach you immediately should you be selected for a donor organ. It is very important that you keep your beeper or phone with you at all times and call (215) 707-1722 any time you are paged or called. We advise that you change the batteries in the beeper monthly, or charge your phone (leaving it ON, with the ringer ON) every night.

It is critical that you stay accessible, so the team knows how to contact you at all times. This is your responsibility: if you go on vacation, if you leave the area for any reason, you must contact the Transplant Nurse Coordinator with phone numbers where you can be reached and when you will be back. When you return from any trip, you must call the Transplant Nurse Coordinator with the update that you are home.

WHEN YOU ARE PAGED OR CALLED, CALL: (215) 707-1722 IMMEDIATELY

If you are hospitalized, for ANY reason during your time on the waiting list, you must let the transplant team know. If you are hospitalized at Temple University Hospital, tell the doctor treating you to notify the Lung Transplant Team. If you are at a different hospital, ask a member of your family to call the Transplant Nurse Coordinator if you cannot. This is important to ensure that if an organ becomes available, time is not wasted.

Pulmonary Rehabilitation Program

Temple patients accepted as transplant candidates will need to find, and enroll in, an outpatient Pulmonary Rehabilitation program.

The overall goals of the program are to reduce your shortness of breath and improve your ability to perform activities of daily living. Improved conditioning prior to transplantation will also improve your ability to recover after surgery. To that end, you will be prescribed specialized exercises designed to improve cardiovascular conditioning and strengthen respiratory muscles.

Ongoing Health Screenings and Appointments

You will stay connected with your transplant team while you are waiting for your donor lung(s), coming in to the hospital every six to eight weeks for routine checkups and receiving certain immunizations and vaccines that will help keep you healthy. Your Transplant Nurse Coordinator will provide you with a schedule of appointments. It is very important that you follow this schedule. Always call your Coordinator to report any illness, or changes in your health, most importantly if you are hospitalized.
How Long Will I Wait?

The major limiting factor for lung transplantation is the availability of donor organs. Currently, average waiting time varies, and can take anywhere from several months to a few years, but may run significantly shorter or longer. Of all the stages in the transplant process, the waiting period is perhaps the most difficult.

Each time an organ becomes available, a process of matching begins in which a centralized, computerized system identifies and ranks the most ideal candidates for that organ.

The ranking is standardized, and based on many factors. The first is something called a lung allocation score, which is a number between 0 and 100 that represents much of the information the transplant team obtained during your evaluation (your test results, level of illness, and the medical urgency of your transplant). The other two primary factors are the biological similarities between you and the donor (blood type, organ size, etc.), and geographic distance between you and the hospital where the donor is located. Patients often want to know how they can increase their standing on the list. Don’t worry; the transplant team will have done its best to get you the highest allocation score that reflects the severity of your condition and the urgency of lung transplantation. Remember, in order to keep your score as high as possible, you will be required to update your medical information at least every six months until you receive your transplant.

Now is a good time to get your finances in order and perhaps get involved in some stress-reducing activities and hobbies.

Financial Considerations

Most insurance carriers accept lung transplantation as a method to treat end-stage pulmonary disease. Often, outpatient post-operative care and pulmonary rehabilitation costs are also covered. Because each operation is different and because each insurance policy can vary, there is no single number that represents the cost of a lung transplant. Because you will be relying heavily on your health insurance benefits, it is critical that you become very familiar with your policy, and that you keep up with your monthly payments (premiums) to ensure you don’t lose your coverage. See the General section of this notebook for more detailed information regarding finances.

Stress and Stress Management Suggestions

We know that this is an extremely stressful time for you and your family, but stress can further aggravate your health condition. Do things that keep you physically and mentally active, social, and happy. There are many ways to manage stress and control anxiety. It is important that you find a method that works for you.
**Physical activity.** Stay as active as your condition will permit, and attend your Pulmonary Rehabilitation classes. This will not only help take your mind off things, but it will help you recover from your operation more quickly. Stay involved with your normal activities to the best of your ability, keeping up with work, studies, or leisure activities. Start a new project or hobby, something “you’ve always wanted to do.” Don’t put your life on hold!

