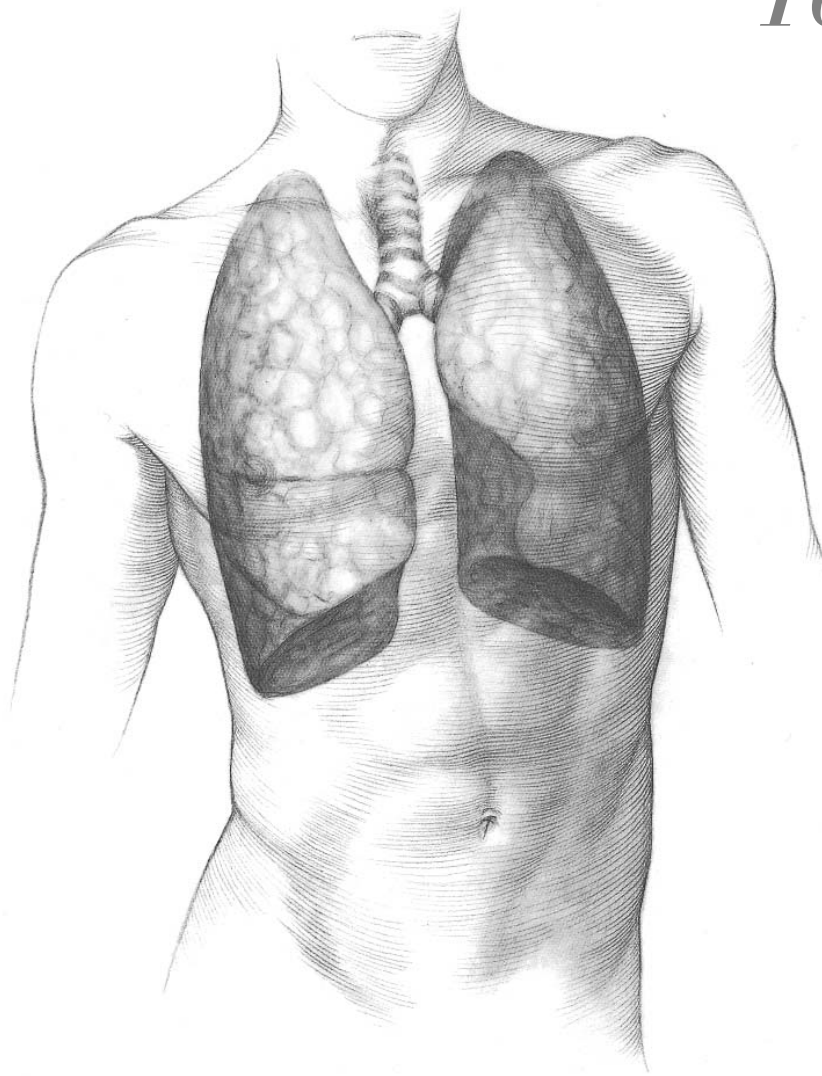


Lung Transplantation

a guide for patients

Part II



Duke Transplant Center
DUKE UNIVERSITY MEDICAL CENTER

Introduction

Congratulations! You have been listed for transplantation! While you wait for “the call,” you should begin to prepare for life after your transplant. This booklet will give you extremely important information, including specific guidelines on how to take care of your new lungs for the rest of your life.

It is very, very important that you learn this information. The transplant coordinators, doctors, and nurses will be thoroughly reviewing all of the material contained in this portion of the book with you after your trans-plant operation.

It is imperative that you understand every detail of your care before you are released from the hospital. You must know what medications to take, at what time, what amount, and for what reason. You must also know the signs and symptoms that could indicate problems with your transplant, how to watch for them, and how to report them.

You will also be responsible for monitoring your health at home and for keeping daily records. You must bring these records with you each time you come to the Lung Transplant Clinic for a follow-up appointment. This will allow us to monitor your condition along with you, and to be on the lookout for any problems that may occur.

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Your Medications

Immunosuppression

Immunosuppression is a concept with which you need to become familiar in order to understand your care. Your immune system is that part of you that is able to recognize when foreign substances enter the body. Throughout your life, your immune system has been fighting off infection by recognizing and destroying foreign matter such as bacteria, viruses, and fungi.

Your transplanted lung(s) are new and foreign to your body, and your immune system recognizes this. If something is not done to stop the process, your body's immune system will recognize your new lungs as foreign and soon begin to destroy them. Preventing this natural response of the body's immune system is called immunosuppression.

Tacrolimus, cyclosporine, prednisone, and azathioprine are some of the drugs that are used for immunosuppression. They are given to transplant patients in order to decrease the body's ability to recognize and destroy foreign substances. Without these medications, rejection of the lungs would certainly occur. It is therefore very, very important that you take these drugs exactly as prescribed for as long as you have the transplant. If you stop taking these medications, your body will reject the lungs.

Being on immunosuppressive drugs does mean that you will be at greater risk for developing infections. It is important, therefore, to take some sensible precautions to avoid infection whenever possible. We will be discussing these precautions later in this booklet.

Safety Information About Medications

Please observe the following precautions when taking your medications. For all medications, remember that medicines can be dangerous, even fatal, if taken accidentally by a child. Make sure your pharmacy has put your prescription medications in child-proof containers, and store all your medicines out of the reach of small children. In addition:

- **Take each medication exactly as prescribed.**
- **Keep all medications in their original containers** with labeling that shows the name, dosage and expiration date, or in the pill box provided by the Lung Transplant Pharmacist. Keep your medications in a dry place away from heat and direct sunlight.
- **Report any side effects** of medications to the transplant team right away.
- **Never change or skip a dose** of medication. Remember, if you stop taking your immunosuppressive medications, your body will reject the transplanted lung(s). If you ever forget to take your medications, call the on-call transplant coordinator as soon as you realize your mistake. Should you experience any vomiting that prevents you from taking your medications, or if you vomit immediately after taking your medications, call the transplant coordinator.

Other Medications

Do not take medications prescribed by other physicians until you check with us first. Many other drugs can interfere with your transplant medications. Certain medications can increase the side effects of transplant medications or decrease how well they prevent rejection. Please call your transplant coordinator about any new medications prescribed for you before you get the prescriptions filled.

Be cautious about over-the-counter medications, too. You may take Tylenol as needed for minor pains, and you may take Dulcolax or glycerin suppositories as needed for constipation. Please do not take any other over-the-counter medications without first checking with your transplant coordinator or physician.

Immunosuppressives and Anti-Infectives

Tacrolimus(also known as Prograf®)

Tacrolimus is an immunosuppressive drug which specifically stops the action of certain white blood cells that are involved in the rejection process. Tacrolimus is available in 0.5mg, 1mg, and 5mg capsules. Tacrolimus is taken twice daily, with the doses 12 hours apart. It is preferable that you take your doses at 10:00a.m. and 10:00p.m. Tacrolimus is best taken either one hour before or 2 hours after a meal.

- Grapefruit and grapefruit juice can increase the absorption of tacrolimus, which can lead to toxic levels in your body. Therefore, do not eat grapefruit or drink grapefruit juice.
- Each time you come for a Lung Transplant Clinic visit, we will be drawing blood for a tacrolimus level. This blood test must be performed before your morning dose of tacrolimus. Therefore, on clinic days, bring your tacrolimus with you so that you can take it as soon as the blood sample has been drawn.
- Do not allow yourself to run out of tacrolimus. Always keep at least two weeks' supply on hand.
- When traveling, do not pack tacrolimus in luggage that will be checked. Keep it with you in a carry-on bag or your handbag. Always have your tacrolimus with you!
- Store tacrolimus at room temperature (59 to 86 degrees).
- After your transplant you may receive tacrolimus under your tongue, but most patients start swallowing tacrolimus capsules before being discharged from the hospital. **Never** take tacrolimus caps under the tongue without consulting your transplant coordinator first.

It is important to periodically determine the amount of tacrolimus in your blood stream so that your tacrolimus dose can be adjusted to your individual needs. We will ask you to have a tacrolimus level measured at least monthly for the rest of your life. This blood should be drawn in the morning before you take your first dose of tacrolimus. The blood can be drawn by your local laboratory and results can be faxed to Duke. You will receive a letter to take to your local doctor and to your lab explaining the procedure for drawing the blood for the tacrolimus level.

Tacrolimus can interact with many other drugs, which can lead to increased or decreased amounts of tacrolimus in your body. Remember to check with the transplant team before starting any new medications.

TACROLIMUS SIDE EFFECTS

Unfortunately, there are side effects to any medication. The following may be side effects of tacrolimus. Please report to your transplant coordinator if you experience these or any other unusual symptoms.

Fine hand tremor: Some patients experience a trembling of the hands, especially in the first month. If this problem continues after that time, please notify your transplant coordinator. If your trembling is increasing, it could mean that your tacrolimus level is too high.

Headaches: Notify your transplant coordinator if headaches are severe or bothersome.

Hair loss: Some patients may notice some mild hair loss.

Increased glucose: Increases in your body's glucose (sugar) levels can occur. Some patients may need to take a pill to control their glucose levels. If glucose levels are especially hard to control, insulin shots may be necessary. You may be asked to monitor your glucose at home.

High blood pressure: If this becomes a problem, it will be treated with an appropriate medication. You will be asked to monitor your blood pressure daily at home. Record sheets are included in this booklet.

Nausea and diarrhea: Stomach side effects can occur with tacrolimus, especially in the first month. Notify your transplant coordinator if you experience these symptoms.

High potassium levels: You may need to restrict the amount of potassium in your diet. The transplant coordinator will let you know if you are experiencing this rare side effect.

Altered kidney function: If too much tacrolimus is given for too long a time, the drug can be harmful to your kidneys. You will usually not experience any symptoms, but your blood level of creatinine, which is a measure of kidney function, may become elevated. The transplant team will follow your lab work and tacrolimus levels closely, and will adjust your tacrolimus dose accordingly. Treatment of altered kidney function as a result of too much tacrolimus usually involves reducing the tacrolimus dose.

Cyclosporine (also known as Neoral® or Gengraf®)

Cyclosporine is an immunosuppressive drug that is very similar to tacrolimus. We use cyclosporine instead of tacrolimus in patients who have special immunosuppressive needs.

Cyclosporine is available in two forms, liquid and capsules.