**Support groups.** You are expected to attend and participate in Temple’s Lung Transplantation Support classes to meet and ask questions of other people going through the same experience. Learning as much as you can about transplantation will also help you decide whether lung transplantation, with its inherent risks, is a good treatment option for you. If you know what to expect, you will feel better throughout the process. Lean on your family and friends to keep you company and distract you.

**Stay healthy!** No smoking, no drinking, and maintain a healthy body weight. Keep up with all routine doctor visits like dental cleanings and gynecological exams. Keep your scheduled appointments with your personal physician and also with your pulmonary doctor in the Lung Transplant clinic. Talk to them or any member of your transplant team about any emotional or physical stresses you are feeling. Remain hopeful and optimistic. Learn relaxation techniques that can help keep you feeling positive.

**Being Prepared**

The good news about your organ may arrive at any time. Because you never know when or where you will be when you get the call, it’s a good idea to be ready.

The transplant team should have a list of contact phone numbers so they can reach you 24 hours a day. You should be carrying your beeper with you at all times, updating your transplant team if you do any traveling. Again, it is your responsibility to be available, and your place on the waiting list may be jeopardized if we try to reach you and cannot.

You should have a plan for getting to the hospital, especially if you will need a ride or other assistance. You may also want to have someone designated to alert the rest of your family that you have gone to the hospital.

Any family members that will be with you at the hospital may want to have a bag already packed with toiletries, a pillow, comfortable clothes, spare glasses, books, or crossword puzzles. You won’t need anything until you come out of Intensive Care (see below), at which time your family can start bringing you your personal items. If your family is from out-of-town, call our concierge service for a listing of hotels and transportation options in the area.

The number is (215) 707-CARE (2273).
WHERE TO GO, WHAT TO DO

When a donor organ becomes available, the Transplant Nurse Coordinator will try to reach you, first at home, by telephone. If we are unable to reach you by phone, we will contact you by cell phone, then beeper. When your beeper activates, call: (215) 707-1722. We will make every effort to give you as much notice as possible, but you should be prepared to come to the hospital as soon as possible after you have been notified.

Do not eat or drink anything after receiving this call. You can take your breathing medication (inhalers, nebulizers), but no pills. Call the Transplant Nurse Coordinator if you have any questions about what you can and cannot take, at (215) 707-1722.

The Transplant Nurse Coordinator will have given you directions on exactly which door to enter and where to go, but you can always call back if you are unsure.

Your family is encouraged to accompany you to the hospital, and every effort will be made to find them a comfortable place to wait. However, we don’t recommend that young children come to the hospital until after the operation is over since the process can be very long—sometimes up to 24 hours—by the time everything is complete.

The Cardiothoracic Surgeon will have spoken to you about the specifics of your individual surgery, but may not be there when you first arrive at the hospital. The Surgeon will have gone to the location of the donor to evaluate and hopefully bring back your organ. So, when you arrive at the hospital, you may “beat” the arrival of your donor organ. You will be “prepped” so you are ready to go when the organ arrives, but this may take a few hours depending on the location and condition of the donor. You will be in a sterile environment, so your family will not be able to keep you company, but many members of your transplant team will be with you to keep you comfortable.
FALSE ALARMS

Unfortunately, when the surgeon evaluates the donor organ, it may be determined that it is not a good match for you. This can be based on many factors, such as the condition of the organ or the levels of antibodies in your bloodstream at the time (making it more likely that your body will reject the organ). Remember, the transplant team is dedicated to obtaining the best possible organ for you, but they are fragile and their condition can degrade significantly in just minutes. The surgeon will not “trade down” for you – we would rather wait for the best possible lung.