The **liquid** preparation is in an olive oil base. It comes in 50 milliliter bottles and each milliliter contains 100mg.

- The liquid cyclosporine dose must be measured with the graduated dropper that comes with each bottle—accuracy is vital.
- Liquid cyclosporine can be mixed with orange juice or apple juice in a glass or plastic container (not styrofoam). Do not mix with grapefruit juice.
- Once your dose is mixed, drink it immediately. Rinse the container with extra juice and drink that to make sure you are getting the entire dose.

Cyclosporine capsules are available in 2 strengths: 100 milligram and 25 milligram. These gelatin capsules contain the cyclosporine in a small amount of vegetable oil.

- Do not remove the capsules from the foil package in which they are wrapped until just before you need to take them. If the capsules dry out, they shrivel up like raisins and the cyclosporine will leak out.
- It is very important that you take your cyclosporine at regular intervals, twelve hours apart. We prefer that you take your doses at 10:00am and 10:00pm.
- Each time you come to the Lung Transplant Clinic, we will draw blood for a cyclosporine level. On these days, bring your cyclosporine with you so that you can take it as soon as the blood sample has been drawn.
- Do not allow yourself to run out of cyclosporine, and when traveling, take into account the considerations that were mentioned with tacrolimus.
- Like tacrolimus, cyclosporine interacts with a lot of medications. Check with your transplant coordinator before starting any new medications.
- Cyclosporine side effects are similar to those mentioned with tacrolimus. There are a few side effects that cyclosporine has that tacrolimus does not have, such as hair growth and gum swelling. Hair growth on the face, arms and body is common with cyclosporine, but usually not a problem. Good dental hygiene is necessary to keep gums in good shape. You should brush your teeth at least twice daily with a soft toothbrush, and use dental

floss daily. We recommend that you see your dentist every 6 months. Please let your transplant coordinator know if you experience gum swelling.

Imuran (also known as Azathioprine)

Imuran is another immunosuppressive drug that works in a complex way to prevent rejection, partly by decreasing the number of white blood cells that could cause rejection. Imuran comes in pill form, and is taken all at one time.

It should be taken at about the same time every day.

The dosage of Imuran will depend on your weight and your white blood cell count. We will monitor your white blood cell count closely, both while you are in the hospital and after you are discharged. If your white blood cell count ever falls too low, we will decrease your Imuran dose.

Side effects of Imuran include decrease in white blood cell count and hair loss (this is generally mild and temporary).

Cellcept (Mycophenolate mofetil)

Cellcept is an important immunosuppressant drug that comes in 500-milligram and 250-milligram capsules. It is sometimes used instead of Imuran in patients who have special immunosuppressive needs. Like Imuran, it works by decreasing the white blood cells that cause rejection.

The normal dose of Cellcept is 1,000 mg every 12 hours. Most patients start out taking 250 mg or 500 mg every twelve hours and increase the dose every three days until they reach the dosage of 1,000 mg every 12 hours.

We will monitor your white blood cell count closely as long as you are taking Cellcept. If your white blood cell count falls too low, we will decrease your Cellcept dose.

Side effects of Cellcept include decrease in white blood cell count and stomach upset such as nausea, vomiting, and/or diarrhea. Taking Cellcept **with food** may be helpful if you experience stomach upset.

Prednisone

Prednisone is another drug that helps to prevent rejection by suppressing the body's immune system. Prednisone is often called a steroid. You will start out taking a fairly high dose of Prednisone, but this dose will be tapered rapidly to a low maintenance level to avoid side effects if possible.

Prednisone Side Effects

Not every patient experiences all of these side effects, but they do occur frequently enough that we want you to be aware of them. Most of the time, the side effects are dose-related. In other words, as your dose is decreased, the side effects should become less troublesome. Side effects of Prednisone include:

Increased appetite: It is very important that you watch your calories and maintain your ideal weight.

Increase in blood sugar level: You may need to avoid concentrated sweets.

Change in appearance: You may notice a rounded face, larger abdomen, and thin skin which may bruise easily.

Increased stomach acid (which may lead to ulcers): Always take your Prednisone with food.

Increased sweating: This often occurs at night.

Acne on the face, back and chest: Wash your skin two to three times a day and keep the area as clean and dry as possible. If acne becomes problematic, an antiseptic wash followed by application of 10-percent benzoyl peroxide ointment is usually helpful.

Muscle weakness (particularly in the legs): Exercise! Walking is one of the best ways to strengthen leg muscles. Increase your exercise every day, and vary your routines.

Eye problems: Inform the transplant team of any blurring or other changes in vision. We will examine your eyes for cataracts.

Joint problems: Inform the transplant team of persistent joint pains; you may need x-rays of your joints.

Delayed wound healing.

Emotional changes: You may notice an increase in restlessness or moodiness while on high doses of Prednisone.

Acyclovir (Zovirax)

Acyclovir works to prevent infection with the herpes virus and spread of the virus. It also helps to inhibit the chicken pox virus and the Epstein-Barr virus, which can cause mononucleosis and certain types of lymphoma. Acyclovir is supplied in 200-milligram and 800-milligram capsules. Take whatever dose is prescribed for you. A typical dose is 200 mg three times per day.