Because time is so critical, you will already have been brought to the hospital and probably “prepped” for surgery. At this point, you will be sent home to wait for a future offer. This can lead to significant disappointment and stress for you and your family; therefore, we will always do our best to avoid these situations. Rest assured, your place on the national waiting list will remain the same.
POST-TRANSPLANT PLAN

POSTOPERATIVE PERIOD

After completion of the surgery, you will be moved to the Cardiac Intensive Care Unit (CICU), which is located on the 2nd floor, Rock Pavilion. Your family will be allowed to visit with you in the CICU.

The average stay in the CICU varies, anywhere from several days to several weeks. Your postoperative care is individualized according to your needs.

You will then be transferred to a special respiratory unit, with staff experienced in caring for patients with advanced lung disease. A multidisciplinary team with physical therapists and respiratory therapists along with pulmonary physicians, surgeons, and nurses will coordinate the tests and treatments required for managing your postoperative course. You will remain here until the team feels you are safe to be discharged. This basically means when your condition has stabilized and you are strong enough to drink and eat on your own, and walk short distances.

GOING HOME

Going home following your transplant can be exciting as well as frightening. As wonderful as it is to return to your home, assuming responsibility for your own well-being may be worrisome. We will help you with the entire transition.

Before you are released from the hospital, you will participate in an educational Discharge Planning class with your Transplant Nurse Coordinator. He or she will walk you through your medications, including what they are and when to take them (and tips to help you keep it all straight!), and how to care for your home testing equipment like your spirometer (details below). You’ll be given guidelines for exercising and returning to other day-to-day activities, and a sheet to take home for quick reference on all these subjects (see Discharge Guide).

The Transplant Nurse Coordinator will be available, via phone, to answer any questions you may have. This phone number and many other important contact numbers are listed on your Discharge Guide. Feel free to call them at any time; there is no such thing as a “silly” or “dumb” question. Remember, if you thought to ask it, someone else probably did too.
RECOVERY AND REHABILITATION

You are now officially in the longest phase of your transplant – the recovery and rehabilitation that will last for the duration of your life.

This will include physical activity, home testing/monitoring of certain lung functions, a strict regimen of medication, a series of routine follow-up appointments with your transplant team, and ongoing attention to your body’s “signals,” to ensure that you stay healthy and your new lungs continue to work with your body.

Physical Activity

Physical activity and progressive exercises are absolutely necessary for your complete recovery. Therefore, a full program of activity will begin while you are still in the hospital. The Physical Medicine and Rehabilitation Department (PMR) will visit you while you are still in the hospital to help plan an exercise program for you. As soon as you are able, you will be encouraged to walk on a daily basis, more and more frequently as you get stronger.

When you go home, you are to continue to walk daily, gradually increasing the distance covered. Many people find a stationary bike or treadmill to be a convenient adjunct to their walking schedule, especially in bad weather. Upper body exercise is limited to range of motion activities until the surgical incision is healed.

Shortly after discharge from the hospital, you will be expected to enter into a full rehabilitation program. This program is available five days a week at Temple. If you are too far from Temple to participate in our program, we will try to help you find one near your home.

For the first two months after surgery, you must ride in the backseat of any car you are in, with the seatbelt fastened across your chest. This is to avoid the serious impact an airbag deployment in the front seat would have on you in the event of an accident. You may begin to drive in approximately eight weeks.

Sexual activity may be resumed at any time during your recovery. Occasionally, long periods of illness and complicated drug regimens impair sexual activity. If you find this to be an issue, please let the doctors know, as there are specialists and therapies that can help.

Please note that each stage of increased activity should begin only after a member of the transplant team gives approval for that particular activity.

Home Testing

Every day, you will be recording many measurements, which will serve as indicators of your health. These include your weight, blood pressure, temperature, fluid
intake, and, if necessary, blood sugar. Each of these tests tells us something important about your post-transplant condition. Ideally, all the data you collect will stay within safe ranges, but we will teach you how to perform the tests and recognize any dangerous changes that you should report to your transplant team.

One very important test you’ll do at home involves use of a spirometer. A spirometer is a small device into which you blow air, and it will give you two readings: your forced vital capacity (FVC) and your forced expiratory volumes at one second (FEV1). Repeat the test three times in a row, recording only your best score for each. If your reading drops, it’s a signal to call the Transplant Nurse Coordinator at (215) 707-1722, as you may be in the early stages of an infection or organ rejection. See Infection and Rejection section.

The spirometer is expensive, running approximately $400-500. Some insurance companies will help you pay for it, but you need to be prepared to purchase it, as it is a vital part of monitoring your health on a daily basis.

General Guidelines

General guidelines for many day-to-day activities, as well as traveling issues, are outlined at the end of the General booklet (see “General Guidelines for Life After Transplant” in the back of your General booklet). Please read these, as they answer many frequently asked questions about your daily life at home.

DETECTING ORGAN REJECTION AND INFECTION

Organ rejection and infection are the most common causes of transplant failure, particularly in the first year after surgery. We will help you learn to catch the signs of potential rejection and infection at the earliest possible stage.

Organ Rejection

Rejection is basically your body’s way of fighting off anything that is different from itself. When your body recognizes foreign tissue (i.e., a transplanted organ), it sets off an immune reaction, which releases specialized blood cells that travel through the blood stream and eventually reach the transplanted organ and try to destroy it. If allowed to continue, the transplanted organ would function poorly, eventually failing entirely.

After your transplant, you will be prescribed a number of medications (called immunosuppressives), many of which are designed to keep your immune system from rejecting the new organ.

Each of the drugs has a specific job designed to interrupt and/or prevent either the recognition or activation phase of the immune reaction, so you must remember to take each one exactly as prescribed.
Even though you will be on these immunosuppressives, it is expected that most lung transplantation recipients will experience at least one episode of rejection, which requires additional treatment, usually involving a trip to the hospital. This can occur at any time following transplantation but is most likely to happen early in the first year. You will be asked to keep a daily watch on your personal health, religiously keeping up with your home testing and hospital follow-up visits so that you can detect the symptoms or indicators of infection or rejection as early as possible.

Symptoms that should be reported include:
- low-grade fever
- cough
- difficulty breathing
- vomiting or nausea
- a reduction in your spirometry reading (see “Home Testing”)

If rejection is detected, treatment is begun immediately. Treatment consists of high dose steroids, usually administered over a three-day period. Adjustments may also be made to your other prescription medications. This process rarely requires hospitalization, and is most often carried out easily and conveniently at home. In the majority of cases, the steroids successfully stop the rejection. In the unlikely case that you need further treatment, you may need to be hospitalized so the transplant team can monitor you.

Infection

The immunosuppressive medications you will be taking will protect your new lung(s) by making your body’s defense system weaker, which will also make you more prone to infection. To help protect you from infections during the first weeks after surgery, visitors and staff will need to wash their hands prior to entering your room. They will also be asked to wear a face mask while visiting you. No flowers should be placed in your room after surgery, as micro-organisms have been found to grow in the water and soil of some plants. Family and friends can help brighten your room with pictures, cards, and/or balloons instead.

In the months and years that follow, infection will continue to be a concern, as the immunosuppressive medications that you will be taking actually put you at greater risk for developing infections.

As we discussed in other sections, you’ll be monitoring your health very closely on a daily basis for the rest of your life. Symptoms of infections are very similar to those of rejection. They include:
- low-grade fever
- change in color or amount of sputum
- persistent coughing
- difficulty breathing
- a reduction in your spirometry reading (see “Home Monitoring Diary”)
MEDICATIONS

You’ll be taking several medications daily, each on a different schedule. Your Transplant Nurse Coordinator will walk you through each medicine and how/when to take it during your Discharge Training, and will provide you with a chart to help you keep it all straight (see “Medication Chart”).