Side effects of Acyclovir may include headache, nausea and vomiting, diarrhea, and dizziness. Report any side effects to your transplant team.

Ganciclovir/Valganciclovir

Ganciclovir is a drug which also inhibits herpes viruses as well as the CMV (cytomegalovirus) virus. If a person is on Ganciclovir, he or she will not take Acyclovir. Usually given intravenously once or twice daily, Ganciclovir is typically administered in the hospital, but may be received at home with

the assistance of a home health care agency. Dosage is determined by body weight.

Valganciclovir (Valcyte) is an oral tablet form of ganciclovir that is usually taken once or twice per day. Instead of taking ganciclovir intravenously, some patients are able to take valganciclovir by mouth. Valganciclovir should always be taken with a **full meal**.

White blood cell counts need to be monitored at least every two weeks while Ganciclovir or Valganciclovir is being given. The length of time the drug is given will depend on individual circumstances, which your physician or transplant coordinator will explain to you.

Nystatin Suspension

Nystatin is a drug used to prevent fungus infections in the mouth and throat. Nystatin suspension is a liquid which you swish in your mouth and then swallow. This drug should be taken four times a day: after meals and at bedtime. Do not rinse your mouth for at least 15 minutes after swallowing Nystatin. If you wear dentures, they should be removed prior to taking this medication.

Septra DS (Bactrim DS, TMP-SMX)

Septra is an antibiotic which is used to help prevent bacterial infections. It is also used to prevent the development of a certain type of pneumonia called pneumocystis carinii pneumonia, which sometimes develops in people who are taking immunosuppressive medications. If you are allergic to sulfa, you should not take this medication.

Septra is started one week after your transplant. You will take one Septra DS (double strength) tablet a day on Monday, Wednesday, and Friday only.

Other Medications

Lasix (Furosemide)

Lasix is a diuretic, or “fluid pill”, used to treat swelling and high blood pressure. Lasix will cause you to eliminate excess fluid by increasing your urine output. The dose of Lasix is tailored to each patient. When you are first discharged from the hospital, a certain dosage will be prescribed for you, but we will need your assistance in making sure that the dosage is correct.

You will be asked to weigh yourself daily. A gain or loss of two or more pounds overnight indicates a change in body fluid, rather than true weight gain. If your weight increases by two or more pounds overnight, or if you have swelling in your lower legs and feet in the late afternoon, you are retaining fluid. If your weight decreases by two or more pounds overnight, if you notice dizziness when standing, or if you are constantly thirsty, then you are eliminating too much fluid. Please notify the transplant coordinator if you experience any of these symptoms.

Potassium Chloride

Potassium chloride is a supplement sometimes given to patients who are taking Lasix. Lasix causes potassium to be eliminated in large amounts from the blood. The dose of potassium chloride is individualized to each patient according to his or her potassium level. It is supplied in powder, liquid, and tablets.

Zantac, Axid, Prilosec, Prevacid, Nexium, Protonix

These medicines are used to decrease the amount of acid in your stomach. You are at risk for developing an ulcer and heartburn because you are taking Prednisone. Taking one of these medicines will reduce this risk. The usual doses of these medications are as follows:

Zantac: One 150-mg tablet twice a day.

Axid: One 150-mg tablet twice a day.

Prilosec: One 20-mg tablet per day.

Prevacid: One 30-mg tablet per day.

Nexium: One 40-mg tablet per day.

Protonix: One 40-mg tablet per day.

Heartburn that occurs despite being on one of these medications should be reported to your transplant coordinator.

Antihypertensives

These are drugs which are used to control high blood pressure. You may or may not be on an antihypertensive, depending on your blood pressure measurements. Cardizem is an antihypertensive frequently used for transplant patients.

Metered Dose Inhalers

Albuterol and Atrovent metered dose inhalers are often used after a lung transplant to help keep the airways open and make breathing easier. The usual dose of these inhalers is two puffs of each, four times a day. Inhalers may be discontinued relatively soon after transplant if they are not helpful.

Metoclopramide (Reglan)

This drug comes in 5-mg and 10-mg tablets. It is usually taken four times a day, about 30 minutes before each meal and at bedtime. Reglan helps with the normal movement of your stomach and intestines. Many patients have problems with nausea and reflux after lung transplantation, and taking reglan may help with these symptoms.

Magnesium Oxide (MagOx)

Because Cyclosporine and Prograf can cause excess loss of magnesium through your kidneys, many patients will need to take MagOx for several months after lung transplantation. MagOx comes in 400-mg tablets, and the dosage is determined according to individual needs.

MagOx should not be taken within 2 hours of taking tacrolimus or cyclosporine.

Managing and Avoiding Complications

Rejection

Rejection of your transplanted lung can occur at any time following your surgery. Episodes of rejection most commonly occur during the first month of transplant. Try not to become too alarmed if you are told that you are experiencing rejection. Episodes of rejection are expected, and other than taking your immunosuppressive medications, there is nothing you can do to prevent them from happening.

Rejection is easily treated if it is detected early. For this reason, it is important for you to be able to recognize signs and symptoms of rejection. These include:

fever;

shortness of breath;

decreased exercise tolerance; and/or

decrease in FEV1 and FVC (these measurements will be discussed in greater detail in another section of this manual).

Very often, rejection will occur without any symptoms that you can detect. For this reason, we will biopsy your transplanted lung at regular intervals. Lung transplant biopsies will be discussed in another section of this manual.

Treatment of rejection usually consists of three daily doses of intravenous Methylprednisolone. This drug is also known as Solu-Medrol, and is an intravenous form of Prednisone. If you are not feeling well, you may be admitted to the hospital to receive the Solu-Medrol. However, if you are having no symptoms, we will arrange for a home care company to give you your Solu-Medrol at home.

When you have received the third dose of Solu-Medrol, we will increase your dose of Prednisone and taper it by five milligrams daily until you are back to baseline. If rejection is extremely severe, or if it persists after the above treatment, a preparation called Rabbit Antithymocyte Globulin (RATG or Thymoglobulin) may be used. We will discuss this therapy in detail with you if it becomes necessary for you to receive it.

Infection

Your immune system is the part of your body that is responsible for fighting infection. When this system is weakened by the immunosuppressive drugs in order to prevent rejection of the transplanted lung, you become more susceptible to infections. Your susceptibility to infection is directly related to the amount of immunosuppression that you are receiving at any given time.

The highest level of immunosuppression is immediately after the transplant operation, and isolation precautions are most strict at that time. Everyone who comes into your room will be required to wash their hands thoroughly in order to prevent transfer of bacteria, viruses and other infection-causing microorganisms to you.

Cytomegalovirus (CMV) Infection

Cytomegalovirus (CMV) is a virus that is very common in the general population. It does not usually cause problems in healthy people, but can cause very serious illness in transplant patients whose immune systems are weakened by immunosuppressive drugs. The risk of CMV infection is especially high during the first few weeks after transplantation, when larger doses of immunosuppressants are needed. Most patients will be given ganciclovir, as previously described, during this time to try and prevent CMV infection.

CMV infection can occur at any time after transplantation, and is easily treated if detected early. For this reason, it is important for you to be able to recognize possible signs and symptoms of a CMV infection. These include:

- fever (may be low-grade and cyclical—e.g., fever in the morning that is gone by afternoon)
- shortness of breath
- decreased FEV1 and FVC
- extreme fatigue
- muscle and joint aches
- decreased white blood cell count

Often, CMV infection will occur without any symptoms that you can detect. For this reason, we will routinely check for CMV infection when you come to clinic with a blood test

Often, CMV infection will occur without any symptoms that you can detect. For this reason, we will routinely check for CMV infection when you come to clinic with a blood test and/or biopsy or culture.

Treatment of CMV infection usually consists of a 14- to 21-day course of ganciclovir, given intravenously twice a day. We will usually arrange for you to receive this treatment at home with the assistance of a home care company. Ganciclovir capsules may be used in some circumstances.

Obliterative Bronchiolitis (O.B.)

Obliterative bronchiolitis (O.B.) is a term that refers to deterioration in the function of a transplanted lung(s) that doesn't respond to currently available medical treatment. New therapies, however, are being developed for this condition and may be available soon. This condition does not affect every lung transplant recipient, and its cause is not fully understood. It may be related to repeated infections or rejection episodes.

If you develop this condition, we will do our best to stabilize and maintain the function of your transplanted lung(s) for as long as possible. This usually involves changing some of your immunosuppressive drugs. You may be considered for another lung transplant in certain circumstances. It is of utmost importance that you:

- take the best possible care of yourself;
- report any signs or symptoms of rejection and infection as early as possible; and
- carefully follow the instructions of the lung transplant team, which are designed to help you avoid the development of O.B.

Common-Sense Precautions

Infections in a transplant patient can be quite serious, even life-threatening. It is therefore very important that you take some precautions to prevent infection whenever you can.

One of these precautions is to avoid large crowds, where someone with a contagious illness could be present. This does not mean that you must always stay at home; it just means using common sense. For example, plan to eat out when restaurants are not crowded, for an early lunch or dinner. Matinee showings of movies are rarely crowded, but later shows often are.

It is also important to avoid a crowd in your own home. If you are staying in a small apartment after transplant, do not invite guests and family members to come out and see you right away. It is best not to have a large number of house guests at any one time for at least two months after your transplant.

Around the House

Light housekeeping will not harm you and is a very good way to get back into shape. It is important, however, to observe the following safety precautions.

- Do not empty vacuum cleaner bags, change furnace filters, or clean very dusty areas such as a garage or attic.
- Do not lift more than five pounds for the first six weeks after your surgery.
- Avoid inhaling strong fumes from some cleaning products such as ammonia or bleach.
- Please wear masks and gardening gloves if you enjoy gardening or working with plants and flowers, since many infectious organisms live in the soil.

Pet Care

If you have always enjoyed having a pet or pets in the house, there is no reason for that to change. Here, too, you should take care to avoid contact with infection-causing organisms.

- Keep your overall number of pets to a minimum. Just as having too many people in one house is unhealthful, so is having too many pets.
- You should wear a mask and gloves when changing cat litter boxes, cleaning up after birds, or cleaning pets' ears. Better yet, get someone else to do these tasks.
- Be sure to take the pets to your veterinarian for their shots and check ups.
- Pets should not be allowed to sleep on your bed.
- Your mattress should be vacuumed at least once a month. This is a good idea even if you don't have pets.