The medicines fall into three main categories: immunosuppressants, to help prevent rejection; antivirals/antibacterials, to help prevent infection; and various drugs to counter the side effects of the immunosuppressants.

Listed below are descriptions of the medicines you will most likely be taking and their side effects. Tell your doctor immediately if you start feeling these side effects and he or she may be able to prescribe additional medicines to help alleviate those symptoms. Never stop any of your medicine without calling your doctor first.

YOUR RESPONSE TO MEDICATIONS WILL BE HIGHLY INDIVIDUALIZED. REMEMBER THAT NOT ALL SIDE EFFECTS OCCUR IN ALL PEOPLE. IT IS IMPORTANT TO REPORT ANY UNUSUAL SYMPTOMS TO THE TRANSPLANT TEAM.

Cyclosporine (trade name: Gengraf, Neoral) or Tacrolimus (trade name: Prograf), Azathioprine (trade name: Imuran) or Mycophenolate Mofetil (trade name: Celcept), and Prednisone are the most commonly prescribed. Your Transplant Nurse Coordinator will detail those for you.

**Cyclosporine (or Tacrolimus)**
This is a strong immunosuppressant medication taken twice a day, every day, to prevent rejection. It changes the immune system by inhibiting your T-cells, the blood cells that cause rejection. Cyclosporine is available in a liquid or capsule. You will take this drug for the rest of your life. The dosage will start out high and be reduced gradually over time.

The most common side effects associated with these drugs are:

**Hypertension (high blood pressure)** – Approximately 80% of transplant patients treated with Cyclosporine develop high blood pressure. This cannot be corrected by changing the dose. You will be taught how to check your blood pressure at home. High blood pressure medication will be prescribed for you if necessary. Exercise and weight control are very helpful in controlling this form of hypertension.

**Kidney dysfunction** – The most serious potential side effect of Cyclosporine is kidney dysfunction. Kidney function is monitored at every outpatient visit by means of a blood test, and the dose of Cyclosporine is adjusted according to your biopsy results and your kidney tests.
Hand tremors – Hand tremors are a common side-effect of Cyclosporine (Gengraf, Neoral) or Tacrolimus (Prograf), but are usually more severe with higher doses, and will lessen over time as your dosage is reduced.

Excessive hair growth – Cyclosporine does not grow hair where it was never intended to be, but thickens and darkens existing hair. For female patients, this may be a cosmetic problem, easily managed with facial depilatories (hair removers).

Swollen and bleeding gums

Headaches

Burning and prickling sensation of hands and feet

Sinusitis (stuffy sinuses)

Prednisone
Prednisone is a steroid that functions as an immunosuppressant, as well as an anti-inflammatory. It is used on a daily basis along with Cyclosporine to prevent rejection. Prednisone is available in tablet form.

The possible side effects of steroids include:

Diabetes mellitus – Prednisone may cause or worsen increased blood sugar or other symptoms of diabetes. Increased blood sugar is treatable. You may be placed on a calorie-restricted diet. Insulin or other medications may be prescribed.

Sodium retention and fluid retention – Prednisone may cause your body to retain water and to develop some fatty tissue in the cheeks, upper back, and abdomen resulting in weight gain. Weigh yourself daily. A diet and/or water pill may be prescribed to lessen your fluid retention.

Calcium loss from bones – A calcium supplement may be prescribed for you.

Fragile skin – Prednisone may cause your skin to bruise more easily and heal slowly. It may be more sensitive to the sun and be more prone to acne. Take care of your skin by washing it with soap and water and wear sunscreen.

Mood swings – While taking large doses of Prednisone, you may notice that your moods become more intense. As your dosage is lowered, this side effect probably will decrease or disappear.

Stomach irritation – Always take Prednisone with food or milk.
**Imuran (or CellCept)**

Imuran (Azathioprine) is another immunosuppressant medication, which is used with Cyclosporine and Prednisone to prevent rejection. It is available as a tablet.