Avoiding Colds and the "Flu"

Now that you have a transplant, you will probably get the same number of colds and flu-like illnesses that you always did, but, understandably, these will cause you more concern than they did before. For both your physical and emotional health, therefore, you should do all you can to prevent colds and flu. This is largely a matter of careful hygiene and common sense.

- You and all of your family members should get a flu shot as soon as they are available each year. This is usually in October. If you have small children, discuss the flu shot with their pediatrician.
- It is very important to wash your hands very frequently, since most infections travel hand-to-hand rather than through the air.
- Do not get into the habit of eating after people (out of bags or bowls of popcorn, for example), drinking after people, or reusing a bathroom glass.

Despite your best efforts, you will catch a cold or flu from time to time. When you do, you should call the transplant coordinator to see if you need antibiotics. Should symptoms of a cold linger, or if you develop a fever, symptoms of chest congestion, or a productive cough, be sure to call the transplant coordinator right away. The lung is the most susceptible site of infection after your transplant, and you may need a chest x-ray.

First Aid and Hygiene

The natural ability of your body to heal wounds will be slowed down because of the immunosuppressive medication.

- Clean any cut or injury and keep a clean, dry dressing on the wound.
- If healing is prolonged or if you experience pain, swelling, redness, or other signs of infection, notify your transplant coordinator right away.
- Notify the transplant coordinator if you notice any unusual rashes, blisters, or other lesions on your skin.

Good care of your teeth and gums is also very important, since your mouth can be a major source of infection.

- Visit your dentist every six months to avoid tooth and gum disease.
- Contact your dentist prior to your appointment in order to obtain an antibiotic before having any dental work done. Remember to check with your transplant coordinator to make sure that the antibiotic prescribed by your dentist is compatible with your Cyclosporine.
- Notify your transplant coordinator if you notice sores, ulcers, or white patches in your mouth or throat.

Symptoms of Infection

If you experience any of the following symptoms of infection, you should notify your transplant coordinator immediately. As always, if there is ever a question, please call and ask!

Temperature greater than 100°F or 38° C

Productive cough, change in color of sputum, or shortness of breath

Sores, blisters, or lumps

Chills or shaking episodes of fever

Flu-like symptoms or severe cold symptoms

Drainage or swelling from a cut or wound

Nausea, vomiting, or diarrhea that is severe and prolonged (lasting more than 24 hours)

Increase in fatigue and decrease in exercise tolerance

Burning on urination, or very frequent urination

Decrease in FEV1 and/or FVC by 10 percent in a 24-hour period, or a downward trend in FEV1/FVC results over three days or more

In addition to increasing your risk of infection, the immunosuppressive medications may increase your risk for developing a cancer. For this reason, you should always use a sunscreen when outside for any prolonged period. Females should do monthly breast self-examinations, and have regular Pap smears and mammograms. All patients should follow the guidelines recommended for the general population for cancer prevention and screening.

Exercise and Nutrition

Pulmonary Rehabilitation

While you are in the hospital, a major part of your recovery will include vigorous physical therapy. The average lung transplant patient no longer needs oxygen by two weeks after the operation, and is able to walk one mile per day by two to four weeks after the operation. The average patient is discharged from the hospital one to four weeks after the transplant operation. Some patients will stay longer or shorter, based on what is best for them. It is normal to compare your situation with that of other lung transplant recipients, but everyone is different, so do not worry if your situation differs from theirs.

Every lung transplant patient is required to participate in the outpatient pulmonary rehabilitation course offered by the Duke Center for Living. The Center for Living is an outstanding exercise facility located very close to Duke Hospital. Its Intensive Pulmonary Rehabilitation Program lasts for approximately four and one half weeks (23 sessions), and meets from 12:30 p.m. to 4:30 p.m. Monday through Friday. The pulmonary rehabilitation staff consists of physical therapists and respiratory therapists who will work with you both individually and within a group to exercise in the proper way.

Prior to beginning the course, you will undergo an exercise test to determine the level of activity at which you should begin. In addition to exercise sessions, classes are offered on various topics of interest related to your lungs.

At the end of the course, you will undergo another exercise test so that we can see the progress that you have made. All patients are given a home exercise program upon completion of the course, and exercise video tapes may be purchased if desired. We expect you to continue a program of regular exercise for the rest of your life. Staying in shape is not easy, but exercise can prevent some of the side effects of your medications, and is one of the best things you can do to help yourself live a longer and healthier life.

Nutrition

Diet and nutrition are very important aspects of everyday care after a lung transplant. Some of the medications that you are taking can cause an increase in your appetite, high blood pressure, high blood sugar and fluid retention. Now that you have had your transplant and your condition has improved, it is important to begin a diet that promotes a healthy lifestyle.

The five basic principles for a healthful diet are discussed below. A dietician will talk with you in detail about how to follow a low-salt, low-fat, low-cholesterol diet—beneficial for everyone, but especially essential for you.

Restrict sodium (salt) intake.