The most common side effects are:

**Stomach irritation** – If it upsets your stomach, try taking it with food.

**Liver damage** – Liver function is monitored at outpatient visits by means of a blood test. Your dosage will be adjusted if any liver damage is found.

**Low white blood cell count** – Your blood tests will be monitored for this change, and your dosage will be adjusted if a decrease is found.

Antivirals/antibacterials help prevent infection by viruses. This is particularly important right after surgery, when you need all your energy to recover. You will most likely be prescribed one of two antivirals: Acyclovir or Valganciclovir.

You may also be prescribed vitamins, supplements or other medicines to help with the side effects of the various drugs in your regimen.
FOLLOW-UP SCHEDULE WITH THE HOSPITAL

Every so often, you’ll be going back to the hospital for a number of follow-up exams and tests. Sometimes you’ll be seen by the doctor, other times you’ll just be going to the outpatient lab for blood work and/or a bronchoscopy.

A bronchoscopy is an examination of the lungs through a small scope. Before the bronchoscopy procedure begins, you will be given medication that will relax you and make you drowsy, along with medication to numb your throat and nose. A tube will then be inserted through your nose and down into your lungs, where samples of tissue are obtained (biopsy). Examination of the tissue will show if there is any rejection or infection present.

All this is to check on your progress and to avoid or intercept the infection or rejection of your organ. You’ll be keeping a close eye on the symptoms of infection or rejection yourself through your daily home testing. However, some patients may have no symptoms during a rejection episode and would be unaware that it is occurring. The bronchoscopy will catch any signs of illness that don’t show up in home testing.

The test is always scheduled for early in the morning (for which you’ll be asked to eat nothing after midnight the night before, except your medications), and you can expect to remain in the short procedure unit for several hours. Because you will be given a mild sedative, you will need someone to drive you home from the hospital.

These tests are done quite often during the first year. During the first three months after transplant, you can expect to have a bronchoscopy as often as every two to four weeks. After the first three months, the time between bronchoscopies may decrease to once every third month.
RESOURCES

At Temple University Hospital:
Lung Transplantation Office
Phone (215) 707-1722
Fax (215) 707-6867

ORGANIZATIONS

One of the quickest and easiest ways to find the answers to your questions about organ transplantation and donation is by looking on the Internet. If you don’t have Internet access at home, try your public library. You can also ask your transplant team if you can access the Internet from the hospital.

The UNOS Patient Web Site
www.transplantliving.org
This site can help patients through the transplant process. It includes information about the waiting list, Organ Procurement and Transplantation Network (OPTN) policies, the matching process, patient and professional profiles, and resources for information.

The Scientific Registry of Transplant Recipients (SRTR) University Renal Research and Education Association (URREA) Web Site
www.ustransplant.org
This site contains information about the organization, what it does, transplant statistics, and research resources.

The OPTN Web Site
www.optn.org
This site has been created to educate, inform, and clarify some of the complexities of the organ transplant process for all those affected by and/or interested in organ donation and transplantation.

The Federal Government Organ Donation Web Site
www.organdonor.gov
This site was created by the Health Resources and Services Administration of the U.S. Department of Health and Human Services. Patients can find answers to frequently asked questions, public affairs and legislative updates, links to other Web sites, and a glossary. There is also a section addressing myths about organ donation and information about various educational events and grant programs. You can download organ donation cards and brochures and order organ donation pins and bumper stickers to use as handouts for community activities to promote organ and tissue donation.
Documentation of Discharge Teaching  
for Lung or Heart/Lung Transplant Patients

1. Medication Teaching
   ❑ Use of pill box
   ❑ Review of medication schedule
   ❑ Medication uses and possible side effects
   ❑ Notification of lung transplant office before taking any other prescribed or over the counter medications

2. Immunosuppression Precautions
   ❑ Wear mask in hospital, and in crowds for the first six months
   ❑ Frequent hand washing
   ❑ Cleaning of micro spirometer and other medical equipment
   ❑ DO NOT clean cat litter box or dig in dirt
   ❑ DO NOT fly in planes for the first 6 months
   ❑ Avoid saunas and swimming pools for six months

3. General Precautions
   ❑ No driving or riding behind automobile airbags for eight weeks post transplant
   ❑ Avoid anyone who may be sick
   ❑ Avoid children who have recently received live vaccine (i.e. varivax or MMR2)

4. Daily Home Monitoring
   ❑ Record daily spirometry (best of three) in log book
   ❑ Record daily temperature, blood pressure, and weight (same time) in log book

5. Hydration
   ❑ Drink ______ glasses of fluid per day

6. Daily Activity
   ❑ Get up and get dressed every day!
   ❑ Continue with home/outpatient rehabilitation as prescribed
   ❑ Increase ADL’s as tolerated

7. Sexual Activity
   ❑ Women of childbearing age must use contraceptives. The effects of many medicines on fetal growth are unknown

8. Contacting the Lung Transplant Team
   ❑ (215) 707-1722. Office hours 9:00 AM to 5:30 PM Monday through Friday. Please leave message with your number. Follow instructions on voice mail if your problem is urgent. Calls are answered within one business day. Call (215) 707-1722 if a problem arises when the office is closed. Identify yourself as a Lung Transplant Patient and ask the answering service to page the Transplant Nurse Coordinator on call.

9. Response to learning – Verbalization Re demonstration

   PATIENT:____________________________________________  FAMILY MEMBER:_______________________________________
   DATES OF TEACHING: ______________/________________/__________________/_________________
   TRANSPLANT NURSE COORDINATOR:__________________________________________________________________
Tips for Taking Your Medicines

Temple Transplantation Program

Use this as a guide to organize and maintain your medication schedule.

Tips about your medicines

• Learn everything you can about your medicines. Your physician, Transplant Nurse Coordinator, pharmacist, support group and educational seminars can help.

• Some of your medications may be available as generics, which means from bottle to bottle, they may look different and go by a different name. Be sure you can read the label on your medication bottles to confirm you are taking what you are supposed to be taking, and that you understand the directions.

• Capsules and time-release tablets should be swallowed whole and never crushed, chewed or opened—otherwise, a large dose can be absorbed too quickly.

• Avoid grapefruit juice, as it may interfere with your medications. Ask your pharmacist for information about your medications' interactions with other foods and other drugs.

• Do not change the dose, skip a dose, or stop taking your medications without your doctor’s approval.

• Some medications need to be refrigerated, especially liquid antibiotics. Check the directions on the bottle.

• Always check with your transplant team before taking any new medicines, even the ones you buy over the counter, including vitamins and herbal remedies.

• Wear a Medic Alert (or similar brand) bracelet or necklace that states you are a transplant recipient and you take steroids (if you do), in case you are ever in an accident and someone finds you unconscious. Some people may wish to engrave their bracelet with the Temple transplant center’s phone number.

• If any medicine changes odor or color, if it gets wet, or if it is soft, sticky, hard or cracked (and it shouldn’t be), it could have lost its effectiveness and should be replaced. Talk to your pharmacist about any changes in your medicines.

• If your insurance company does not require you to use a particular pharmacy, shop around. Prices can vary dramatically.

• Let your insurance company and transplant team know if you are having trouble paying for your medicines.

• Carry a list of your medicines and their doses in your wallet or purse. Share this list with your other doctors.

• Try to buy all your medicines from the same pharmacy. Many pharmacies keep a profile on their customers so that they can track whether or not a new drug will cause problems if taken with the patient’s other medications.

• Unwanted hair growth, caused by some medications, can be removed with shaving, waxing, or hair removal (depilatory) products.

• Limit your sun exposure and use a sunscreen.

• Do not take all your medicines at one time because it is more convenient. The doses are spread out to maintain the proper drug level in your body.
**Tips about organizing your medications**

To prevent your medicine regimen from interrupting your daily routine, plan ahead, organize your time and consider the following tips:

- Use tools to help organize your medicines, such as a pillbox that has individual compartments labeled with the days of the week. Please be aware, some medications cannot be put out ahead of time.
- If there are no children or grandchildren in the house, clear plastic Ziploc bags labeled with days of the week and times of the day can help, but they must be kept in a safe place—away from children and pets who may think the contents are snacks.
- Use an alarm clock, watch or charts to remind you of the times for medicines.
- Ask your transplant team to help set up your medicine times to fit your schedule.
- Set up a time each week to organize your medicines for the whole next week.
- Get into a routine. Take your medications at the same time each day.
- Keep track of how much medicine you have left. Don’t ever run out, even one dose.
- Mark your calendar so you remember to reorder your medications ahead of time.
- At first, you may want to have a family member or friend help you sort out and reorder your pills.
- Keep your medication in a cool dry place, out of the sun and extreme heat.

**Tips on traveling**

- Always keep extra doses of your medicine with you when you travel in case you are delayed or miss a plane, train or bus.
- Keep your pharmacy’s phone number with you.
- Never pack your medications in your luggage; always carry them with you or they may get lost or be exposed to temperatures that are too cold or too hot.
- Mail-order pharmacies can ship your medicines if you are away from home for an extended period of time.
- Carry a letter (or prescription) from your doctor about your medicines in case you have any problems with customs when traveling overseas. You may be able to fill your prescription in a pharmacy at your travel destination.
- Prevent infection. Wash your hands often and thoroughly, especially before eating. This is even more important the first few months after your transplant, when you are taking higher doses of anti-rejection medication.

**What to do if you miss a dose:**

Call your Lung Transplant Nurse Coordinator at (215) 707 – 1722
Call your Heart Transplant Nurse Coordinator at (215) 707 – 3782

*Content is direct reprint from HRSA, pages 43-45, and UNOS, p 41.*
# Medication Chart:

**TEMPLE LUNG CENTER** (215) 707-1722 OR (215) 707-3336

<table>
<thead>
<tr>
<th>MEDICATION</th>
<th>ACTION</th>
<th>ROUTE OF ADMINISTRATION</th>
<th>DOSE</th>
<th>TIME SCHEDULE</th>
<th>SPECIAL INSTRUCTIONS</th>
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</table>
| Cyclosporine or Prograf | Anti-rejection | Capsule                  |      | 8 AM & 8 PM   | NEVER MISS  
Dose changes frequently-follow MD/RN orders not the bottle |
| Prednisone          | Anti-rejection | Pill                     | 20mg | 8 AM          | NEVER MISS  
Avoid sweet and salty food |
| Cellcept            | Anti-rejection | Capsule                  | 500 mg | 8 AM & 8 PM   | NEVER MISS |
| Valcyte             | Anti-Viral    | Capsule                  |      | 8 AM          |              |
| Mycelex             | Anti-fungal   | Dissolve in mouth        |      | 4 times a day  
After meals and before bed |
| Nystatin            | Anti-fungal   | Swish & Swallow          | 1 tsp | 4 times a day  
After meals and before bed |
| Bactrim DS          | Anti-biotic   | Pill                     | one  | 8 AM          | Only Monday, Wednesday & Friday. Drink 8 oz |
| Magnesium Oxide     | Supplement    | Over the counter Pill    | 400 mg | 8 AM        |              |
| Multivitamin        | Supplement    | Over the counter Pill    | one  | 8 AM          |              |
| Zantac              | Protects stomach | Pill                     | 150 mg | 8 AM        |              |
| Folic Acid          | Supplement    | Pill                     | 1 mg  | 8 AM          |              |
| Calcium&Vit D       | Supplement    | Pill                     | 500 mg | 8 AM, 12 PM  
& 8 PM  |              |
### Home Monitoring Diary

**TEMPLE LUNG CENTER (215) 707-1722 OR (215) 707-3336**

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