Dietary sodium, or salt, can cause you to retain fluid and contributes to high blood pressure. Reducing the amount of sodium in your diet will help to prevent these problems. You should never add salt to food at the table. You should also avoid obviously salty foods, such as chips, salted nuts, and salted popcorn. Canned, processed, and preserved foods also contain high amounts of sodium. Get into the habit of reading labels for salt or sodium added in the foods that you buy in the grocery store.

Modify fat and cholesterol.

Reducing the overall amount of saturated fats and cholesterol in your diet is recommended in order to lower blood cholesterol levels. High cholesterol levels have been directly related to the development of heart and blood vessel disease because of fatty deposits that build up in the walls of blood vessels. Blood cholesterol levels can be lowered if polyunsaturated fats are substituted for saturated fats and cholesterol in your diet.

Even if your cholesterol level is normal, it is recommended that you decrease the fat content and the amount of cholesterol in your diet. Cholesterol and saturated fats are generally found in foods that come from animals. It is therefore wise to decrease your intake of foods such as red meat, egg yolks, and high-fat dairy products. Polyunsaturated fats, such as vegetable oils, should be substituted for saturated fats whenever possible.

Reduce concentrated sweets and sugars.

Prednisone is often associated with an increase in the level of sugar in your blood. Therefore, it is recommended that you decrease the amount of concentrated sweets and sugars in your diet.

Reach and maintain your ideal body weight.

The goal of any good diet is to reach and maintain your ideal body weight. Your dietitian will help you determine what is your ideal body weight, and will counsel you to help you gain weight if you are underweight, or lose weight if you are overweight. If you are already at your ideal body weight, a good diet will help you to maintain it.

Limit alcohol intake.

Alcohol intake should be limited to a rare cocktail or glass of wine only on special occasions. The medications you are taking will not react well with a large amount of alcohol over time.

Following these dietary guidelines is one way you can help prevent some of the complications related to your transplant medications and lead a longer, healthier life.

Sexual Activity

Sexual activity may be resumed after your incision heals, which is usually about six weeks after surgery. You should be careful at first to minimize the weight or strain that is put on your incision, especially over the breast bone in patients with a bilateral lung transplant. Pain is the best indicator that too much weight is being put on the incision.

In today's world, sex is sometimes a life-and-death matter, and everyone who is sexually active should take precautions to make sex as safe as possible. This is especially true for you, as the immunosuppressive medications that you are taking make you more susceptible to sexually transmitted diseases, as well as other infections.

The use of a latex condom is essential to safe sex. Using a condom does not guarantee that you will not get a sexually transmitted disease, but it is your best preventive measure. Some diseases that can be acquired sexually are hepatitis, CMV (cytomegalovirus), AIDS, herpes, and candida (yeast infection).

If you are certain that your partner is faithful, use of a condom may not be necessary. But since something as simple as a woman's common vaginal infection could cause serious infection in a male transplant patient, complete, candid communication with your partner is essential. In such a situation, even faithful partners should use a condom or abstain from sexual intercourse.

Single people must insist on using a condom when a relationship becomes sexual. This is not always an easy or comfortable thing to do, but you have come too far to make what could be a very dangerous mistake.

Finally, do not forget about **birth control**. Pregnancy could be hazardous for a female lung transplant patient. Your transplant coordinator and doctor are available to discuss these matters with you if you so desire, so please don't be afraid to ask about your concerns.

Monitoring and Follow-Up

Biopsies

After your transplant, you will have a biopsy of your transplanted lung(s) at regular intervals to check for the presence of rejection. Biopsies will be done at one month; three months; six months; nine months; twelve months; twenty-four months and thirty-six months. After the third year, post-transplant biopsies are only done if needed to help evaluate symptoms.

Biopsies are done through a lighted tube, called a bronchoscope, that is inserted through your nose or mouth and into your transplanted lung(s). You should not eat or drink anything after midnight the night before you are scheduled for a biopsy. You will be given medication to help you relax before your biopsy if necessary. Your throat will then be sprayed with a numbing medication, and the bronchoscope will be inserted through your nose or mouth. Insertion of the bronchoscope is normally uncomfortable and will make you cough. You will be monitored closely throughout the procedure, so try to relax as much as you can.

After your doctor has carefully examined your lungs through the bronchoscope, several tiny pieces of lung tissue will be removed. When the biopsy is finished, you will be required to remain in bed with nothing to eat or drink for the next two hours. The tissue from your biopsy will be taken to a special laboratory, where it is examined carefully under a microscope for the presence of rejection and infection. You will be notified of the results of your biopsy the following day.

Lab Studies

When you have completed the pulmonary rehabilitation program and are ready to return home, some of your care will be taken over by your local doctor. We will send a letter to your doctor describing your transplant experience and your current condition, and instructing him or her in obtaining lab studies.

Periodically, you will need to have a blood count and blood chemistries drawn. You will also need to have a Cyclosporine or Prograf level check. These lab studies are generally done at least monthly, and more often if necessary. Your transplant coordinator will give you specific instructions on when to obtain blood work. Please remember that whenever blood for Cyclosporine/Prograf level is to be drawn, it should be drawn first thing in the morning, before you take your morning dose of Cyclosporine/ Prograf.

The lung transplant team members are available to your doctor 24 hours a day if he or she needs our help. If your doctor wants to start you on any new medications, we would like you to let us know so that we can keep your records up to date and monitor any potentially dangerous drug interactions. We will also continue to follow you at regular intervals in the Duke Lung Transplant Clinic.

Self-Monitoring

You will be asked to measure your temperature, weight, blood pressure, and FEV1/FVC on a daily basis once you are at home. Charts for recording these measurements are included in the back of this booklet.

Temperature

Your temperature should be taken at the same time each day, and whenever you feel feverish. If your temperature is above 100° F or 38° C, call your transplant coordinator. Fever may indicate that you have an infection or a rejection episode. Do not take any medications that can lower your temperature, such as aspirin or Tylenol, unless instructed to do so by your transplant coordinator.

Weight

Weigh yourself at the same time each day, preferably in the morning. Weigh yourself with the same type of clothing on and on the same scale each day. A weight gain of three to five pounds in a 24-hour time period is significant, and needs to be reported to the transplant coordinator.

Blood Pressure

Your blood pressure should be measured and recorded daily. Your nurse will teach you how to measure your blood pressure if you do not know how, or do not have a family member who can do it for you. You will also need to purchase a blood pressure cuff if you do not already have one. We generally recommend the digital read-out type cuffs because they are more convenient. Please call your transplant coordinator for blood pressure higher than 150/90 or lower than 90/60.

Lung Volume (FEV1/FVC)

“FEV1” stands for forced expiratory volume in one second, and “FVC” stands for forced vital capacity. These are measurements of the amount of air that you can blow out of your lungs. A hand-held machine called a microspirometer will be given to you while you are in the hospital. The hospital respiratory therapist will teach you to measure FEV1 and FVC with this machine.

You must be faithful in measuring these lung volumes every day and reporting any decrease to the transplant coordinator. A decrease in FEV1 of 10 percent or more in a 24-hour time period, or a downward trend in both FEV1 and FVC over several days, can alert us to rejection or other lung problems.

The key to treating problems in your transplanted lung(s) is to deal with them quickly, before permanent damage is done. Therefore, please remember to record these measurements daily and to report changes as necessary. All home records should be brought to each Lung Transplant Clinic visit for review by the transplant coordinator and your doctor.

A formal measurement of FEV1 and FVC (called “spirometry”) should be done on a monthly basis. We will schedule this test when you come to Duke for clinic visits, and will ask your local doctor to perform this test during the months you do not come to Duke. Please help by reminding your local doctor that this test, as well as blood work, should be done monthly, with results sent to the Duke Lung Transplant Office.

Long-Term Follow-Up

Long-Term Follow-Up

Medical Condition Alert Bracelet

We strongly recommend that each lung transplant patient wear an identifying tag on either a bracelet or necklace after transplant. The following information should be included:

Your name

Lung transplant recipient

Immunosuppressed

1-800-249-5864 or 1-919-684-2240

Other serious conditions, such as diabetes or epilepsy, should also be included on the tag.

Clinic Visits

You will be seen quite frequently in the Lung Transplant Clinic during the first two months after your discharge from the hospital. As time passes and your condition improves, we will see you less frequently.

At each clinic visit, you will have blood drawn, a chest x-ray, and pulmonary function tests before seeing your doctor and transplant coordinator. A Cyclosporine or Prograf blood level will be drawn each time you come to clinic. Remember, **do not take your Cyclosporine/Prograf until after the blood has been drawn.**

In addition, please remember to:

- **bring a day's supply** of all your medications with you, in case you are delayed;
- **bring your home records** with you to each clinic visit; and
- **organize your questions** for your doctor and transplant coordinator.

You will normally be finished with your clinic visit by the end of the day; however, certain extra studies may be ordered on the days that you are to have a biopsy. You will receive a schedule in the mail for each clinic visit.

Going Back to Work

It is our goal to make it possible for patients who have been employed to return to work after transplant. Most patients can go back to work about three months after their transplant.

Depending on the type of work you do and your financial situation, you may need to return to work as soon as possible. If this is the case, we will help you work out an arrangement with your employer.

It may be best to start back to work part-time and eventually move toward full-time work. We will assist you in dealing with your employer and insurance company by providing them with any information they require to help you get back to work again.

A Final Word

Please remember that it will always be important for you to practice good health habits and to take good care of yourself. A balanced life—one that includes good nutrition, rest, exercise, work, and play—will do wonders for your health. Please take your medications correctly, keep up with your daily records and monthly spirometry and blood work, and come for your scheduled Transplant Clinic visits.

Remember that we are only a phone call away at any time. The lung transplant coordinator can be called at the Lung Transplant Office (1-800-249-5864) during normal business hours Monday through Friday. The on-call transplant coordinator can be reached for emergencies that occur on nights, weekends, and holidays by calling 919-684-8111 and asking for beeper #0114.

It is hard to believe now, but in several months you will not think about your transplant every day. All that you've been through, and all the work you've done to make your lung transplant a success, is toward one ultimate goal—to give you a fresh chance to enjoy life. We hope this enjoyment soon comes as naturally as breathing!

Record Keeping

Patient Record Sheet

Week of _____

	MON	TUE	WED	THUR	FRI	SAT	SUN
Temperature Before Breakfast							
Before Dinner							
Weight							
Blood pressure							

Things to mention to my Transplant Team:
