

AFTER LUNG TRANSPLANTATION



ITNS Lung Transplant Handbook

A Guide for Your Health Care after Lung Transplantation

Forward

ITNS and a dedicated task force started this project nearly two years ago after it was realized there was no consistent format to educate and prepare new and potential lung transplant patients. A decision was made to use the recently completed heart transplant patient learning handbook (2011) as a baseline, to utilize the same format, and adapt it specifically for our lung patients. This collaborative work sponsored by the International Transplant Nurses Society through the generous support of a grant from CSL Behring.

As the task force traversed its way through this project, greater respect was gained for the patient, their families and donor families. As transplant professions, we now better understand their loss, joy, regrets, anger and, eventually acceptance. These patients, their families and donor families face unimaginable struggles in an effort for a hopeful future. Their strength and perseverance is admirable and their endurance became an example for us all to follow.

This patient education manual represents the contribution of a multitude of nurses, doctors, coordinators, medical professionals, patients, and families. This would not have been possible without the personal devotion and support of the many reviewers, writers and editors who volunteered their time, experience, and devotion to life. Our desires are only to improve medical outcomes and the livelihood of the patients we serve.

These educational materials are a culmination of all current efforts in Transplant medicine. It is everything we know of the past and is currently as up to date as it can be in an era where medical innovation is moving at lightning speed. Thank you to all from the past, present and future who will be a part of editing, writing, teaching and learning about lung transplantation.

ITNS Lung Transplant Handbook Task Force 2011

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Congratulations if you have already received a lung transplant! This manual provides important information about your care as you and your family prepare for discharge from the hospital. As you are learning now, lung transplantation is far more than the operation you recently experienced. It is important for you to learn about your care so that you will have the best possible outcome with your healthy lungs. You are the most important member of the transplant team. Your active participation in your care will lead to a successful recovery.

Purpose

This handbook provides general information for care after lung transplantation. It also will give you an idea of what to expect during the transplant process. Transplant centers often have different care routines, monitoring guidelines, and immunosuppressive routines following lung transplant. It is important to check with your transplant coordinator when you have a question or concern about any aspect of your care. Review this handbook with your nurse, transplant coordinator, or clinical nurse specialist and know your center's specific guidelines. **Your transplant center's specific guidelines should always be followed.**

Your Responsibilities

You are the most important caretaker of your transplanted lung. To have the best outcome as a transplant recipient you should:

- ✓ Know all your medications: doses, times and why you are taking them.
- ✓ Follow your medication schedule daily and make changes only as ordered by your transplant team.
- ✓ Maintain routine contact with your transplant team through your transplant coordinator.

My transplant coordinator is:

Phone number: _____

Fax number: _____

Email address: _____

- ✓ Attend follow-up appointments and/or transplant clinic visits.
- ✓ Have blood tests drawn and other tests and procedures done on time.
- ✓ Monitor your weight, blood pressure, temperature and spirometry.
- ✓ Maintain a healthy lifestyle that includes a balanced diet and regular exercise.

Your Transplant Team

It is important for you to maintain regular contact with your transplant team. Team members will provide medical care, advice, and support for you and your family throughout the transplant process. There may be many members of your lung transplant team. These people include:



You!

You are the most important member of the transplant team. You should have a good understanding of your medical care and be actively involved in your care by talking with members of your team and keeping your clinic appointments. Support from your friends and family is also helpful in your care and recovery.

Your Family or Support Team

Your support team may include people who will take you to and from doctors' appointments

Team Member	What they do	Contact Information

Lung Transplant Surgeon

Lung transplant surgeons are medical doctors who specialize in surgery of lung transplantation. The surgeons assess your lung condition and determine whether lung transplantation is the best treatment for your illness. The lung transplant surgeon will perform the operation and will be involved in your care as you recover from surgery.

My transplant surgeon(s): _____

Transplant Office number: _____

Transplant Pulmonologist

A transplant pulmonologist is a medical doctor who specializes in the care of the lung. Your local transplant pulmonologist may have referred you for lung transplant evaluation to the transplant center. At the transplant center, the transplant pulmonologist on the transplant team will review your pulmonary history and any other conditions you may have. This doctor will prescribe medications and treatments for lung disease and will decide what tests are needed to complete the transplant evaluation. After lung transplant, pulmonologists often manages follow-up care.

My transplant pulmonologist: _____

Office number: _____

Management varies by transplant center, so you may have follow-up care with a lung transplant surgeon or transplant pulmonologist. Your surgeon or pulmonologist will be responsible for managing your medications and any medical issues directly related to your lung transplant. For health problems not related to your lung transplant, you should continue to contact your local physician, general practitioner, or primary care physician (PCP). Your transplant coordinator will help you plan your follow-up care after you leave the transplant center.

Lung Transplant Coordinator (RN, CCTC)

Transplant coordinators are usually licensed registered nurses (RN). They are experienced in the care and management of patients with lung disease. The transplant coordinator will also help you prepare for discharge after transplant and may be involved in your follow-up care. In most transplant centers, the transplant coordinator is the patient's most important link to the transplant center. Your coordinator may refer you to other team members for services that you need and will be available to discuss any questions or concerns you may have as you begin to adapt to life following your transplant. The initials CCTC after your coordinator's name mean that your coordinator has passed a certification examination and is a Certified Clinical Transplant Coordinator.

My coordinator: _____

Phone: _____

Nurse Practitioner (NP) or Physician Assistant (PA-C)

A nurse practitioner (NP) is a registered nurse who has completed advanced education (usually a master's degree) and training in the diagnosis and management of common medical conditions and chronic illnesses. Physician Assistants (PA) are non-physician clinicians who are licensed to practice medicine with a physician's supervision. Most PAs also have a master's degree. NPs and PAs provide a broad range of health care services. They provide some of the same care as physicians while working closely with a supervising physician. A nurse practitioner or physician assistant working at a transplant center might manage your daily medical care when you are in the hospital or may follow your progress in the outpatient clinic.

My NP or PA: _____

Phone: _____

Staff Nurses (RN)

The staff nurses work with members of the lung transplant team to coordinate the everyday activities of your care during your hospital stay. Your staff nurse will care for you daily as you recover and will also teach you about your medications and care after transplant.

My primary nurses: _____

Transplant unit phone: _____

Clinical Nurse Specialist (CNS)

A clinical nurse specialist is a registered nurse with an advanced practice degree (master's or doctorate) in a nursing specialty. The transplant clinical nurse specialist may be involved in the transplant evaluation as well as post-transplant care. This team member provides information about the transplant process, assesses problems you may be having while in the hospital or at home, provides supportive care and counseling, and will help you prepare for discharge.

My CNS: _____

Phone: _____

Medical Social Worker (MSW)

A medical social worker in transplantation specializes in helping patients and families cope with the stresses and challenges of the transplant process. Your social worker may help you by identifying community support agencies, assisting you and your family in finding housing while staying in the hospital area, helping with financial difficulties, providing emotional support, and providing information and referrals for support groups or counseling.

My social worker: _____

Phone: _____

Dietician/Nutritionist (RD)

The registered dietician (RD) or nutritionist specializes in helping patients improve their health by understanding and eating a diet that is healthy for them. This clinician determines your ideal body weight and will discuss any food restrictions you may have before transplant or after transplant. The dietician will also teach you about nutritional guidelines after transplant. The dietician may also work with you on special instructions if you have diabetes, high blood pressure and/or high cholesterol.

My dietician: _____

Phone: _____

Transplant Clinical Pharmacist

A pharmacist is a licensed medical professional who dispenses prescribed medications. As part of the transplant team, the transplant clinical pharmacist may help monitor your medications while you are in the hospital and during clinic visits. In some centers, the pharmacist rounds daily with the transplant team and may also be involved in your discharge teaching. This team member provides information about your medications to you and your support person/family.

My pharmacist: _____ Phone: _____

My pharmacy: _____ Phone: _____

Transplant Financial Counselor

Depending on your country’s health system, a financial counselor may be available to review your insurance coverage. This team member works with your insurance company to approve your evaluation for transplant as well as the transplant surgery and your care after transplant. The financial counselor provides information to you and your family on what expenses to expect for the future. Assistance programs, other types of insurance, and/or fundraising options for expenses not covered by your insurance may also be discussed.

My financial counselor: _____

Phone: _____

Transplant Psychologist

A psychologist may be assigned to the team to assist in determining psychological fitness. They may also be available to assist in adjusting to lifestyle changes.

My psychologist: _____

Phone: _____

Respiratory Therapist

Depending on the health care system, a respiratory therapist may be assigned to provide inhaled treatments and pulmonary therapy. In some institutions there is a respiratory therapist who has received additional education and works with lung transplant patients.

My respiratory therapist: _____

Phone: _____

Physical and Occupational Therapist

Many lung transplant patients are debilitated and may require extensive therapy. Therapy may be needed before and after transplant. Physical and Occupational Therapists are commonly utilized to maximize abilities preoperatively and to rehabilitate post operatively.

My physical therapist: _____ Phone: _____

My occupational therapist: _____ Phone: _____

Other members

Other Team Members	What they do	Contact Information

MEDICATIONS



One of the most important responsibilities you will have after your transplant surgery is taking your medications. Here are some things you should know about your medications as you learn how to take care of yourself after transplant:

The brand name and generic name of all my medications

Medications usually have two names. The brand name is the name given to the medication by the pharmaceutical company that produces it. The generic name is the common (nonbranded) name of that medication. For example, Prograf® and tacrolimus are the same medication. Prograf® is the brand name and tacrolimus is the generic name. There can be several brand names for a generic medication. Bactrim®, Septra®, and Cotrim®, for example are all brand names for the antibiotic trimethoprim/sulfamethoxazole.

The purpose or reason for taking my medications

A medication often has more than one use and may be prescribed for different reasons. You should always know why you are taking

each medication. For example, fluconazole is a medication used to treat a fungus infection, but it can also be used to increase tacrolimus levels.

What each medication looks like

You must be able to recognize each tablet or capsule by color, shape, and size. Many medications have a similar appearance with only slight differences. Look closely at your medications to be sure that you are taking the correct tablet or capsule. Magnesium oxide, sodium bicarbonate, and some generic forms of Bactrim® are all large, round, white pills. If you look closely, though, you will see some different markings on each.

When to take each medication

It is important to know what time you need to take each medication. Some medications, such as the anti-rejection medications tacrolimus and cyclosporine, must be taken on time every day. This is because a certain level of that medication must be maintained in your bloodstream to help prevent rejection. Work with your coordinator or nurse to arrange a medication schedule that is easy for you to follow.

How to take each medication

Most patients can swallow their tablets or capsules. Sometimes, particularly for children or people with swallowing problems, a pill may be cut, crushed or mixed with food or a liquid. Discuss how to take each of your medications with your nurse or coordinator. Some pills should not be crushed because breaking up the pill will decrease how well it works.

How long each medication will be taken

Some medications may be prescribed for 7 to 14 days, such as antibiotics. Others, like your anti-rejection medications, must be taken for your lifetime. Some medications

can be discontinued after a complication or side effect has resolved. For example, if you have diarrhea, alert your transplant center and they will let you know if you should take loperamide (Imodium®). You may then take loperamide (Imodium®) until the problem gets better. Be sure to know how long you are take each of your medications.

The most common side effects of each medication

Every medication has some side effects, but these are not experienced by everyone. Some side effects can be very mild while others lead to additional complications. For example, some antibiotics can cause diarrhea and stomach upset. You should know the most common side effects that each medication may cause and what will be done to relieve or lessen that side effect.

Any special instructions for taking the medications

Some medications must be taken with food or on an empty stomach. Others must be taken a certain number of hours apart from other medications. Discuss any special instructions for your medications with your transplant team. Many of the medications can cause a reaction with certain foods such as grapefruit or pomegranates. Therefore, many centers advise against eating grapefruit or pomegranates. Ask your doctor if there are any food restrictions.

What should I do if I am late, miss a dose, or forget to take a dose?

If you are very late taking a medication or have skipped a dose, either because you forgot or you have been vomiting, call your transplant coordinator. After asking you a few questions and considering your current health status, your coordinator will advise you on what to do.

How to order my medications

Your transplant coordinator, nurse or social worker will help you find the most convenient way to get your medications. As you are preparing for discharge, have your caregiver get your medications at the hospital pharmacy or at a retail pharmacy in the area. Be sure that you have at least a 30-day supply of all your medications before you leave the hospital.

How to order my refills/repeat prescriptions

The number of refills you have for each medication depends on how long you will be taking the medication. Your insurer may also specify the amount of medication that can be given, for example, a 30-day or 90-day supply. After the prescription has been given to your pharmacy, you may call for refills/repeat prescriptions. All new prescriptions and any dose changes in medications you are already taking must be called in or sent to your pharmacy by your physician. It is very important to monitor the number of pills you have so you can order your refills before you run out of medication. Contact your transplant coordinator if you are having any problems ordering your medications or refills.

The cost of my medications

It is important to know your financial responsibility for your medications so you can plan ahead. In the United States, some medications may be completely covered by insurance, while others have co-payments where you pay a small part of the total cost of the medication. Often, insurance companies have a certain amount (deductible) you must meet before the insurer pays for the medications. It may be helpful for you or a family member to call your case manager or approved pharmacy provider before your medications are

ordered. A toll-free number for “prescriptive authorization” is usually on the back of insurance cards. This contact person should be able to tell you what your cost is for each prescribed medication. Internationally, medication costs vary by country. You should discuss the possible cost of your medications with your transplant coordinator, social worker and/or transplant financial counselor.

Patient assistant programs – medication cost assistance

Some transplant organizations work closely with assistance programs. This may be a program that puts potential patients in contact with other transplant patients. Other programs may range from programs providing assistance with pharmacy, finding assistance to pay for medications, or assistance in locating housing close to the hospital. Ask your coordinator or pulmonologist if there are any patient assistant programs.



Medication Guidelines

Medications should be taken daily and always as prescribed. Taking your medications correctly and following your medication schedule will help you have a healthy, active lifestyle as a lung transplant recipient.

To avoid the possibility of rejection, before starting ANY new medications, herbals, vitamins or over the counter medications, it is extremely important to contact your transplant center.

Call your transplant coordinator if you:

- Unable to take your medicines because you are nauseated,
- Are feeling sick
- Are vomiting
- Have diarrhea
- Have forgotten to take your medications
- Have missed any doses
- Have noticed that the directions on the label of the medication container are different from what you were told to take
- Feel you are having an unusual reaction or side effect to a medication
- Would like to take an over-the-counter cold remedy, cough suppressant, diet aid, or herbal medicine
- You have been prescribed to take any new medication by your local doctor
- Would like to take acetaminophen (Tylenol®)/paracetamol for fever
- If any changes are made to your current medications by another doctor

Organize a medication schedule that fits well with your daily routine

Work with your transplant coordinator, nurse, or pharmacist to arrange a schedule that fits into your daily routine. A convenient schedule will improve your success for taking all your medications at the right time every day. Some people find it helpful to follow a written schedule or a check-off list. Pill reminder containers and medication alarms may also be helpful. Pill containers can be stocked with a week's supply of medications. Medication alarms can be set to remind you to take your medications on time. Always keep a copy of your medication schedule with you. If you are being seen in transplant clinic, your doctor's office, or in an emergency room, it will help to have a current list of your medications. Some people find it difficult to take medicines that are prescribed more than two times a day. If this is a problem for you, ask your doctor if the medicine can be taken less frequently. In some cases, the amount of medication can be changed and the dosage times decreased. For example, instead of taking two tablets of magnesium three times a day, your doctor may adjust the dose to three tablets two times a day.

Storing your medications:

Keep medications in the original container with the caps closed. If you use a pill reminder container, keep the container sealed. It is important that you can recognize different medications when they are together in a pill container in case a dose has changed. If you have trouble removing child-resistant caps, ask your pharmacist to use regular medication container caps. Store your medications in a cool, dry place away from direct sunlight.

Do not store medications in the kitchen or bathroom because moisture and heat may

interfere with the effectiveness of some medications.

Do not allow liquid medications to freeze. Do not store medications in a refrigerator unless instructed to do so by your pharmacist.

Keep all medications in a safe place, out of reach of children and pets.

It may be helpful to keep a few doses of your medications in another place, aside from your household. Sometimes transplant recipients will store extra doses of anti-rejection medications at a family member's house, in their office, or with the school nurse in case of an emergency.

It is helpful to bring your medications, filled medication container and/or medication list with you for clinic visits or if you are admitted to the hospital. This will insure that you will not miss any doses.

Commonly Prescribed Medications Following Lung Transplantation

This section contains information about medications that are commonly prescribed following lung transplantation. This information is meant to be a general guide for the lung transplant recipient and is not all-inclusive. It does not replace your doctor's advice. Always contact your transplant coordinator or your transplant team to be aware of your center's specific recommendations about your medications.

If you are pregnant or planning to become pregnant, your transplant physician and obstetrician/gynecologist should be consulted to review and discuss your current medication routine and your medication history. Some medications may be harmful to the fetus.

Medications to Treat or Prevent Rejection

Tacrolimus (Prograf®)



Purpose: Tacrolimus is used to prevent or treat rejection after lung transplant. Tacrolimus prevents rejection by inhibiting or suppressing the immune system so that the immune system does not attack the cells of the transplanted lung, causing rejection. Tacrolimus may be used by itself or in combination with other anti-rejection medications (immunosuppressants) to prevent rejection.

Dosage: Tacrolimus is available in several types of capsules. Patients are usually asked to take a dose in the morning and in the evening, about 12 hours apart. You can take your doses at 8 AM and 8 PM, for example. It is important to take tacrolimus at the same time every day to maintain a steady level of immunosuppression so that the lung is protected from rejection. Most transplant centers advise that patients not be more than one hour early or one hour late in taking their doses of tacrolimus.

Side effects: The side effects of tacrolimus vary and are usually related to the blood level of the drug. Side effects are more commonly seen when levels are high, particularly in the early weeks after transplant and during treatment for rejection. The most common side effects include:

Nervous system side effects

High tacrolimus levels may cause headache, trouble sleeping, numbness and tingling of the hands and feet, hand tremors,

or an increased sensitivity to bright or blinking lights. These side effects are more commonly seen with high tacrolimus levels. Difficulty speaking and seizures are very rare side effects, but have occurred with very high levels. Nervous system side effects usually resolve as the tacrolimus level decreases.

Kidney dysfunction

Tacrolimus can cause the blood vessels that carry oxygen-containing blood in the kidneys to get smaller or constrict. When these tiny vessels constrict, the flow of oxygenated blood into the kidney is decreased. Because of this effect on the kidneys, some patients may have high blood pressure, high blood levels of potassium, low blood levels of magnesium, and/or abnormal kidney function tests. Your doctor will maintain the lowest tacrolimus level that is safe for you so that you have few, if any, kidney side effects. Long term problems with kidney function can occur in some patients.

Infection: If you are taking tacrolimus, your immune system is suppressed. Because your body's natural ability to fight infections is decreased, you may be more likely to develop infections. You are at greatest risk for developing infections when your tacrolimus level is high. You are also at risk for infection if you are being treated for rejection and receiving higher doses of tacrolimus and other anti-rejection medications. Other side effects that may be experienced with tacrolimus are nausea, diarrhea, high blood sugar, and mild hair loss.

Additional information:

Do not change the dose of tacrolimus or take it more or less often than prescribed for you by your transplant physician.

Tacrolimus levels are monitored through blood tests. Levels are monitored daily in the early period after transplant, then less frequently over time.

Most patients have a tacrolimus level checked monthly or every other month by the time they are several months post-transplant. Although management of immunosuppression varies by transplant center, levels are higher during the first 3 months after transplant or during treatment for rejection. Levels are usually lowered slowly over time and may continue to be decreased after one to two years if there is no rejection.

Tacrolimus levels should be drawn one to two hours before taking a dose or about 10 to 12 hours after the previous dose. On days when you are having blood work, be sure to have your labs drawn before taking tacrolimus so that an accurate trough level is obtained. Bring a dose with you to take after your labs have been drawn so you will not be late taking your dose.

Food can affect the tacrolimus level. Eating a full meal within two hours of taking tacrolimus may lower the level by as much as 30%. Some transplant centers prefer that patients not eat for an hour before or an hour after taking tacrolimus. Please check with your coordinator or transplant pharmacist for your center's guidelines. You should not eat grapefruit or drink grapefruit juice while taking tacrolimus. A chemical in grapefruit can interfere with the enzymes that break down tacrolimus. Seville oranges, grapefruit, grapefruit juice, or the herbal products of grapefruit will increase tacrolimus levels. Patients who are taking tacrolimus may develop a very high level of their medication if grapefruit is taken at any time of day.

Some medications should not be taken at the same time as tacrolimus. For example, sucralfate (Carafate®), Mylanta®, Tums®, magnesium oxide, magnesium gluconate (Magonate®), sodium bicarbonate (Bicitra®, Polycitra®) should be taken two to four hours after the dose of tacrolimus.

Tacrolimus interacts with some medications, causing higher or lower levels. Always check with your transplant coordinator before starting any new medication to be sure that it does not interfere with tacrolimus.

If you miss a dose of tacrolimus, take it as soon as you remember. If it is near the time for the next dose, skip the missed dose and resume your regular schedule. Call your transplant coordinator if you have missed a dose because your levels may need to be monitored more frequently.

Store tacrolimus capsules at room temperature and away from the reach of children and pets.

If you are planning to become pregnant, discuss the use of tacrolimus with your transplant physician and obstetrician/gynecologist.



Cyclosporine (Sandimmune®, Neoral®, Gengraf™)



Purpose: Cyclosporine is used to prevent or treat rejection after a lung transplant. Cyclosporine prevents rejection by inhibiting or suppressing the immune system so that the immune system does not attack the cells of the transplanted lung, causing rejection. Cyclosporine may be used by itself or in combination with other anti-rejection medications to prevent rejection.

Dosage: Cyclosporine is available in two products (formulations), but these products are not the same. They are cyclosporine (Sandimmune®) and cyclosporine-modified (Neoral®, and Gengraf™). Cyclosporine is made by several pharmaceutical companies. Your body absorbs these cyclosporine formulations in different ways. Because of this difference in absorption, be sure that your pharmacist always gives you the brand of cyclosporine that your doctor has prescribed. Both types of cyclosporine are available as capsules. The cyclosporine-modified products (Neoral® and Gengraf™) are also available as liquids. You may find that the liquid form of cyclosporine tastes better if diluted with milk, chocolate milk, or orange juice. Mix cyclosporine and a room temperature liquid in a glass or cup and stir the mixture with a metal spoon. Do not use styrofoam or soft plastic cups because the medication may cling to the foam container or plastic. Hard plastic containers are acceptable for safety reasons with small children.

Cyclosporine is prescribed to be taken once a day or twice a day. It should be taken at the same time each day to insure a steady level of immunosuppression. Most transplant centers advise that patients not be

more than one hour early or one hour late in taking their doses of cyclosporine.

Side effects: The side effects of cyclosporine vary and are usually related to the blood level of the drug. Side effects are more commonly seen when levels are high, particularly in the early weeks after transplant and during treatment for rejection. The most common side effects are nervous system side effects. High levels of cyclosporine may cause headache, hand tremors, trouble sleeping, and numbness and tingling of the hands and feet. These side effects are more commonly seen with a high level and usually resolve as the level is lowered.

Kidney dysfunction: Cyclosporine can cause the blood vessels that carry oxygen-containing blood in the kidneys to get smaller or constrict. When these tiny vessels constrict, the flow of oxygenated blood into the kidney is decreased. Because of this, some patients may have high blood pressure, high blood levels of potassium, low blood levels of magnesium, and/or abnormal kidney function tests. Your doctor will maintain the lowest cyclosporine level that is safe for you so that you have few, if any, kidney side effects. Long term problems with kidney function can occur in some patients.

Infection: Cyclosporine suppresses the immune system. Because your body's natural ability to fight infections is decreased, you may be more likely to get infections. You are at the greatest risk of developing infections when your cyclosporine level is high.

Cosmetic side effects: Cyclosporine can cause some changes in your appearance. Excessive hair growth can occur. Patients may also develop bleeding and tenderness

of the gums. The gums can swell and become overgrown. Acne may develop or worsen in adolescents or younger adults taking cyclosporine.

Additional information: Do not change the dose of cyclosporine or take it more or less often than prescribed for you by your transplant physician. Cyclosporine levels are monitored through blood tests. Levels are monitored daily in the early period after transplant, then less often over time. Most patients have a cyclosporine level checked monthly by the time they are several months post-transplant. Although management of immunosuppression varies by transplant center, levels are usually higher in the early period after transplant or during treatment for rejection. Levels may be decreased and maintained at a lower level after one to two years if there have been no episodes of rejection. Cyclosporine levels should be drawn one to two hours before taking a dose or about 10 to 12 hours after the previous dose. On days when you are having blood work, be sure to have your labs drawn before taking cyclosporine so that the trough level is accurate. Bring a dose with you to take after your labs have been drawn so you will not be late taking that dose.

Take your cyclosporine in the same way and at the same time every day to maintain a steady level.

You should not eat grapefruit or drink grapefruit juice while taking cyclosporine. A chemical in grapefruit can interfere with the enzymes that break down cyclosporine. Seville oranges, grapefruit, grapefruit juice, or the herbal product of grapefruit will increase cyclosporine levels. An increased cyclosporine level increases your risk of infection and serious side effects.

Some medications should not be taken at the same time as cyclosporine. For example sucralfate (Carafate®), Mylanta®, Tums®, magnesium oxide, magnesium gluconate (Magonate®), sodium bicarbonate (Bicitra®, Polycitra®) should be taken two to four hours after cyclosporine.

Cyclosporine interacts with some medications, causing higher or lower levels. Always check with your transplant coordinator before starting any new medication to be sure that it does not interfere with cyclosporine.

If you miss a dose of cyclosporine, take it as soon as you remember. If it is near the time for the next dose, skip the missed dose and resume your regular dosing schedule. Call your transplant coordinator if you have missed a dose. Levels may need to be checked more often until the cyclosporine level is steady again.

Cyclosporine capsules and liquid should be stored at room temperature and away from direct sunlight. Cyclosporine capsules are packaged in individual blister packs. Do not open the blister pack until you are ready to take the medication because air and light will damage the medication. An opened bottle of cyclosporine liquid may be used for up to two months.

Be sure to keep cyclosporine medications out of the reach of children and pets.

If you are planning to become pregnant, discuss the use of cyclosporine with your transplant physician and obstetrician/gynecologist.

Prednisone (Deltasone®) or Prednisolone (Orapred®)



Purpose: Prednisone is a steroid used to help prevent or treat rejection in organ transplantation. It prevents rejection by inhibiting the cells in the immune system that cause rejection. Prednisone is given with tacrolimus or cyclosporine.

Dosage: Prednisone is available in several strengths. It is also available in a liquid form called prednisolone. Prednisone is usually prescribed once daily and should be taken in the morning. If taken at night, it can affect your sleep. If prednisone is prescribed twice daily, you can take a dose in the morning and the second dose with dinner.

Side effects: Prednisone may cause many side effects, but these vary depending on the dose, frequency, and duration of your treatment. The most common side effects include: an increased appetite, weight gain, stomach irritation and/or stomach ulcers, mood changes, irritability, anxiety, and acne. You may also retain fluids which can make your face, hands, and ankles look “puffy.” Side effects that can occur with higher doses over a longer period of time include bruising, high blood pressure, high cholesterol levels in the blood, high blood sugar, muscle weakness, night sweats, bone weakening, delayed wound healing, vision problems due to cataracts and glaucoma, and growth delay in children.

Additional information:

Be sure that you know your correct dose of prednisone and that you have the correct strength of tablets. Because prednisone is available in several strengths, it is easy to get confused.

Do not change the dose of prednisone or take it more or less often than prescribed.

If prescribed once a day, prednisone should be taken in the morning so that you do not have trouble sleeping.

Do not stop taking your prednisone without talking to your doctor. If you stop taking your prednisone serious complications may occur.

Prednisone should be taken with food because this medication can cause stomach upset.

If you miss a dose of prednisone, take it as soon as you remember. If it is near the time for the next dose, skip the missed dose and resume your regular dosing schedule. Call your transplant coordinator if you have missed a dose. Since your own body’s production of a natural steroid is disturbed when you take prednisone, missing doses could make you sick.



If you are taking prednisone, examine your skin routinely for bruising. Be sure to tell your doctor or transplant coordinator if you have any wounds that are not healing well. Take good care of your skin. This is especially important if you also have diabetes.

Your physician may advise you to avoid concentrated sweets, like candy bars and soda, while taking prednisone. High blood sugar can occur with higher doses of prednisone. Patients who already have diabetes may find it more difficult to control their blood sugar when they are taking prednisone.

Because prednisone can irritate the stomach lining, patients who take prednisone are at risk of developing stomach ulcers. Stomach ulcers are irritations of the lining of the stomach that can cause an upset stomach or abdominal pain. Because of this risk, you will be prescribed an antacid to protect your stomach from these complications. Occasionally, ulcers can become more serious and cause bleeding. Bleeding in your stomach and GI tract can cause your stools to look black and tarry and can cause your vomit to look like coffee grounds. Call your transplant coordinator immediately if you have any of these signs of a bleeding ulcer.

Sirolimus (Rapamune®)



Purpose: Sirolimus is used to prevent rejection in organ transplant recipients. It prevents rejection by inhibiting the cells in the immune system that cause rejection. Sirolimus may be the only immunosuppressant that is prescribed for you, but sometimes physicians prescribe it to be taken with tacrolimus or cyclosporine.

Dosage: Sirolimus is available in 1 mg (white) and 2 mg (yellow) tablets. It is also available in a liquid. Sirolimus is usually taken once or twice daily and should be taken on time to ensure a stable level of immunosuppression, just like tacrolimus and cyclosporine.

Side effects: The side effects of sirolimus vary and are usually related to the level of the drug. The most common side effects are an increased risk of infection, nausea, diarrhea, a low red blood cell count (anemia), high cholesterol and/or triglyceride levels in the blood, a low white blood cell count, headache, acne, mouth sores, arthritis, swelling of the hands and feet, and muscle cramping. Side effects usually resolve or lessen as the dose is decreased.



Additional information: Do not change the dose of sirolimus or take it more or less often than prescribed for you by your transplant physician.

Check with your transplant coordinator or pharmacist about the correct time to take your dose of sirolimus. This is important because sirolimus works with tacrolimus and cyclosporine. Some centers prefer that sirolimus be taken about four hours from these medications. Other centers recommend taking the medications at the same time.

Sirolimus is usually not started immediately after transplant like other anti-rejection medications because it can affect wound healing. Patients may be prescribed cyclosporine or tacrolimus for the first six to eight weeks after transplant, and then changed to sirolimus. In some cases, sirolimus may be added.

The dose of sirolimus may be increased during an episode of rejection or to prevent rejection if your level is low. The dose may be decreased if you have an infection or if you have complaints or complications due to side effects of the medication.

Sirolimus levels are monitored through blood tests. Levels are monitored one to two times weekly in the early period after transplant, then less frequently over time. Most patients have a sirolimus level checked monthly or every other month by the time they are several months post-transplant. Your ideal sirolimus level depends on whether it is the only immunosuppressant you are taking or if you are taking it with tacrolimus or cyclosporine. The level also depends on your transplant center's management of immunosuppression.

Sirolimus levels should be drawn one to four hours before taking a dose or 20 to 24 hours after the previous dose if it is taken once a day. Your coordinator will tell you what time of day to have your level drawn.

On days when you are having blood work, be sure to have your labs drawn before taking sirolimus so that an accurate trough level can be obtained. Bring a dose with you to take after your labs have been drawn so you will not be late taking your dose.

If you miss a dose of sirolimus, take it as soon as you remember. If it is near the time for the next dose, skip the missed dose and resume your regular dosing schedule. Call your transplant coordinator if you have missed a dose.

Sirolimus tablets should be swallowed whole without crushing or breaking. The medication is coated on the outside of the pill, so if the pill is crushed or broken, some of the medication will be lost.

If you take the liquid form of sirolimus, mix your dose in one to two ounces of orange juice or water in a glass or cup. Discard the syringe used to measure the liquid sirolimus after each use. Do not use a styrofoam or paper cup because sirolimus may cling to the container. Rinse the container with another ounce of water or orange juice and swallow that amount as well. You should also rinse your mouth with more water or orange juice after swallowing the medicine. Some patients have developed mouth ulcers from the liquid form. These ulcers usually get better over time or resolve if the dose is decreased.

Store sirolimus tablets at room temperature and out of the reach of children. The liquid form of sirolimus must be refrigerated after

the bottle is opened. The bottle of medicine will be good for one month after opening.

If you are planning to become pregnant, discuss the use of sirolimus with your transplant physician and obstetrician/gynecologist.

Azathioprine (Imuran®)



Purpose: Azathioprine is used to help prevent or treat rejection in organ transplant recipients. Azathioprine is usually given with tacrolimus, cyclosporine, and/or prednisone.

Dosage: Azathioprine is available as a tablet and a liquid. It is usually taken once daily and should be taken at about the same time each day.

Side effects: Azathioprine may lower the number of white blood cells in your body, the cells that fight infection. It may also lower platelets, which are cells that help your blood clot. Other side effects may include nausea, vomiting, and rash. Azathioprine may also be harmful to the liver resulting in an increase in the liver function tests. It can cause an inflammation of the pancreas.

Additional information:

Do not change the dose of azathioprine or take it more or less often than prescribed.

The dose may be decreased if you have an infection or if you have complaints or complications due to side effects of the medication.

If you miss a dose of azathioprine, take it as soon as you remember. If it is near the time for the next dose, skip the missed dose and resume your regular dosing schedule.

Call your transplant coordinator if you have missed a dose.

Azathioprine interacts with a medication called allopurinol, a drug used to treat gout. Call your transplant coordinator if you are diagnosed with gout or if a doctor has prescribed this medication for you. Patients who take azathioprine may never take allopurinol.

If you are taking azathioprine and considering becoming pregnant, consult your transplant physician and obstetrician or gynecologist.

Mycophenolate mofetil (Cellcept®) Mycophenolate sodium (Myfortic®)



Purpose: Mycophenolate (MMF) is used to help prevent or treat rejection in lung transplant recipients. It is usually given with tacrolimus, cyclosporine, and/or prednisone.

Dosage: Mycophenolate is available in two formulations: Cellcept® and Myfortic®. Myfortic® has a special coating on it to help decrease stomach upset and other gastrointestinal (GI) side effects. Mycophenolate can be prescribed up to four times a day. It should be taken at about the same times each day.

Side effects: Mycophenolate may lower the number of white blood cells in your body, the cells that fight infection. It may also lower the number of platelets which help your blood clot. Other side effects may include nausea, stomach irritation, vomiting, and diarrhea. Side effects may decrease



over time or resolve with a lower dose of mycophenolate.

Additional information:

Do not change the dose of mycophenolate or take it more or less often than prescribed.

The dose of mycophenolate may be increased during an episode of rejection or to prevent rejection.

The dose may be decreased if you have an infection or if you have complaints or complications due to side effects of the medication.

Mycophenolate capsules should be swallowed whole and should not be opened. The powder inside the capsule may be harmful if inhaled. Mycophenolate tablets should not be broken or crushed.

Some programs measure blood levels. On days when you are having blood work, be sure to have your labs drawn before taking mycophenolate so that an accurate level can be obtained. Bring a dose with you to take after your labs have been drawn so you will not be late taking your dose.

If you miss a dose of mycophenolate, take it as soon as you remember. If it is near the

time for the next dose, skip the missed dose and resume your regular dosing schedule. Call your transplant coordinator if you have missed a dose.

If you are a woman of childbearing age and taking mycophenolate, it is important to discuss the use of this medication with your transplant physician and obstetrician/gynecologist. Women of childbearing age should use contraception while on this medication. If mycophenolate is discontinued, contraception should be continued for an additional six weeks to ensure that the drug is eliminated from the body before becoming pregnant.

Antithymocyte globulin: ATG (Thymoglobulin, Atgam®)

Purpose: Antithymocyte globulin (ATG) is an immunosuppressant given in some transplant centers as a “pre-conditioning” agent immediately before transplant surgery. One dose of ATG is given before or during transplant surgery to reduce the body’s immune response and possibly reduce the risk of rejection. Some transplant centers also use ATG to treat rejection that does not resolve with steroids.

Dosage: ATG is available only as an intravenous (IV) solution and is administered in the hospital.

Side effects: During the ATG infusion, patients may have fever, chills, rash, low blood pressure, increased heart rate, or difficulty breathing. To minimize this “infusion reaction,” patients are usually treated with methylprednisolone (Solumedrol®), acetaminophen (Tylenol®) paracetamol, and diphenhydramine (Benadryl®) before and during the infusion. The infusion may also be slowed down to decrease side effects. Patients are closely monitored to watch for side effects from the infusion.

Later side effects include a low white blood cell count, a low platelet count, pain, headache, fever, abdominal pain, diarrhea, and high blood pressure, nausea, swelling of the hands and feet, and an increased level of potassium in the blood.

Because ATG can increase the risk of viral infections, patients may receive medications to prevent viral infections.

OKT3 (Orthoclone®, muromonab-CD3)

Purpose: OKT3 is an immunosuppressant that is used in some patients to treat moderate to severe rejection.

Dosage: OKT3 is an intravenous (IV) solution and is administered in the hospital. It is given through an IV once a day for 5 to 14 days.

Side effects: Because some patients have a reaction to the first or second dose of OKT3, they are monitored closely during treatment. In some transplant centers, patients are transferred to the Intensive Care Unit (ICU) for 24 to 48 hours after the first dose. Methylprednisolone is given before the dose of OKT3 to help decrease the severity of this reaction. OKT3 may cause low blood pressure, a high heart rate, fever, chills, and/or flu-like symptoms. Patients may also experience wheezing, difficulty breathing, headache, confusion, seizures, or fluid in the lungs.

Other side effects include headache, high blood pressure, tremor, rash, itching, diarrhea, nausea, vomiting, joint pain, sensitivity to light, kidney dysfunction, and an increased risk of infection.



Everolimus (Certican®) Everolimus

Purpose: Everolimus is used to prevent rejection in organ transplant recipients. It prevents rejection by inhibiting the cells of the immune system that cause rejection. Everolimus may be the only immunosuppressant that is prescribed for you, or it may be prescribed to be taken with tacrolimus or cyclosporine.

Dosage: Everolimus is available in tablets. It is also available as a dispersible tablet that breaks apart or dissolves in water. Everolimus is usually prescribed twice daily. Doses should be taken 12 hours apart. It is important to take everolimus on time every day to have a stable level of immunosuppression. Most transplant centers advise that patients not be more than one hour early or one hour late in taking their doses of everolimus.

Side effects: The side effects of everolimus vary and are usually related to the level of the drug. The most common side effects are an increased risk of infection, high cholesterol and/or triglyceride levels in the blood, a low white blood cell count, anemia, acne, nausea, diarrhea and headache. Side effects usually resolve as the dose is decreased.

Additional information:

Do not change the dose of everolimus or take it more or less often than prescribed for you by your transplant physician. Everolimus is usually not started immediately after transplant like other anti-rejections medications. It is usually prescribed at six to eight weeks after transplant.

The dispersible tablet should be placed in a plastic cup with water. Wait for about two minutes so the tablet can break up in the water. Then swallow the entire solution. Rinse the cup with more water and swallow that amount of water as well. Be sure to discuss how to prepare this medication with your nurse, transplant coordinator, or pharmacist

Your dose of everolimus may be increased during an episode of rejection. The dose may be decreased if you have an infection or if you have problems with side effects of the drug.

If you miss a dose of everolimus, take it as soon as you remember. If it is near the time for the next dose, skip the missed dose and resume your regular dosing schedule. Call your transplant coordinator if you have missed a dose.

Everolimus tablets should be swallowed whole without crushing or breaking. The medication is coated on the outside of the pill, so breaking or crushing can result in a loss of some of the drug.

Store everolimus tablets at room temperature.

If you are planning to become pregnant, discuss the use of everolimus with your transplant physician and obstetrician/gynecologist.

Medications to Treat or Prevent Infection

The following section includes some of the most commonly prescribed medications to prevent or treat infection following lung transplant.

The medications that you take to stop your body from rejecting your new lung(s) also affect your immune system. Your body's ability to fight bacterial, viral and fungal infections is decreased. As a result, you are at greater risk of getting infections. Your doctor may prescribe one or more drugs to protect you from infection or to control infection.

Inhaled Medications

Most lung transplant recipients are used to taking inhaled medications before transplant to help prevent and treat shortness of breath, wheezing, cough or a tight feeling (bronchospasm) in the chest. After transplant some patients continue to need these medications for a period of time. This is especially true for patients who undergo single lung transplant.

Cystic Fibrosis patients often require inhaled antifungal and antibiotics before and after transplant to treat and prevent lung infections. They may be used alone or in combination with oral or intravenous medications.

Dosage: The dose is different for each drug.

Side Effects: The most common side effect is breathing difficulty (shortness of breath, chest tightness, cough or wheezing) during or after inhalation treatments. To help

prevent this, a dose of a bronchodilator like salbutamol is often ordered to be taken just before the inhaled antibiotic/ antifungal medications. Hearing loss or ringing in the ears may also be a side effect of Tobramycin.

Additional Information: It is important to wash out your nebulizer with soap and water after taking these medications.

Many medications can be given by inhalation including: antifungals like Amphotericin B and antibiotics such as Colistin, Tobramycin, Amikacin and Pentamidine (PCP prophylaxis).

Short acting bronchodilators like: albuterol, salbutamol and ipatropium may be prescribed alone or in combination with inhaled steroids. Common examples include Advair and Symbacort. There are several different inhalers available and your doctor will choose the best one for you.

Antibacterial and Antifungal Medications

Azithromycin

Purpose /Action: Azithromycin prevents bacteria from growing by interfering with the cells making a certain type of protein; this is called "protein synthesis". Azithromycin is used to treat or prevent certain bacterial infections, most often those causing middle ear infections, strep throat, pneumonia, and sinusitis. In recent years, it has been used primarily to prevent bacterial infections in individuals with weakened immune systems. Dosage: 250 mg orally taken 1 hour before or 2 hours after medications or meals 3 times per week.

Side effects: Most common side-effects are gastrointestinal: diarrhea, nausea, abdominal pain, vomiting. Other reactions include skin sensitivity to the sun causing sunburn in a short time, rash, dizziness, fatigue, and headache.

Special Considerations: Notify your doctor if you notice blood in your bowel movement, as colitis can occur during and up to several weeks after Azithromycin therapy.

Drug Interactions: Take this medication on an empty stomach. Separate your dose of Azithromycin from your other medications by at least 2 hours this includes: Digoxin, antacids, and Coumadin. Azithromycin can increase Prograf® (Tacrolimus) levels.

Fluconazole (Diflucan) Nystatin (Mycostatin®, Nilstat®) and Clotrimazole (Lotrimin®, Lotrisone®, Mycelex®), fluconazole, Itraconazole, Voriconazole, Amphotericin B.

Purpose /Action: is an antifungal drug used in the treatment and prevention of superficial and systemic fungal infections. Fluconazole can be used first-line for the following indications: mold, Cryptococcosis, Histoplasmosis, prophylaxis of Candidiasis (Trush), and Aspergillus in immunocompromised people

Purpose: When you are taking antirejection medications, particularly prednisone, you have a greater chance of getting a fungus infection. This infection usually develops in the mouth and throat (thrush), in the vaginal area, or on the skin in warm moist areas. Fungal infections may also occur in the lungs. Some Cystic fibrosis patients

are particularly prone to fungal infections. Most lung transplant programs give patients antifungal medications to prevent fungal infections for a while after transplant.

Dosage: The dosage is different for each drug. Nystatin, a liquid antifungal medication, is used to prevent or treat thrush, a fungal infection that appears in the mouth. There is also a lozenge form (Mycelex® troche) that should be dissolved slowly in the mouth. Vaginal creams, suppositories, and ointments are also available for fungal infections that develop in the vagina or on the skin. For a fungal infection in the lung, like aspergillus, a stronger medication called Voriconazole may be prescribed.

Side effects: Side effects may include nausea, vomiting and diarrhea as well as decreased liver function. There will be a need to monitor liver function closely. Side effects of clotrimazole also include mouth irritation or a stinging sensation.

Additional information:

Nystatin oral solution should be swished, like mouth wash, and held in the mouth for at least 30 seconds before swallowing.

The clotrimazole lozenge should be dissolved slowly in the mouth.

You should not eat or drink for 15 to 20 minutes after taking nystatin oral solution or the clotrimazole lozenge so that the medication can be absorbed into the tissue of the mouth and esophagus.

Oral antifungal medications are usually taken twice a day. It is important to take these medications on an empty stomach to ensure proper blood levels.

Special Considerations: Notify your doctor if you have any side effects to the medication. You must continue to take all the medication as directed even after you are feeling better.

Drug Interactions: Fluconazole can increase Cyclosporine and Tacrolimus levels. Let your doctor know what medication you are taking, as some undesirable reactions have occurred with patients who are taking any benzodiazepine or benzodiazepine derivative such as: Alprazolam (Xanax), Chlordiazepoxide (Klopidol, Librax, Libritabs, Librium), Clonazepam (Klonopin), Clorazepate (Tranxene and Novo-Clopate), Diazepam (Valium), Estrazolam (ProSom, Eurodin), Flurazepam (Dalmane and Dalmadorm), Midazolam, Quazepam (Doral, Dormalin), Triazolam (Halcion, Hypam, and Trilam). Fluconazole may increase and prolong levels of these drugs causing increased depression of the central nervous system that can result in decreased rate of breathing, decreased heart rate, and loss of consciousness and psychomotor impairment which is comprised of a slowing down of thought and a reduction of physical movements.

Trimethoprim/ sulfamethoxazole (TMP-SMX), Bactrim®, Septra®, Co-trimoxazole, Cotrim®)



Purpose /Action: TMP/SMX is used to prevent or treat a type of pneumonia called pneumocystis jiroveci pneumoni (PJP). Patients who have suppressed immune systems have an increased risk of getting this type of pneumonia.

Dosage: TMP/SMX is available as a tablet or liquid. The dose and duration of treatment to prevent PJP varies by center. Some centers prescribe Bactrim® three times a week which is to be taken for the rest of the patient's life. Since the treatment for PJP may differ at other transplant centers, be sure to know how your transplant team wants you to take this drug.

Side effects: Patients who are allergic to sulfa drugs may also be allergic to TMP/SMX, and may develop a rash, itching, or hives. If you are allergic to medications containing sulfa, please tell your transplant doctor so a different medication to prevent PJP can be prescribed. Other side effects of include nausea, vomiting, diarrhea, mouth ulcers, a low white blood cell count, a low red blood cell count (anemia) or a low platelet count. TMP/SMX can cause an increase in liver and kidney function tests in some patients. This medication should be taken with plenty of fluids to reduce the risk of irritation of the urinary tract.

Dapsone and Mepron (Atovaquone)

Purpose /Action: Used to prevent or treat a type of pneumonia called pneumocystis jiroveci pneumoni (PJP) and toxoplasmosis. Patients who have suppressed immune systems have an increased risk of getting this type of pneumonia. Dapsone is a sulfone with anti-inflammatory immunosuppressive properties as well as antibacterial and antibiotic properties. Dapsone acts against bacteria and protozoa in the same way as sulphonamides. Dapsone is absorbed rapidly and nearly completely from the gastrointestinal tract. Mepron (Atovaquone) appears to act by inhibiting nucleic acid and energy synthesis.

Dosage: The usual dosage of Dapsone or Mepron is 100 mg daily.

Side effects: Side effects include nausea, headache, and rash, which are common, and insomnia, psychosis and peripheral neuropathy. Toxic hepatitis and cholestatic jaundice have been reported. Jaundice may also occur as part of the Dapsone / Mepron reaction or Dapsone / Mepron syndrome.

Special Considerations: A full blood count and liver function test should be obtained prior to initiating therapy. Side effects may be more frequent in patients receiving multiple drug therapy. The reaction always involves a rash and may also include fever, and jaundice.

Pentamidine aerosols are commonly used for patients who have sulfa allergy.

Pentamidine Isethionate Nebulizer solution

Purpose /Action: Used to prevent or treat a type of pneumonia called pneumocystis jiroveci pneumoni (PJP). Patients who have suppressed immune systems have an increased risk of getting this type of pneumonia. Additionally, Pentamidine has demonstrated good results in the treatment of yeast infections caused by the organism *Candida albicans*.

Dosage: The usual dose of Pentamidine 300 mg which is given by nebulizer.

Side effects: Include dizziness, tiredness, headaches, confusion, drop in blood pressure, rapid heart rate, burning in the throat, nausea, metallic taste, decreased appetite, anemia, shortness of breath,

cough, increased serum creatinine and blood urea nitrogen (BUN), if administered by injection pain at the site of injection.

Special Considerations: Use the aerosol until the chamber is completely empty, which can take as long as 45 minutes and follow the treatment plan as outlined by your doctor. Tell your doctor if you have had an allergic reaction to this medication, have kidney disease, or have problems controlling you blood sugar.

Drug Interactions: Let your doctor know if you are taking any of these medications before starting Pentamidine— Aminoglycosides, Amphotericin B, Capreomycin, Colistin, Polymyxin B, Vancomycin, Fosfarnet, or Cisplatin.

Antiviral Medications

Ganciclovir (Cytovene[®], Cymevene[®]) and Valganciclovir (Valcyte[®])



Purpose /Action: Ganciclovir and Valganciclovir are medications used to prevent or treat certain viral infections that commonly occur in patients who have a suppressed immune system. Cytomegalovirus (CMV), herpes simplex infections (HSV), and Epstein Barr Virus (EBV) infections are usually treated with Ganciclovir or Valganciclovir, depending on transplant center protocols.

Dosage: Ganciclovir is usually given twice daily for 14 days through an IV to treat an active CMV infection. In some cases, it may be given longer until the infection

resolves. Some transplant centers give Ganciclovir one to two times daily for up to 14 days after transplant to prevent CMV, particularly if the patient has a higher risk for developing this infection. Valganciclovir (Valcyte®) is the form of Ganciclovir that is taken by mouth. It is available as a tablet or a liquid. Valganciclovir may be prescribed daily for three to six months after transplant to prevent CMV or per center protocol.

Side effects: May include nausea, vomiting, headache, pancreatitis, irritation of the vein from the IV infusion (phlebitis), confusion, and seizures. Ganciclovir can decrease the white blood cell count and platelet count, but this usually resolves by decreasing the dose or by stopping the medication. Ganciclovir is eliminated from the body by the kidneys, so patients with kidney problems receive a lower dose. Studies in animals have shown that Ganciclovir affects fertility and sperm production. Male and female transplant patients of childbearing age should use contraception if they are receiving Ganciclovir. Contraception should be continued for several months after the medication is stopped. Women should not breastfeed during treatment with Ganciclovir.

Additional information: If you are diagnosed with CMV, the first few doses of IV Ganciclovir are usually given in the hospital. If you are doing well, you may be discharged to complete the IV treatment at home with nursing support.

Special Considerations: It is important to drink plenty of fluids while taking Ganciclovir or Valganciclovir because these drugs are eliminated by the kidneys. Patients are encouraged to drink two or three liters of fluid daily (unless fluid restricted) during their course of treatment.

Valganciclovir tablets should be swallowed whole and taken with food. Avoid handling crushed or broken tablets. Wash the affected area thoroughly if your skin comes in contact with the powder.

There is an increased risk of infection while on Ganciclovir and Valganciclovir therapy. Call your transplant team if you have fever, chills, unhealed sores, or white plaques in your mouth.

Cytomegalovirus Immune Globulin (CytoGam®, CMV-IVIG)

Purpose /Action: CytoGam® is a medication used to prevent and treat cytomegalovirus (CMV) and Epstein Barr Virus (EBV) infections in patients who are immunosuppressed.

Dosage: CytoGam® is given through an IV infusion in the hospital or clinic. The dose and frequency vary depending on different transplant center routines. CytoGam is used to treat an active infection or to help prevent infection.

Side effects: Side effects are uncommon, but when they do occur include flushing, sweating, muscle cramps, back pain, nausea, vomiting, wheezing, chills and fever.



**Acyclovir
(Zovirax®),
Valacyclovir
(Valtrex®),
Famciclovir (Famvir®)**



Purpose /Action: Acyclovir is a medication used in the treatment of certain viruses, particularly herpes simplex infections (HSV-1, HSV-2) and chickenpox and shingles (varicella zoster infections). Valacyclovir and Famciclovir are similar medications that can also be used to treat these infections. These medications help decrease the pain caused by the herpes lesions (sores) and also helps them heal.

Dosage: The dose of acyclovir depends upon whether it is being given to prevent or treat an infection and on the type of infection being treated. Patients with open herpes lesions (sores) are usually treated with intravenous (IV) acyclovir. When the lesions become crusted, the medicine is changed to oral acyclovir until all the sores are healed.

Side effects: The most common side effects of acyclovir are headache, tiredness, dizziness, seizures, insomnia, fever, rash, nausea, vomiting, diarrhea, elevated liver function tests, muscle aches, and kidney dysfunction.

Special Considerations: If you have herpes, acyclovir will not prevent you from spreading herpes to others. Intercourse should be avoided when symptoms of genital herpes are present or when there are active lesions (sores) in the genital area. Condoms can help prevent the spread of genital herpes.

Gastrointestinal (GI) Agents

**Antacids and Acid Inhibitors
GI Agents and Antacids:
Sucralfate (Carafate®)
Antacids: Mylanta®, Tums®,
Rolaids®, Maalox®, Di-Gel®**

**H2-Blockers: Famotidine
(Pepcid®) Cimetidine
(Tagamet®) Ranitidine
(Zantac®)**

**Proton-Pump Inhibitors
(PPIs) Omeprazole
(Prilosec®) Lansoprazole
(Prevacid®) Pantoprazole
(Protonix®) Esomeprazole
(Nexium®) Rabeprazole
(Aciphex®)**

**Motility agents: domperidone
(Motilium) and Reglan**

Purpose: Lung transplant recipients are at great risk of gastrointestinal (stomach) upset for several reasons including damage to a nerve that goes to the stomach (vagus nerve). This can result in delayed emptying of the stomach, bloating, reflux (heart burn) decreased appetite, nausea and vomiting. Nausea, vomiting, diarrhea, and decreased appetite often occurs because of the higher doses of immunosuppressive medications are needed in the first few months. Medications such as prednisone and Cellcept increase the risk for developing ulcers.

It is common for lung recipients to need medication like domperdone (Motilium) to increase motility and decrease symptoms of heart burn. Reflux (heart burn) has been associated with risk of infection and rejection in lung transplant recipients. It is very important that lung recipients avoid lying down within 2 hours of eating a meal. Your transplant team may advise you to raise the head of your bed if you have significant heart burn or reflux.

You may be prescribed one or two GI agents and/or antacids after transplant to treat symptoms of reflux, bloating, nausea, diarrhea and decreased appetite.

Sucralfate works by coating existing ulcers and the lining of the stomach. This coating protects the tissue from irritation by stomach acid. Acid blockers (H₂ blockers and PPIs) work by blocking acid production so you have a decreased amount of acid in your stomach.

Dosage: Each antacid is dosed differently. Your risks for developing stomach ulcers and the length of time after transplant will determine which GI agents, antacids and/or acid blockers are prescribed for you.

Side Effects: Most patients are able to take these medications without any problems. Side effects are rare but can include

headache, diarrhea, nausea, vomiting, and abdominal pain.

Additional Information:

Antacids may increase or decrease the absorption of many medications. Antacids (Carafate®, Mylanta®, Tums®, Roloids®, Maalox®, Di-Gel®) should be taken two hours away from other medications, particularly Tacrolimus, cyclosporine, Sirolimus, and Everolimus.

Antacids should be taken on an empty stomach so that the stomach is coated with the medication. Antacids should be taken before meals so the antacid does not bind with phosphorus in the foods you eat and lower phosphorus levels in your blood.

Omeprazole (Prilosec®) and lansoprazole (Prevacid®) capsules should be swallowed whole and not chewed. The capsules contain time-released granules that are slowly released in the body over 12 to 24 hours.

Esomeprazole (Nexium®) capsules can be opened and the granules mixed with water before taking.

Prevacid® is also available as a tablet that dissolves in the mouth (Prevacid Solu-tab) and as granules that can be mixed with water.



Medications to Treat Electrolyte Imbalances

Purpose: Sometimes medications can cause the electrolytes in your body to be out of balance. Electrolytes are substances your body needs to maintain fluid balance and to help with other functions of your body. Sodium, potassium, chloride, magnesium, calcium, and phosphorus are some of the electrolytes found in your body.

Medications to treat or prevent electrolyte imbalances may be needed for several reasons. Sometimes these imbalances are due to side effects of other medications. For example tacrolimus can cause magnesium levels in your blood to be lower than normal. Sometimes imbalances can occur if your kidneys are not working well. If you have a lot of diarrhea because of an infection or as a side effect of a medication, the bicarbonate level in your blood may be low. When electrolytes are higher or lower than the normal range, medications such as the ones listed below are used to treat the imbalance.



Medication	Use	Possible Side Effects
Magnesium oxide Magnesium plus protein Magnesium gluconate (Magonate [®])	to treat or prevent low magnesium levels	diarrhea, abdominal cramping, muscle weakness, high magnesium level, low blood pressure
Fludrocortisone (Florinef [®]) Kayexalate	to treat or prevent high potassium levels	high blood pressure, edema, headache, rash, low potassium
Sodium bicarbonate, sodium citrate, citric acid (Bicitra [®])	to treat or prevent low bicarbonate levels	edema, increased gas, abdominal distention, low levels of potassium and/or calcium, high levels of sodium
Sodium and potassium phosphate (Neutra-Phos [®]) Potassium phosphate (Neutra-Phos K [®])	to treat or prevent low phosphorus levels	low blood pressure, a high phosphorus level, nausea, vomiting, high potassium levels, diarrhea
Potassium chloride (K-Dur [®])	to treat or prevent low potassium levels	high potassium, nausea, vomiting, diarrhea, abdominal pain, muscle weakness, heart problems

Blood Pressure Medications



Purpose: High blood pressure (hypertension) is a common condition that is seen in the general population. A normal blood pressure is 120/80 mmHg.

Patients who have blood pressures that are always around 140/90 will need to be treated for high blood pressure. Patients who also have diabetes and/or poor kidney function will need to be treated for high blood pressure if their pressures are 130/80.

After Lung transplant, patients who have had high blood pressure will likely need to continue their treatment for hypertension.

Sometimes, high blood pressure occurs after transplant in patients who had a normal blood pressure. Many transplant centers may ask you to check and record your blood pressure at home. Home blood pressures are often more accurate reflection than those checked in clinic.

Hypertension after transplant can be a side effect of some medications, particularly the anti-rejections medications. High blood pressure also occurs if the kidneys are not working well.

There are several medications that can be used to treat high blood pressure. They work in different ways to control hypertension.

Sometimes patients are prescribed more than

one blood pressure medication because the medications work together to control hypertension. Sometimes a diuretic (“water pill”) is needed to work with these medications. Your doctor will prescribe the blood pressure medications that are right for you.

High blood pressure is also treated with a nutritious diet and regular exercise.

You will be encouraged to follow a diet that includes whole grains, fish, fruits, and vegetables while lowering the amount of red meat, salt and sugar in your diet.

This table includes some common medications used to treat high blood pressure.	
Medication	Possible Side Effects
ACE inhibitors Enalapril (Vasotec [®]) Lisinopril (Prinivil [®]) Ramipril (Tritace [®] , Altace [®])	headache, low blood pressure, dizziness, faint feeling, cough, fatigue, vertigo, insomnia, high potassium, increased creatinine levels
Calcium Channel Blockers Amlodipine (Norvasc [®]) Nifedipine (Procardia [®]) Isradapine (DynaCirc [®]) Diltiazem (Cardizem [®]) Verapamil (Isoptin [®]) Felodipine (Plendil [®])	Swelling of the feet and ankles, headache, flushing, palpitations, affects levels of some anti-rejection medications, low blood pressure
Beta Blockers Atenolol (Tenormin [®]) Metoprolol (Lopressor [®] , Toprol XL [®]) Bisoprolol (Emconcor [®] , Zebeta [®]) Carvedilol (Kredex [®])	low heart rate, low blood pressure, fatigue, dizziness, chest pain, swelling, sexual dysfunction, erectile dysfunction, depression
Diuretics Furosemide (Lasix [®]) Hydrochlorothiazide (Diuril [®])	dry mouth, thirst (dehydration) low potassium levels, high blood glucose levels, weakness, palpitations, ringing in ears (tinnitus), rash
Alpha Blockers Doxazosin (Cardura [®]) Prazosin (Minipress [®])	dizziness (especially when standing suddenly), allergic reaction, chest pain, palpitations, rash

Cholesterol-Lowering Medications

Statins: Atorvastatine (Lipitor®), Fluvastatin (Lescol®), Pravastatin (Pravasine®, Pravachol®) Rosuvastatin (Crestor®) and Simvastatin (Zocor®)

Purpose: Patients may develop high cholesterol after lung transplant. High cholesterol is a side effect of some antirejection medications. Some patients also have a family history of high cholesterol.

Dose: Medications to lower cholesterol (statins) are usually prescribed once a day. A variety of these medications are available. Your doctor will choose the cholesterol-lowering medication that is best for you.

Side effects: Side effects vary depending on which cholesterol-lowering medication you are prescribed. Side effects may include mild stomach pain, gas, bloating, stomach upset, heartburn, nausea, constipation, and skin rash. Rare side effects include muscle pain and tenderness or weakness with fever and dark colored urine. Statin medications can also affect how well your liver works. The side effects of these medications usually resolve by lowering the dose of medication or stopping the medication, if necessary.

Ezetimibe (Zetia®, Ezetrol®)

Purpose: Your transplant doctor will prescribe ezetimibe when high cholesterol levels cannot be controlled by cholesterol lowering medications (statins). Ezetimibe

works by reducing the amount of cholesterol that is absorbed by the intestine from the food you eat. Ezetimibe is usually used with other cholesterol-lowering medications. Lifestyle changes including a nutritious diet that is low in cholesterol, weight-loss, and exercise are also important in helping to reduce high cholesterol.

Dose: Ezetimibe is available in tablets and is usually prescribed once a day.

Side effects: The most common side effects are headache, diarrhea and muscle cramps.

Additional information:

Statins and ezetimibe should be taken at the same time every day. Patients who are being treated with statins and ezetimibe should avoid grapefruit and grapefruit juice. Talk to your doctor about how to take your cholesterol-lowering medication. Some can be taken with food while others should be taken on an empty stomach.

Medications to Improve Bone Density

Biphosphonates Alendronate (Fosamax®), Risedronate (Actonel®)

Purpose: Biphosphonates are prescribed to prevent or treat osteoporosis, a weakening of the bones as they become less dense. This condition can be caused by prednisone (steroids). Biphosphonates are usually prescribed in combination with calcium and vitamin D.

Dose: Both medications are available in tablets to be taken daily or weekly.

Side effects: The most common side effects are nausea, stomach upset, stomach cramps, diarrhea and irritation of the esophagus.

Additional information:

Biphosphonates should be taken in the morning on an empty stomach with at least 8 ounces (240 ml) of water. Do not lie down after taking biphosphonates. This position may increase the risk of reflux (when the stomach contents back up into the esophagus). Standing or sitting up decreases heartburn and the risk of injury to your esophagus from the reflux of stomach fluid. Being upright will also help you get the full dose. Wait at least 10 minutes before drinking fluids other than water, eating food, or taking other medications.



Over-the-Counter (OTC) Medications

After lung transplant, patients may have complaints about common every day illnesses, just like everyone else.

People often take over-the-counter (OTC) medications to treat common illnesses such as the flu, colds, and diarrhea. If you want to take an OTC medication for any cold or flu symptoms, be sure to contact your doctor or transplant coordinator before taking these remedies. Some OTC medications could interact with your transplant medications. It is also important that your transplant team knows when you are ill because your illness could be related to your transplant, rather than being a routine community-acquired illness.

OTCs for Diarrhea

Diarrhea may occur after lung transplant as a side effect of some commonly prescribed medications. Magnesium often causes diarrhea. You may have diarrhea if you eat foods that are spoiled or that you do not tolerate well. Food allergies cause diarrhea in some people. Diarrhea also can be a symptom of an infection in your gastrointestinal (GI) tract, or the result of a common virus.

If you have diarrhea for more than 24 hours or if you develop fever with diarrhea, contact your transplant team.

If you have diarrhea, your transplant medications may not be absorbed well in your intestine. This could result in low levels of immunosuppression. If your immunosuppression level is lower than it should be, you could be at risk of rejection.

Your doctor will prescribe the appropriate medication if you have diarrhea. If you have a bacterial infection in your GI tract, an antibiotic will be prescribed. Do not take an OTC medication for diarrhea unless told to do so by your doctor. Loperamide (Imodium®) and attapulgite (Kaopectate®, Donnagel®, Rheaban®) are common OTC medications that treat diarrhea.

OTCs for Constipation

If you are constipated, you may get some relief by increasing fiber in your diet. Eat plenty of bran, whole grains, fresh fruits, and vegetables. Drinking plenty of fluids can also help. Talk to your doctor about this if you are fluid-restricted. Activity also helps. Gradually increase your activity level and try to exercise daily. Narcotics, including codeine, increase the risk of constipation. Most patients on narcotics require routine stool softeners to prevent constipation.

Contact your transplant team if constipation continues to be a problem. Do not take any OTC medications for constipation unless told to do so by your doctor.

The most commonly used OTC medications for constipation include Metamucil®, Fiber-Con®, Senokot®, Milk of Magnesia, and Miralax®, Colace® (docusate) are stool softeners. They may be prescribed immediately after surgery to prevent constipation and straining to have a bowel movement. Enemas to lubricate the intestine can also be helpful in some patients who are constipated.

OTCs for Headache and Muscle Aches

If you have a headache or muscle aches that do not occur with fever, most transplant centers recommend taking acetaminophen Tylenol® (paracetamol).

Check with your transplant team for the recommended dose of acetaminophen/paracetamol and the frequency of dosing. Be sure you know your center's guidelines about using acetaminophen/paracetamol. If your headaches worsen or become more frequent, or if you also have fever or are vomiting, contact your transplant team. Ibuprofen products (Motrin®, Advil®, Nuprin®, Midol®, Brufen®, Nurofen®) and naproxen products (Naprosyn® or Aleve®) are common OTC medications used to treat headaches, muscle aches, and joint pain. Ibuprofen and naproxen products are not recommended by most transplant centers, particularly in the first few months after transplant. These medications can affect the kidneys and the liver. They can also cause stomach ulcers and bleeding in the stomach and GI tract. Do not take these medications without speaking to your transplant team first.

OTCs for Colds, Coughs, and the Flu

If you have cold or flu symptoms, particularly with fever, call your transplant team. Be sure you know your center's guidelines for what to do if you have a cold or the flu. If your doctor thinks your symptoms might be related to your lung transplant, you may be asked to come for a check-up and/or have labs drawn. Check with your transplant team before taking any OTC drugs because they can increase your blood pressure.

Most OTC cold and flu medications contain a combination of medications such as an antihistamine to dry your secretions and help you sleep, acetaminophen for aches and fever, and/or a cough suppressant. Avoid taking more than one OTC cold medication at the same time. Many OTC cold remedies have the same ingredients so you could accidentally take too much of an ingredient.

OTCs for Seasonal or Environmental Allergies

Over-the-counter allergy medications can help relieve the symptoms of seasonal allergies such as hay fever or allergies to pollen, dust, animal dander, or certain foods. There are several OTC medications that can be used to relieve allergy symptoms. If you have an allergy, contact your transplant team for your center's recommendations.

Nutritional Supplements

After lung transplant, you may be advised to take a daily multivitamin, vitamin supplements, and/or mineral supplements. This may be because of poor nutrition before transplant due to chronic disease or a difficult recovery after transplant. Your dietitian will give you guidelines for healthy eating after lung transplant and will discuss your specific dietary needs. Always check with your transplant team before taking any nutritional supplement that has not been prescribed for you.

Herbal Products

Herbal products, herbal remedies, and some herbal teas should be avoided after transplant. Most transplant centers strongly tell transplant recipients to avoid all herbal products. In the United States, herbal products are classified as dietary supplements by the Food and Drug Administration (FDA).

These products have not been tested for effectiveness, side effects, and drug interactions. Product safety and doses are not regulated. Herbal remedies may interact with your transplant medications or affect your transplanted lung.

St. John's Wort is an example of an herbal remedy that can cause complications in transplant recipients.

St. John's Wort is a well-known herbal supplement used to treat depression. This herb increases the metabolism, or breakdown, of medications. In transplant patients, this increase in metabolism causes a decrease in cyclosporine, tacrolimus, or sirolimus levels. Lower levels of these immunosuppressants will increase your risk of rejection.

Herbal supplements should be avoided. If you are interested in taking any herbal products, discuss your center's guidelines about herbal remedies with your transplant team. Never take an herbal supplement without telling your transplant team. These products can interact with your medications and lead to significant problems with your lung transplant.



REJECTION

Your body will consider the transplanted lung a foreign object. Your body's immune system is designed to seek and destroy any foreign object that it finds, such as a cold virus, a flu virus and a transplanted organ. The process of trying to destroy the foreign object, the transplanted organ, is called rejection. Rejection occurs as your body's immune system responds to the presence of the donor's lung. Rejection actually shows that your immune system is working! However, in transplant recipients, this normal immune response must be suppressed to protect the transplanted lung.

To reduce or limit rejection of your transplanted lung, you must take your anti-rejection medications as prescribed for the rest of your life. Unfortunately, sometimes even with immunosuppression and good medical care, your body's immune system will try to reject your lung. This often occurs within the first six months after transplant. Most patients who have received lung transplants will have at least one rejection episode in the first year after transplant. Rejection does not necessarily mean that your transplanted lung is going to fail. Most episodes of lung rejection can be treated successfully with anti-rejection medications if caught early.

There are two types of rejection, acute rejection and chronic rejection. In acute rejection lymphocytes (known as T cells) are involved in the immune reaction. They identify the lung as foreign and attack the cells of the transplanted lung. Acute rejection typically occurs during the first year after transplant although it can occur at any time. Humoral (vascular) rejection is generally referred to as chronic rejection occurs when antibodies (proteins that the

body makes to protect itself) damage to the airways and interfere with lung function. Episodes of acute rejection are treated by increasing or changing immunosuppression. Stronger treatments may be used if necessary to treat acute rejection in order to prevent the more serious chronic rejection type. Chronic rejection can lead to organ failure and death or retransplantation.

How do I know I am rejecting my lung?

During rejection the transplanted lung does not work as well as it should. If you are rejecting you may have some mild symptoms or a combination of several symptoms. These symptoms may include shortness of breath and a cough. Rejection does not necessarily mean that your transplanted lung is going to fail. Sometimes rejection occurs without any warning symptoms and may be the same as those seen in lung infection. The most common symptoms related to rejection include:

- Fever of 100.4° F or 38° C or higher
- Shortness of breath with light to moderate activity
- General malaise, not feeling well or not feeling "quite right"
- Flu-like symptoms such as chills, aches, dizziness, headache and pains
- New chest pain or tenderness
- Fatigue, weakness, extreme tiredness and lethargy
- Decrease in home spirometry
- Decreased appetite and/or nausea

You can help your transplant team detect possible rejection by paying close attention to changes your symptoms day to day and reporting changes to the transplant team. Contact your transplant team immediately if you have any of these symptoms. Do not assume they are due to other minor illnesses such as a cold or flu. Do not try to treat your symptoms by yourself or wait until your next

clinic visit or check-up. Some programs ask patients to check and record their spirometry every day and contact the transplant team if there is a drop in lung function.

How is lung rejection diagnosed?

Rejection does not usually mean that your donor lungs will no longer function or that you will need another transplant. Diagnosing and treating rejection as early as possible will help you get treatment in a timely manner, avoid complications and have a successful outcome.



Although knowing and reporting the symptoms above can help detect rejection, sometimes lung rejection occurs without any symptoms. That is why getting bronchoscopy with biopsy on a routine schedule is very important. A bronchoscopy is used to find rejection in the transplanted lung.

A bronchoscopy is a routine part of medical follow-up after lung transplantation. At most transplant centers the bronchoscopy procedure is performed within the first 3 to 6 weeks after the transplant surgery and several times over the first year. The frequency of the bronchoscopy procedure decreases over time, but bronchoscopy schedules vary between transplant centers. Some transplant centers continue routine biopsies for years, while others perform follow-up bronchoscopies only if the patient is having symptoms or reduced pulmonary function.

A bronchoscopy is a visual exam of the breathing passages of the lung (airways). This involves placing a thin tube-like instrument called a bronchoscope through your nose or mouth down into your lungs. There is a mini-camera attached at the tip, which brings images up on a video screen. This test is done when it is important for the doctor to see inside the airways of your lungs or to take a sample of mucus or tissue from the lungs. Some lung transplant programs do routine bronchoscopies to check for rejection; others do this test only if there is a drop in lung function or increase in mucous production. Most programs will do a bronchoscopy before you are sent home to make sure that the areas where your new lungs are attached to the old airways are healing well. It will take at least 3 months for complete healing of this attachment.

A bronchoscopy is done to check for:

1. Infection—to obtain better samples from the lung. These samples are sent to the lab to see if there is any infection.
2. Lung spot—infection, cancer and inflammation may cause an abnormal finding in the lung on X-ray or CT scan. This test allows the doctor to take samples from the affected area.
3. Ongoing lung collapse (atelectasis)—This is caused by a blockage in the airway such as a peanut, tumor or thick mucous. This test allows the doctor to see the blockage, sample and or remove the substance. This helps to open the airway.
4. Bleeding—when a patient has coughed up blood. This test can help the doctor to find the cause.
5. Noisy breathing and airway narrowing—This test allows your doctor to look at the throat, vocal cords and major airways to identify problems. Causes of this type of breathing may include vocal cord paralysis or weakness, floppiness in the airways (bronchomalacia), narrowing of the airway (stenosis) or a blood vessel pressing on the outside of the airway.
6. Rejection—If your transplant doctor suspects rejection, he may do a lung biopsy through the bronchoscope. These samples are sent to the lab where they are looked at see if you are having rejection.

Preparing for a bronchoscopy:

You cannot eat or drink for about 6 hours before this test or from midnight before the procedure. Your transplant team will advise you with regards to medications. If you are diabetic and take insulin, check with your transplant team about holding your insulin. Also, if you are taking medications that thin the blood (aspirin, warfarin, lovenox, plavix) check with your transplant team on how to adjust or hold these medications before this test.

Before the test you may inhale an aerosol (nebulize) spray of medication which numbs the throat area and prevents coughing and gagging during the procedure. Or you may be given an injection to dry out your secretions. An intravenous will be started so you can receive a sedative. The sedative will help you to relax, but may not put you to sleep.

What happens during the bronchoscopy:

You will be lying down with the head of the bed tilted up slightly. Oxygen tubing will be placed into your nose and you will be placed on monitors to measure your blood pressure, heart rate and oxygen levels. A mouth guard will be placed between your teeth to protect you from biting down on the tube. Your eyes will be covered with a towel to prevent any fluid from dripping into them, as well as protect them from the light on the end of the bronchoscope. The tube is slowly advanced down the back of your throat, through the vocal cords and into the airways. You will not be able to talk. The test takes between 5 and 45 minutes depending on why the procedure is being done.

Risks of bronchoscopy:

Bronchoscopy is a safe procedure. Serious risks, such as an air leak or serious bleeding are uncommon.

- There may be some discomfort and coughing while the bronchoscope is passed through your nose or throat into the lungs.
- The level of oxygen may fall during the procedure; this drop is usually mild and the level returns to normal without treatment. Your oxygen level will be continuously monitored during the procedure.
- The airway may be injured by the tube particularly if the lung is already very inflamed or diseased. If the lung is punctured, it may cause an air leak (pneumothorax) around the lungs,

which can cause the lung to collapse. This complication is not common and is more likely if a deep biopsy is taken. If there is a large or ongoing air leak, it may need to be drained with a chest tube.

- Bleeding can occur, but is more likely if the airway is already inflamed or damaged by disease. Usually bleeding is minor and stops without treatment.

What happens after the procedure?

Patients vary in their wake-up times. You will need to stay in the recovery area for at least an hour before the sedation wears off. You will need to wait at least 4 hours before eating or drinking anything. You will also need to arrange for a ride home as it is recommended you do not drive for at least 12 to 24 hours after this test. Some hospitals require a responsible person to be with you at the time of check in. You may be sent for a chest x-ray after the procedure to make sure you do not have an air leak.

It is unlikely you will have any problems after the test other than a mild sore throat, hoarseness, cough or muscle aches. If you have chest pain, increased shortness of breath or cough up more than a few tablespoons of blood once you leave the hospital, fever, chills, nausea or vomiting contact your nearest emergency department immediately or your transplant center.

How is acute lung rejection treated?

If acute rejection is diagnosed from the lung biopsy, your transplant team will prescribe treatment based on your medical history, the type of rejection you have and how long it has been since you have had your transplant.

Treatment for lung rejection depends on several factors: the severity of the rejection, and the effect of the rejection process on



your lung function, any previous episodes of rejection, your symptoms (if any), and your current immunosuppression routine.

Mild to moderate rejection is usually treated by increasing the amount and/or frequency of your antirejection medications. If you are taking prednisone, the dose may be increased. If you are not taking prednisone, it may be prescribed for a few days or weeks to treat the rejection. Sometimes an IV form of prednisone (Solu-Medrol®) is given for several days to treat rejection that does not resolve with oral prednisone. Another way to treat rejection is by adding or combining other anti-rejection medicines, such as mycophenolate mofetil, sirolimus, everolimus (available in Europe only) or azathioprine.

Depending on your symptoms, the severity of rejection, and your treatment, you may receive care as an out-patient or in the hospital. A repeat biopsy/bronchoscopy is usually scheduled after the treatment for rejection. If the rejection persists, more

treatment may be required. Persistent rejection is treated using stronger medications.

In humoral type rejection, antibodies (proteins that the body makes to protect itself) cause damage to the blood vessels which results in decreased blood flow to the lungs. This is a type of rejection that is treated differently than acute rejection. Humoral (vascular) rejection is treated by a process called plasmapheresis. During plasmapheresis, blood is taken out of the body by a special machine and the blood and plasma are separated. The blood is returned to the body, but the plasma is treated to remove the harmful antibodies that are causing the rejection. This process is called plasma exchange. The plasma exchange sessions are completed over a two to three week period. Patients may also be treated with heart failure medications to improve any symptoms they have from lung failure.

What happens after rejection resolves?

As rejection resolves and your lungs recover, your maintenance doses of antirejection medications may be adjusted. The level of your antirejection medication, usually tacrolimus or cyclosporine, may be reduced.



Your transplant team's goal is to have you on the lowest amount of immunosuppression possible so that you do not reject your lung and have good lung function. Lower immunosuppression also helps decrease your risk of infection and other side effects of higher levels of immunosuppressive medications.

What is chronic rejection?

Chronic rejection or Obliterative Bronchiolitis (O.B.) is a syndrome where the airways become inflamed. It can occur in the transplanted lung 6-18 months after transplant. Obliterative Bronchiolitis is more difficult to treat because of the progressive and permanent changes it causes to the lung tissue. Currently there are no curative treatments for chronic rejection. The aim of treatment for Obliterative Bronchiolitis is to maintain lung function and slow the progression.

Will I always have to be concerned about rejecting my lung?

The risk of rejection decreases over time but rejection of the lung can occur at any time. Your transplant team will discuss your test results, medication changes, and/or treatment plan with you. Good communication with your transplant team and following your care routine are key factors for a successful outcome after lung transplant.

Taking your medications as prescribed will reduce your risk of rejection. Getting your immunosuppression blood tests and keeping appointments for routine follow-ups are also important. Paying attention to subtle changes in your symptoms will help detect possible rejection early when it is more likely to respond to treatment. It is also important to report any changes in your condition to your transplant coordinator or transplant team in a timely manner.

Possible surgical complications

Diaphragmatic Injury may occur during the transplant surgery. Your diaphragm helps your lung expand. The phrenic nerves to the diaphragm may be cut or damaged. This can lead to decreased functioning of the diaphragm. Recovery of the phrenic nerve is very slow. This condition is usually temporary and does not require treatment.

Pleural effusion is an accumulation of fluid around the lung which may lead to chest pain, shortness of breath and nonproductive cough. This may be treated with medications or be drainage of fluid. This can easily be diagnosed with a chest x-ray.

Pneumothorax is a collection of air in the pleural space causing collapse of the lung. Symptoms of this may include a sudden sharp chest pain and increased difficulty breathing. It can be easily found with a chest x-ray. There are many causes of pneumothorax and the treatment is placement of chest tube. This allows the air to drain and the lung to re-expand.

**INFECTION*****Why am I at risk for getting infections?***

Lung transplant patients require antirejection medications to suppress their immune system so that the transplanted lung is not rejected. These drugs reduce the ability to fight off infection. This risk is highest in the first three to six months after transplant and when immunosuppression is increased to treat rejection.

If you are doing well, have good function of your transplanted lung, and have not had any episodes of rejection, your transplant doctor may slowly lower your level of immunosuppression after a few months. Using less immunosuppression, when possible, will help reduce your risk of infection.

How can I decrease my risk of infection?

There are many ways to stay healthy after lung transplant and reduce your risk for infections.

Discuss how you can prevent the risk of infection with your transplant team. Know your center's specific guidelines. The following guidelines are often recommended for transplant recipients.

Hand washing

Practice good hand washing techniques. Use warm water and soap, and scrub vigorously for 1 minute. Be sure to scrub between your fingers and under your nails. Waterless liquid soaps and gels can also be used when there is no visible dirt on the hands. These products are easy to carry with you in your purse or pocket. Wash your hands well before eating and preparing food, after going to the bathroom, after changing diapers, after playing with pets and before caring for any wounds or doing any dressing



changes. Report any changes in the wound such as increased redness, swelling, or drainage to your transplant team. Encourage all of your family and friends who are in contact with you to practice good hand washing techniques. Avoid putting your fingers or hands in or near your mouth; this is the most common way to spread colds and flu.

Contact

Avoid close contact with people who have obvious illnesses such as colds and flu. Avoid crowds, particularly when in a closed area like an indoor shopping mall, during cold and flu season. Do not share eating utensils, cups, glasses or toothbrushes with others since many viral illnesses are spread through saliva and mucous. Do not share razors, nail clippers or other manicure tools.

Pets

If you have pets, be sure that they are healthy and have had all their vaccines. Do not handle animal waste. Do not change cat litter, clean bird cages, fish or turtle tanks. Some types of pets should be avoided such as reptiles, turtles, amphibians (frogs), hamsters, and guinea pigs. These animals can carry infections that could cause you to become ill. Some transplant centers also recommend that transplant recipients avoid having caged pet birds in their homes, such as parrots or parakeets.

Swimming

Small standing bodies of water such as ponds or small lakes that may contain infectious organisms should be avoided. Swimming in oceans or large lakes may be permitted at six months after transplant if the water is tested to be safe for the general population by the local health department and if you are able to tolerate more strenuous exercise. Public hot tubs should be avoided.

What are some common signs of infection?

Some symptoms that may be related to infection include: fever greater than or equal to 101° F (38.5° C), new onset of body aches or pain, nausea, vomiting or diarrhea lasting more than 24 hours, any flu-like symptom such as cough, body aches, or chills, changes in wound appearance such as increased drainage, redness, foul odor, and/or pain and tenderness around the incision site. Whenever an infection is suspected, it is important to contact your transplant team to discuss your symptoms so that the problem can be diagnosed and treated promptly.

What infections are most common?

There are 3 types of organisms that cause infections: bacteria, fungi, and viruses.

Bacterial Infections

Bacterial infections mostly occur very early after transplant surgery. Infections from bacteria can occur any time the skin is opened through central vein catheters, surgical drains, and wounds. Patients can develop bacterial pneumonia, particularly if they had complications during or early after surgery and had a prolonged stay in the intensive care unit. Urinary tract infections may occur from having a urinary catheter to drain urine. If you have an infection caused by bacteria, your doctor will locate the site of infection and what type of bacteria is causing that infection. You will be given an antibiotic for several days to treat the bacterial infection. The antibiotic may be given through an IV or as an oral medication depending on the type and severity of the infection.

Fungal Infections

Fungal (yeast) infections are most common in the first three months after transplant.

Candida albicans, the most common fungus, looks like a white plaque or coating on the tongue and inside the mouth. This infection is also called thrush. It may make your mouth tender and sore and you might have difficulty swallowing. If thrush is not treated, it can spread to the esophagus, stomach, and intestine.

A fungus can cause vaginal infections (vaginitis) in women. The vaginal area may become very itchy and often produces a thick yellow or white discharge. Transplant patients who are highly immunosuppressed or taking high doses of prednisone are at risk for getting fungal infections. Most

fungus infections are non-invasive, meaning that they do not get into the bloodstream. *Candida* infections are treated with antifungal medications that are applied directly to the skin (topical medications) such as nystatin, lotrimin, or clotrimazole. Fungal infections in the blood are rare and are treated with IV anti-fungal medications.

Viral Infection Cytomegalovirus (CMV)

is a common community-acquired virus. Although it is not a serious illness for healthy individuals, CMV is of more concern to people who are taking immunosuppressive medications.

Because CMV is such a common infection, transplant centers often prescribe drugs to prevent this infection, particularly in patients who are considered to be at high risk for getting the virus. Two drugs that are often given to prevent CMV are ganciclovir or valganciclovir. This has helped to decrease the rate of this infection in transplant recipients. When possible, maintaining a lower level of immunosuppression will also decrease the risk of getting this virus.

Symptoms of CMV may include fever, cough, nausea, diarrhea and headache. A low white blood cell count and a low platelet count may also be seen. The most common site of CMV infection is in the GI tract. CMV in the GI tract can cause diarrhea, nausea, vomiting, abdominal pain, and/or bloody stools. If CMV infects the lungs, symptoms include fever, coughing, shortness of breath, or wheezing.

To check for CMV infection, your doctor will complete a physical examination, obtain blood tests, ask you about your symptoms, and assess your risk factors for getting this virus. The diagnosis is confirmed through a special blood test called the CMV-PCR.

This test detects CMV in your blood. Depending on symptoms, biopsies can also be taken of lung or bowel tissue to see if the virus has infected those organs.

CMV is treated with intravenous (IV) ganciclovir for 14 days or longer until the CMV-PCR shows that the infection has resolved. Some transplant centers prescribe six to ten weeks of oral valganciclovir (Valcyte®) after the course of IV ganciclovir is completed. In some cases, immunosuppression may be lowered during the infection to help the immune system fight the virus.

Epstein-Barr Virus (EBV) and PostTransplant Lymphoproliferative Disorders (PTLD). Epstein-Barr Virus or EBV is a very common virus. Most adults have been exposed to it at some point in their lives. EBV is the virus that causes mononucleosis. EBV can occur at any time following transplant, but most often occurs within the first year. This virus causes the B cells of the immune system to multiply or proliferate at a higher rate than usual.

Lung transplant recipients who are at a higher risk for developing EBV includes those who have never had EBV and have received a EBV positive lung and have received high doses of immunosuppression.

EBV is usually a mild to moderate viral illness but in rare cases, can become a more serious condition. This form of EBV is called PTLD, or post-transplant lymphoproliferative disease. Tumor growth or lymphoma is seen with PTLD.

Patients who are at high risk of developing EBV-related problems are followed closely through a blood test called an EBV-PCR. This blood test will be obtained regularly to check for EBV in the blood. Because

being immunosuppressed has caused the virus to develop, the best treatment for EBV and PTLD is to lower the level of immunosuppression until the infection resolves. But, lowering immunosuppression can increase the risk of rejection, so patients must be monitored closely.

Treatment for EBV and PTLD varies by transplant center, but usually includes decreasing immunosuppression and giving IV medications to help control the virus. Patients are followed very closely during this time when their immunosuppression is decreased so that if they begin to reject, immunosuppression can be resumed or increased.

TRANSPLANT CLINIC

After discharge from the hospital you will be followed as an outpatient at your center's transplant clinic. Most patients are seen several times within the first month, then less often as they improve and return home. Although clinic routines vary by center, long-term patients who have good lung function may be seen once or twice a year. Blood tests are also checked on a routine basis to check for any problems.

Most transplant centers will continue to manage immunosuppression while the patient's local physician and/or pulmonologist will manage routine care. Some centers transfer all patient care to the local doctor in the long term if the patient is doing well.

ACTIVITY

Exercise

Exercise improves your overall health. It makes you feel better and can help control stress. Regular exercise can help maintain a weight that is right for you. It can also help prevent bone loss (osteopenia and osteoporosis).

Any physical activity that you can do is beneficial. Walking, swimming, riding a bicycle, lifting light weights, playing golf or tennis, participating in yoga classes may be good for you. For some patients that were severely debilitated prior to transplantation, housework may be used to build up endurance before beginning an exercise regime. Most importantly, staying active is key to living a full and healthy life.

It is common to feel tired or weak as you recover from lung transplant. If you have been in the hospital for a long time before or after your transplant, you may have lost some muscle mass and strength from prolonged bed rest. You may also find that your sleep pattern is disturbed. Regular exercise and good nutrition will help you get back to a more active routine.

Transplant patients should discuss how to start an exercise program with their transplant team so that a safe exercise plan can be developed. It is important to talk with your transplant team about increasing your activity level and when to begin an exercise routine.

While you are in the hospital, you may receive physical therapy to help you regain strength and increase your activity level. Your physical therapist can help you start a simple exercise routine.

Pulmonary rehabilitation can be very helpful following lung transplant. These programs help lung transplant patients gradually and safely increase their activity level. They also teach patients how to exercise safely after lung transplant and can also help increase a patient's confidence in their ability to exercise.

Talk to your transplant team or physical therapist about a pulmonary rehabilitation program in your area.

For the first six months after transplant, you may be advised to avoid any strenuous activity, heavy lifting, or more intense exercise programs. Check with your transplant team for your center's guidelines. The best activity in the first few weeks after transplant is walking.





Most centers recommend that you avoid any activities or sports with a high risk of injury like football, wrestling, skiing, water skiing, or motorcycling.

To be healthy and fit is an important goal, but using common sense to reach this goal is just as important. Even months or years after your lung transplant, exercising when you are sick with a fever is not a good idea.

You should stop exercising immediately and call your doctor if you experience the following while exercising:

- Pain or pressure in your chest, neck or jaw
- Intense fatigue that is not related to a lack of sleep
- Unusual shortness of breath
- Dizziness or light-headedness during or after exercise
- A continuing rapid or irregular heart rate during or after exercise

Returning to Work or School

Transplant patients return to work or school at various times after recovery from transplant surgery. Your return depends on the extent of your illness before transplant, recovery time, complications, and lung function after your lung transplant. When possible, it can be helpful for you to return to work or school on a part-time basis. You can

gradually increase your hours as your energy and strength improves. Discuss returning to work or school with your doctor and transplant team. They can help you decide when you should return to work or school.

Vocational rehab programs may be available to help re-train you if you cannot return to your previous job duties.

Driving

Most lung transplant recipients can resume driving by six to twelve weeks after transplant, depending on their recovery period, complications, and medications. Do not drive if you are still taking narcotics for pain.

Your reflexes and judgment may be affected from being ill, from having a lengthy hospitalization, or by some medications. It is best to discuss this issue with your transplant team before getting behind the wheel. It is a good idea to practice driving in an open lot or away from other traffic for the first time as you get used to driving again. It may be helpful to have another licensed driver in the car with you for the first few times that you drive.

When driving or in a car, always wear a seat belt. The seat belt will provide a safe restraint in case of an accident.

YOUR LIFESTYLE AFTER LUNG TRANSPLANT

Sun Exposure and Skin Cancer

Screening

Transplant patients have an increased risk of developing skin cancer. This risk is up to 65 times greater than in people who have not had a transplant. The medications that transplant patients take to suppress their immune system cause this increased risk. Your chance of developing skin cancer is also related to how old you are at the time of transplant, the types of anti-rejection drugs you have taken, how long you have taken antirejection medications, and the amount of immunosuppression you have received.

Additional risk factors for skin cancer include having:

- fair or easily burned skin
- lots of freckling
- red or blonde hair
- blue, green or hazel eyes
- history of extensive sun exposure
- family history of skin cancer
- previous skin cancers

Almost all skin cancers can be cured if caught early. Transplant patients should examine their skin every month.

Look for any new or changing growths including pink patches or spots, scaly growths, bleeding spots, or changing moles. Report any changes promptly. Your doctor should thoroughly examine your skin during your annual check-up or refer you to a dermatologist.

If you are at high-risk for developing skin cancer, it is a good idea to see

a dermatologist annually. Transplant recipients should always use a sunscreen with a sun protection factor (SPF) of at least 30 to protect their skin from light rays that can damage the skin. Make sure to reapply it every 90 minutes and after exposure to water. If you are burning or tanning with sunscreen on, you are not using enough sunscreen or reapplying it often enough.

Sunscreen should be used on all exposed areas of skin. It is also important to wear sunglasses, a broad-brimmed hat, and protective clothing (long sleeves, long pants). Outdoor activities should be avoided or limited during the time when the sun's rays are the strongest, between 10:00 AM and 4:00 PM. Transplant patients should not use tanning booths.

Travel

As you recover and return to a more normal routine, you may want to travel or go on a vacation. Check with your transplant team for your center's guidelines on traveling after your transplant. Some centers recommend waiting for 6 to 12 months before you take an extended vacation, particularly one that may be farther away from major hospitals or transplant centers.

If you are planning a vacation, you may be advised to have your routine blood tests taken before you travel. Call your coordinator to review your medications, blood test results, or any specific care needs. If you are traveling to a different time zone, discuss how to adjust your medication times with your coordinator. Before you leave, be sure to know where the closest hospital and/or transplant center is located in case of an emergency. Take enough medication to last your entire trip plus some extra in case your trip is extended.

If you are traveling by plane, pack your medications in a carry-on bag.

Check with your medication insurance to see what your pharmacy options are when traveling. A national chain pharmacy may be able to fill medications for you out of town. Mail order pharmacies can ship prescriptions to an address other than your own if you give them advanced requests.

When traveling on an airplane, you may be asked to wear your mask and change it every hour due because a damp mask does not work. Hand washing is the best way to prevent spreading of germs.

If you are traveling to a foreign country, you may need a letter from your transplant team that lists all of the medications that you take. Some transplant programs give patients an antibiotic to take with them in case they develop an infection and do not have access to a pharmacy.

Taking extra medications and packing them in a different bag may also be helpful should you or the airline misplace your luggage.



Take important phone numbers with you in case you need to call your transplant center while you are away. You may want to drink bottled water if you are traveling in areas where sanitary conditions are of concern. Use caution with ice in beverages. Eat only well cooked foods. Only eat fresh fruit and vegetables if you can wash them thoroughly in safe water.

Whether traveling by air, car or train, you should get up about every hour to walk around to help prevent blood clots in your legs.

Most transplant centers discourage travel to third world countries for patients who are immunosuppressed. The risk of getting infections in these areas is high and appropriate healthcare may not be available. Also some foreign travel may require immunizations that are not safe for patients who are immunosuppressed, such as measles and smallpox. If you plan to travel in this type of area, please discuss this with your transplant team so that you are fully informed of the risk. Protect yourself from disease-carrying insects, like ticks and mosquitoes. Never go barefoot, even at the beach. It is also helpful to learn more about the health concerns in your desired area of travel through the Travelers' Health website sponsored by the Centers for Disease Control at <http://www.cdc.gov/travel/destinat.htm>

This site discusses current illnesses and diseases occurring in that region, required vaccinations, health risks, and how to stay healthy during your visit.

Another helpful website on travel is the Transportation Security Administration at www.tsa.gov Click on Our Travelers, then Air Travel, then Travelers with Disabilities and Medical Conditions.



Safe Food Handling

Safe food handling is important for everyone. However, transplant recipients may be at an increased risk of getting an illness from certain foods because their immune system is suppressed. The following guidelines will help decrease your risk of getting an infection from food:

Always follow the safety instructions on food packaging.

Avoid raw or undercooked meat, fish (sushi, oysters), poultry, or eggs.

Cook foods thoroughly and serve them hot.

Always check labels on meats, fish, and dairy products for freshness and “sell by” dates.

Eat only pasteurized milk, cheese, and fruit juices.

Store foods appropriately. Place foods in the refrigerator or freezer as soon as possible if they require cold storage.

Wash your hands thoroughly with warm water and soap before and after preparing food, particularly if you have touched raw meat, fish, or poultry.

Wash all surfaces that come in contact with raw meat, fish, or poultry.

Scrub all raw fruits and vegetables before cooking or eating them.

Avoid eating from street vendors, salad bars or buffets due to possible contamination by others and unsafe food temperatures.

Drinking Water

It is safe for you to drink treated municipal tap water after your lung transplant. If you live in an area that has well water, it is best to boil that water at a rapid boil for at least 1 minute before using it for drinking.

Well water should be tested by your local water authority every 6 to 12 months, even if you are not using it for drinking water. Some transplant centers advise transplant patients to boil well water if they are using it for brushing teeth, washing fresh fruits and vegetables, or making ice cubes or cold drinks. If you have any concerns about your drinking water, contact your local health department. The health department will be able to advise you about the safety of your water and the need for further testing.

Pets

Pets can be an important part of your family life.

Research has shown that pets help relieve stress and have positive physical and psychosocial benefits, as well as possibly improving our quality of life. One study has reported that older adults who had pets were better able to handle crisis situations.

Although pets do carry a number of diseases that can be transmitted to humans, few are life-threatening. If you follow some common-sense guidelines, your risk of getting an infection will be decreased.

Wash your hands thoroughly after petting or playing with your pet, particularly before you eat, drink, or handle food. Avoid letting your pet lick your face. Some transplant centers suggest keeping your bedroom a pet-free area.

Be sure that your pet is healthy, has regular check-ups, and has received its required immunizations. If your pet is ill, have him seen by your veterinarian as soon as possible. Provide flea and tick protection for your pet year-round, as your vet advises.

Groom and/or bathe your pet regularly. If you have a cat, have your veterinarian trim your cat's claws regularly.

If possible, avoid your pet's bodily fluids (urine, feces, vomit). If your pet has an accident, ask someone else to clean the area. If you must clean up after your pet, wear gloves and a mask, then clean the area well with a disinfectant.

Do not change your cat's litter box. The litter and liner should be replaced often. The litter box should be cleaned at least monthly



with a disinfectant or boiling water. If you need to clean the litter box, wear a mask and disposable gloves. Wash your hands well after cleaning the litter box.

Avoid cleaning fish tanks. If you must clean your fish tank, wear disposable gloves and a mask. Wash your hands after you are done.

Contact your transplant team immediately if you are bitten by any animal.

Avoid stray or sick animals.

Some pets should be avoided by transplant patient. The following animals are considered high-risk animals by the Centers for Disease Control for people who are immunosuppressed: Reptiles, (lizards, snakes, turtles), baby chicks, ducklings, and exotic pets including monkeys, squirrels, skunks, ferrets, wild rabbits, and others.

Some transplant centers also suggest that amphibians (frogs), hamsters, guinea pigs, and caged birds should not be kept as pets in the home.

Plants and Gardening

Many centers recommend that transplant patients avoid exposure to live plants and soil for 3 to 12 months after transplant. If you have a cut on your skin while working in your garden, you are at greater risk of infection because many types of organisms grow in the soil.

If you are a gardener, be sure to wear barrier-proof gloves when you are working in the soil. Some programs recommend wearing a mask when working in the garden especially when dry and windy. It is also helpful to wash your hands often while gardening. Avoid working around compost piles, wet leaves, and rotting organic matter when possible. Avoid burning leaves and trash. These materials may contain mold which can cause major respiratory infections in immunosuppressed patients and have toxic fumes you should avoid. Check with your transplant team for your center's guidelines about gardening.

For lawn mowing wear a respirator mask (thicker mask can be obtained at a hardware store) to avoid inhaling dirt and grass clippings.

Power washing may result in contaminated water, spores, mold or other infectious materials becoming airborne. To avoid this risk, wear a mask.

Routine Screenings and Examinations

When you return home, you will resume routine care with your local doctor and other health professionals. However, most transplant centers prefer to manage immunosuppression and any transplant related care such as episodes of rejection, lung biopsies, and some transplant-related infections.

Check with your transplant team so that you know whom to call when you have any signs or symptoms of illness. You may be told to see your local doctor and then return to the transplant center for further evaluation. Your local doctor may be asked to perform certain blood tests and send the report to the transplant center.

Your Local Primary Care Physician (PCP)

Your local doctor may be an internal medicine physician (internist), respirologist (pulmonologist) or family doctor who will see you for routine medical care and follow the recommendations of the transplant center. This physician usually manages preventative healthcare, routine physical examinations, immunizations, and complications related to high blood pressure, diabetes, high cholesterol, or bone disease. It is important that you maintain close contact with your local physician.



Your transplant team should have the contact information for your local doctor before you leave the transplant center. The transplant team will forward information to your local doctor about your transplant surgery, any complications you may have had after transplant, and your current care plan.

Your transplant team will also describe the transplant center's role in your care and how the doctor can work cooperatively to be sure you do well. Your local doctor plays an important role in examining you for any possible complications. Be sure to see this doctor regularly and have reports of those visits sent to your transplant program.

Medic-Alert Identification

Many centers recommend that patients wear a Medic-Alert necklace or bracelet that identifies them as a transplant patient in case of an accident and/or if emergency care is required. Medic-Alert is a nonprofit membership organization in the United States that is recognized around the world.

The organization's goal is to protect and save lives by providing information during emergencies. These tags are recognized by emergency operations teams as they care for patients who are unable to communicate their health issues.

Your transplant team can give you a Medic-Alert brochure or you can contact them to become a member at 1-800-432-5378 or through the website at <http://www.Medicalert.org>. As a member, you can order Medic-Alert tags and submit information about your lung transplant, allergies, your current medications, and other health conditions that will be included in your file.



Other centers may only require you to have a medical alert bracelet (pendant) that has the transplant center's phone number, that you are immunosuppressed and any other medical condition you may have (like diabetes or a seizure disorder).

Dental Care

Keeping your teeth and gums healthy is an important part of your care after transplant.

Just like anyone, transplant recipients can develop gum disease, tooth decay, mouth ulcers, dry mouth, and mouth infections. Some dental problems may be related to side effects of some of the medications you take after transplant. You can develop infections more easily because your immune system is suppressed. Bacteria that are commonly in the mouth can cause infection.

You should visit your dentist and dental hygienist for regular check-ups and cleanings every six months. If you develop problems, you may need check-ups every three or four months. Examine your mouth often and call your doctor and/or dentist if you have chipped or cracked teeth, tooth pain, swellings or sores in your mouth, red or swollen gums, bleeding, or white patches on your tongue or the lining of your mouth.

Be sure to brush your teeth at least twice a day, particularly after meals and before going to sleep. Floss between your teeth daily to remove food particles and plaque.

If you are having your teeth cleaned or having a procedure that may injure your gums, some transplant centers recommend taking an antibiotic before the procedure to prevent infection. Your dentist will prescribe the appropriate antibiotic. Contact your transplant coordinator about your center's protocol for infection prevention before dental procedures.

Eye Care

Eye and vision check-ups are important for everyone. Vision screenings check how well you see. The need for a dilated eye exam by an eye doctor (ophthalmologist) is usually determined by age or a specific eye problem. For this test, the eye doctor uses eye drops to temporarily enlarge the pupil (the black center) of the eye. When the pupil is enlarged, the eye doctor can see the inside of the eye more easily. The dilated eye exam can detect serious problems such as glaucoma, cataracts, diabetes, infection, and cancer.

Transplant patients have an increased risk of eye problems because their immune systems are suppressed. Eye problems can also be a side effect of some medications, especially prednisone. Discuss the risk of developing eye problems with your transplant team. Some transplant centers recommend ophthalmology exams every year for those at risk. Ask your transplant team how often you should have an eye exam.

If you need a prescription change in your glasses or contacts, it is best to wait until

your steroid dose is at the lowest dose. This will allow your eyes to stop changing from the steroid changes.

Diabetic patients should have a dilated eye examination with an eye doctor at least once a year.

The most common eye problems seen after transplant include cataracts, changes in the pressure of the eye (intraocular pressure) leading to glaucoma, scarring in the layer of blood vessels behind the retina, and damage to the small blood vessels in the retina due to diabetes (diabetic retinopathy).

Eye infections have also been reported but are not as common now due to improved drugs prevent infection and rejection.

Call your local doctor and/or eye doctor if you have any symptoms of eye problems including:

- eye pain
- changes in vision such as blurring, double vision, or fading of colors
- flashes of light
- sensitivity to light
- seeing spots
- the appearance of dark spots in your vision
- distorted or wavy lines or edges of objects
- dry eyes with redness, itching, and/or burning



HEALTH CONCERNS

Gynecologic Examinations

Recommendations for routine gynecologic and breast exams vary by country, so it is important that you follow your doctor's advice and guidelines.

Many transplant centers advise their female transplant patients who are 18 years of age or older and/or are sexually active to have a gynecologic exam every year. The exam should include a pelvic exam to detect any problems of the uterus, a breast exam to check for changes in the breast tissue, and a Papanicolaou's smear (Pap smear) to detect any changes of the cervix.

Women ages 18-39 should have a breast exam every three years, or as needed, and should perform monthly breast self-exams. Women 40 years of age and older should also have a yearly mammogram and perform monthly breast self-exams. The doctor may advise women who have a family history of breast cancer or other risks to have a mammogram before the age of 40, or more frequently. Your doctor will tell you how often you need a mammogram.

Sexual activity

Sexual activity is an important part of your adult life. Before transplant, you may have decreased desire (libido) to have sex or have been unable to have sex (impotence) because of health problems and activity limitations. After transplant, your desire and ability to have sex returns. Most transplant centers advise that patients wait for six to eight weeks before resuming sexual activity. How quickly you are ready to have sex after transplant depends on how you feel. Ask your transplant team when it is medically safe for you to have sex. A general gauge of readiness (physically) is when you can climb 2 flights of stairs. Avoid pressure or strain on the incision sites.

There are many reasons why patients can have problems with sexual activity.

Problems could be from complications related to your original lung disease, medications, or in your relationship. When you are ready to resume sexual activity, it may be helpful to discuss any concerns you may have with your partner. If you have any questions or concerns about resuming sexual activity, be sure to talk with your doctors.





Fertility and libido

Fertility for both men and women may return quickly after transplant. Studies report that regular menstrual cycles start within a few months to a year after transplant for most women. Many men who had difficulty with sexual activity before transplant report improvements in erections. It is common for men and women before transplant to have low levels of sexual activity because of their illness, activity limitations, and low desire (libido).

Although some differences are reported with the type of organ transplant, most men and women report an improvement in their desire for sexual activity and in their sexual functioning after they have recuperated from their transplant.

Safe sex

Safe sex practices are important for everyone who is sexually active to avoid the risk of contracting sexually transmitted diseases (STD). Transplant patients have an increased risk of getting STDs because their immune system is suppressed.

Practicing safe sex is the best way to prevent STDs. Safe sex practices include: having sex with only one partner (a monogamous relationship), washing your

genitals before and after sex, always using latex condoms with spermicide, avoiding sex with anyone who has sores, a rash, or a foul discharge from their genitals and avoiding anal sex.

Birth control and pregnancy

When you resume sexual activity after transplant, a reliable method of birth control should be used. Barrier methods (condoms, diaphragms, and spermicidal jellies) are most often advised. When one or more barrier methods are used, it is possible to prevent conception as well as provide protection from STD. Some transplant centers have approved the use of low-dose oral contraception (“the pill”). However, oral pills place the transplant patient at greater risk for blood clots, high blood pressure, gastrointestinal (GI) problems, coronary artery disease, and depression. Cyclosporine levels may be higher in patients who take cyclosporine and “the pill”. Also, it is important to remember that the pill prevents pregnancy when taken correctly, but it does not protect against STDs.

Generally, becoming pregnant or fathering a child has been safe and successful for many women and men who have received organ transplants. Pre-pregnancy counseling is important so that you can plan your pregnancy to achieve the best possible outcome for you and your baby.

Most transplant centers advise that female transplant recipients wait about two years after transplant to become pregnant. This allows for a reasonable amount of time to be sure that the transplanted organ is healthy and functioning well. The risk of pregnancy may be greater for lung transplant patients because of higher doses of immunosuppression required and a greater risk of infection.

When considering pregnancy the first thing that should be considered is overall good health. Once this has been established, female lung transplant patients should have: stable function of the transplanted lung, stable level of immunosuppression, good kidney function, normal blood pressure or well-controlled high blood pressure, and normal blood glucose levels or well controlled diabetes. You should see a high risk doctor to discuss your situation BEFORE becoming pregnant.

If you are thinking about getting pregnant after your lung transplant, it is important to remember that each pregnancy has its own unique concerns and possible risks. There are many issues to consider about your current health, the function of your transplanted lung, and your medications.

Planning with a complete understanding of the issues and with good medical care before, during, and after pregnancy can lead to the best outcome for you and your child.

Pregnancy outcomes of transplant patients in the United States are being followed through the National Transplantation Pregnancy Registry (NTPR). You may contact the NTPR through the registry's toll free number at 877-955-6877 to request more information. Your transplant team can discuss the findings of the NTPR in greater detail with you if you are thinking about becoming pregnant.

For more information about pregnancy, refer to *Pregnancy and Parenthood After Transplant: What You Should Know*. Published by the International Transplant Nurses Society. Available at: <http://www.itns.org/education/patient-materials>.

Prostate screening

The prostate is a walnut-sized gland that is part of the male reproductive system. It is located in front of the rectum and below the bladder. The prostate makes the fluid that carries sperm. Prostate cancer is one of the most common forms of cancer in men. Although the cause of prostate cancer is not known, some risks have been identified. These include:

Age: The risk of getting prostate cancer is greater as men get older.

Family history: A man is more likely to develop prostate cancer if his father or brothers had prostate cancer.

Race: Prostate cancer is more common in some racial and ethnic groups. It is more common in African American men than Caucasian men. Men of Hispanic, Asian, Native American, or Pacific Islander descent are less likely to develop prostate cancer than white men.

A blood test called the prostate-specific antigen test (PSA) is used to screen for prostate cancer. This test measures the level of a substance (enzyme) produced by the prostate and checks whether or not this level is within the normal range. Another test used to screen for prostate cancer is the digital rectal examination (DRE). For this examination, the physician inserts a gloved lubricated finger gently into the rectum to feel the back of the prostate. The physician checks the size of the gland and feels for any irregularities.

Doctors recommend that all men who expect to live for at least 10 more years should be given the opportunity to have the PSA blood test and DRE every year, starting at age 50. Men who are African American or have a family history should be tested earlier.

It is important that you discuss prostate screening with your doctor. You should know your risk factors for prostate cancer and the pros and cons of screening to make the best decision for you.

Colorectal Screening Tests

Recommendations for colorectal examinations vary by country, so it is important that you follow your doctor's advice and guidelines.

Colorectal screening (examination of the large intestine and rectum) is recommended for both men and women 50 years of age and older to detect signs of colorectal cancer. This cancer is an abnormal growth of tissue that occurs in the colon (large intestine) or rectum. It is the third most common cancer after prostate cancer and lung cancer in men. In women, it is the third most common cancer after breast cancer and lung cancer. Colorectal cancer is very treatable when diagnosed at an early stage. It can be prevented through regular screening tests that can find abnormal growths (precancerous polyps). These growths, or polyps, can be removed before they turn into cancer. Screening is important because polyps and colorectal cancer may not cause any symptoms, particularly in the early stages.

There are several tests or procedures used to screen for colorectal cancer. Your doctor will advise you about when you should be screened for colorectal cancer and which test or tests are right for you. In addition to routine screening, it is very important to tell your doctor about any changes in your stools or bowel routine including: an increased or decreased amount of stool, a change in stool color, a change in the

firmness or texture of your stool (hard stools or liquid/watery stools), or the appearance of blood in the stool.

Bone Density Screening

Osteoporosis is a disease in which the bones become fragile and more likely to break or fracture. Most people think that osteoporosis occurs only in women, but men can develop this condition as well. Although any bone can be affected by osteoporosis, the bones of the hip, spine, and wrist are at greatest risk. If not prevented or if left untreated, osteoporosis can progress painlessly until a bone breaks.

Risks factors for developing osteoporosis include:

Age: Your bones become weaker and less dense as you age.

Gender: Women are more likely to develop osteoporosis because of the effects of menopause and because they have less bone tissue than men.

Family history: Osteoporosis tends to run in families.

Race: White and Asian women are at greater risk. Hispanic and African American women have a lower risk.

Bone structure and weight: Small-framed women weighing less than 127 pounds/58 kilograms are at greater risk for osteoporosis.

Menopause: Women lose up to 20% of their bone mass within the first five to seven years after menopause.



Life style: Smoking, high alcohol intake, not getting enough calcium in your diet, and not exercising or having an inactive lifestyle can lead to osteoporosis.

Medications: Certain medications, such as prednisone, can increase the risk of osteoporosis.

Chronic disease: Some long-term health conditions, such as chronic kidney disease, can increase the risk of osteoporosis.

Transplant patients are at an increased risk for getting osteoporosis. Some anti-rejection medications can cause osteoporosis, particularly in the first 6 to 12 months after transplant when immunosuppressant levels are high.

Prednisone, cyclosporine, and tacrolimus are all associated with osteoporosis. Your chance of getting osteoporosis depends on your general risk factors as well as the amount of immunosuppression and length of time you are taking large doses.

There are several things you can do to prevent osteoporosis.

Eat a well-balanced diet that is rich in calcium and vitamin D. Talk to your

transplant dietician for advice about the amounts and types of foods that are right for you, particularly if you have other health problems.

Be active! Exercise daily and include aerobic and weight-bearing exercises in your routine.

Live a healthy lifestyle. Do not smoke. Avoid alcohol or follow your transplant center's guidelines on alcohol intake.

Ask your doctor about your need for having a bone mineral density (BMD) test. A BMD measures the density of your bones, or bone mass, and is painless and safe. Guidelines for this test are based on your age, risk factors, and any recent fractures.

Medications may be helpful in some people. Although osteoporosis cannot be cured, there are several types of drugs that treat this problem.

Your doctor and transplant team will always monitor your immunosuppression levels and your risks for developing osteoporosis. In some cases, medications or doses may be changed to decrease your risk. Never stop or change these medications on your own. Talk to your transplant team about your risks for developing osteoporosis after transplant.

Immunizations

Immunizations are an important part of routine healthcare for everyone. Most adult transplant patients usually receive all required immunizations before transplant, but infants and young children may not because of their age or being too ill. If a transplant patient needs immunizations, there are some important exceptions.

Transplant patients cannot receive immunizations that contain a live vaccine.

Receiving a live vaccine may cause major health problems because a transplant patient could develop the virus that he/she is being immunized against. This is because live vaccines contain a small but weakened amount of the live virus.

There are several live vaccines. The most common live vaccines that immunosuppressed patients should never receive are:

Oral polio (Sabin): The oral polio (Sabin) vaccine contains a live but weakened form of the polio virus. It is given to provide immunity against the polio virus (poliomyelitis). Some centers recommend that transplant recipients avoid contact with anyone who has had the oral polio vaccine for up to eight weeks since the virus might be shed in their stool and saliva.

MMR (measles, mumps, rubella): The MMR is a live vaccine given to children at 12 to 15 months of age and again at four to six years of age. As an adult, you should not need this vaccine. You do not need to avoid a child who has recently received the MMR or the individual vaccines.



Varivax® (chickenpox or varicella vaccine): This is a live vaccine given to children at one year of age to prevent them from getting chickenpox (varicella). People who are immunosuppressed should not receive this vaccine. Some centers advise transplant patients to avoid close contact with a child who has received the Varivax® injection. Check with your transplant team for your center's guidelines.

Other vaccines you may not receive:

- Flu mist
- Typhoid, live virus (S. Typhi, Ty21c
- BCG (attenuated mycobacteria, given for bladder cancer)
- Yellow fever
- Cholera
- Shingles vaccine

Tetanus Vaccine

The general public is advised to get a tetanus booster every 10 years. Some transplant centers advise getting a tetanus booster every 5 years. If your center advises receiving a booster every 10 years, if you get a dirty injury or cut or are bitten or scratched by an animal, you should get the tetanus booster right away.

Polio Vaccine

The Salk injection is an inactivated polio vaccine that contains “killed” polio virus. This “shot” form of the polio vaccine should be used in all immunosuppressed patients instead of the oral vaccine. This injection does not pose a risk to someone who is immunosuppressed. Transplant recipients who have infants should be sure that their child receives the Salk injection.

The Influenza Vaccine (“flu shot”)

The flu shot is an inactivated (killed) vaccine. It contains influenza strains (types) that are expected to be seen that year. People who want to decrease their risk of getting the flu should get the flu shot. Older people, very young children, and people with certain health conditions are at high risk for becoming very sick with the flu.

Transplant patients are usually advised to get the flu vaccine every year. Ask your transplant team for your center’s guidelines. The best time to get the vaccine is in October or November, although your doctor may advise you to get it earlier. It takes about 2 weeks for protection to develop in your body and this can last for almost a year. Sometimes a booster of the influenza vaccine is recommended in January. Most transplant centers advise that caregivers and other people in the household who have close contact with the transplant patient also get the flu vaccine.

People should not get the influenza vaccine if they have had: a severe allergic reaction to eggs an allergic reaction to the flu shot in the past or Guillain-Barré Syndrome. This is a disease that results in muscle weakness and sometimes paralysis.

Check with your transplant team about getting the flu vaccine or any other vaccine if you are within the first three to six months

after transplant or if you have recently been treated for rejection. You should not get the flu vaccine if you have a fever. You will need to wait until you no longer have a fever.

Be sure to reschedule an appointment to get the vaccine at a later date when you are feeling better.

A new form of the flu vaccine that is given as a nasal spray has been available since 2003 for use in healthy people, ages 5 through 49 years. Transplant recipients and people with suppressed immune systems cannot get this form of the flu vaccine. The nasal spray flu vaccine (flu mist) contains weakened live influenza viruses instead of killed viruses. This live vaccine may place them at high risk for complications from the flu. Family members should not get this form of vaccine as it is live virus and could not pass it along to the person with a suppressed immune system.

Pneumovax

A pneumococcal polysaccharide vaccine or pneumovax is recommended for adults 65 years or older and others in special risk categories such as those with breathing problems. This vaccine protects against 60-70% of the strains responsible for causing pneumococcal disease. The most serious diseases include blood infections, meningitis and pneumonia. Check with your transplant center regarding the scheduling and frequency of this vaccine.



Other Health Concerns

Smoking

Both active and passive smoking are risks to everyone's health. Smoking can cause cancer, heart disease, and lung disease. Smokers may have prolonged respiratory infections because of the effect of smoke on the lungs. Transplant patients who smoked before transplant are strongly encouraged to stop smoking. Nicotine found in all cigarettes is broken down or metabolized by the liver as a result, some medications, particularly tacrolimus and cyclosporine, may not work well. Levels of these medications may be lower in smokers.

Your transplant team or social worker can find local support groups to help you stop smoking. You can also contact the American Heart Association (<http://www.Americanheart.org>), American Lung Association (<http://www2.lungusa.org>), or the American Cancer Society (<http://www.cancer.org>) for more information and support. If you are interested in using any drugs to help you stop smoking, discuss this first with your transplant team.

Recreational/Illegal Drug Use

Drugs such as marijuana, cocaine, LSD, and Ecstasy are toxic chemicals that are harmful to the body. These toxic drugs will harm the liver and interfere with the break down or metabolism of transplant medications. Marijuana is known to carry a mold or fungus called *Aspergillus* which can cause a serious, life-threatening illness in people who have suppressed immune systems.

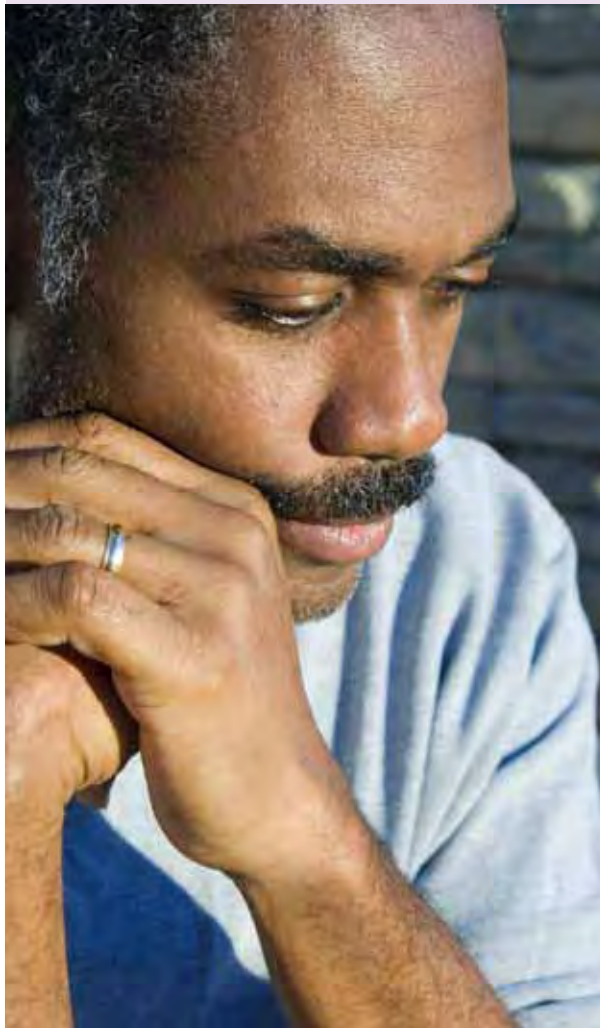
The illegal use of drugs is not tolerated by any transplant center. If you have had problems with recreational/illegal drugs in the past or are concerned you may want to use them again, discuss this issue with your



transplant team. Help is available through counseling and support programs.

Understanding Your Emotions after Transplant

The transplant process can be a very difficult emotional experience. Some transplant patients have more emotional problems and stress before transplant when they are waiting for a lung transplant. Others have more stress after transplant as they learn to cope with the changes in their life. In the early months after transplant, transplant patients can have a variety of emotions including anger, frustration, guilt, and depression.



These feelings can affect you for many reasons and in many ways. What is emotional or stressful for you, may not be as stressful for another person. Some common symptoms people have when they are dealing with emotional problems may include: feeling sad, depressed, angry, anxious, or overwhelmed, crying frequently, or easily being unable to focus or concentrate, not sleeping well, sleeping too much, being unable to fall asleep, mood changes, and changes in appetite.

Feeling emotional can also be a side effect of medications or an underlying medical problem. Talk to your transplant team about how you feel. They will ask how you are

feeling emotionally when you come for your clinic visits. It is always important to check for any medical problem that can affect how you feel.

You can also help yourself! It is important to develop positive ways of dealing with your emotions and feelings after transplant.

Some things you can do to help yourself include:

Exercising and being active as possible.

Participating in social activities with friends and family at home and in your community.

Eating a healthy diet.

Establishing a good sleeping routine. Take naps if needed and get adequate rest.

Relaxing through music, social activities, arts and crafts, yoga, and/or meditation and deep breathing.

Be aware of how you feel.

Let your family and friends know that you need their support. Talk to them about how you feel. Talking or just spending time with them can be helpful.

Talk to other transplant patients through support groups. Sometimes it is helpful to talk to other people who have shared the same experience.

Talking to a professional counselor may also be helpful. Your transplant team can refer you to someone who can help.

GLOSSARY OF TERMS

A

ABO testing	Blood tests that classify human blood into one of four groups: A, B, O or AB.
Anemia	A decreased amount of circulating red blood cells in the body. Anemia may result from blood loss, destruction of red blood cells, or a decrease in the production of red blood cells. The hemoglobin level is decreased in patients with anemia.
Antibody	An antibody is a protein produced by the immune system in response to specific antigens. Antibodies help the body fight organisms that cause infection. They also attack foreign substances.
Antigen	An antigen is a substance usually found on the surface of cells that identifies the cell as “self” or “non-self.” The antigen causes an immune response through antibody production against the antigen.
Arteriogram	An arteriogram is a radiologic study (x-ray) or picture of the arteries in an organ system. The arteries are visualized through a special dye that is injected in the blood stream.

B

B cells	B cells are a type of lymphocyte, or white blood cell, that are made in the spleen and are responsible for the body’s immunity. B cells produce antibodies which help fight infection and attack foreign substances.
Biopsy	<p>A biopsy is a procedure that removes a small amount of tissue from an organ, tumor, bone, or other tissue from the body. It helps your doctor find out more information about that organ or tissue.</p> <p>In a transplant patient a biopsy is done to diagnosis rejection of the transplant organ.</p> <p>A lung biopsy is performed to examine lung tissue. A tiny amount lung tissue is removed. This tissue is examined under the microscope by a pathologist to look for any signs of rejection or infection in the transplanted lung.</p>

- Blood Urea Nitrogen** A test that indicates kidney function. The BUN is a product of protein (BUN) breakdown normally excreted by the kidney.
- Bronchoscopy** Bronchoscopy is an examination of the larger airways (trachea and bronchi) using an instrument called a bronchoscope. During this procedure your doctor can visualize and obtain lung samples. Bronchoscopy may be done to diagnose problems with the airways and lungs.

C

- Calcium** A mineral measured in the blood that is required for bone growth and for blood clotting. It is also needed for the heart and nerves to function.
- Catheter** A flexible tube that enters or exits the body. Catheters may be used to drain body fluids (a urinary catheter drains urine) or to give fluids or medications through a vein (a central venous catheter).
- Cholesterol** A form of fat that performs necessary functions in the body but can also cause heart disease. Cholesterol is found in animal foods such as meat, fish, poultry, eggs and dairy products.
- Chronic** A problem that develops slowly and lasts a long period of time. Chronic disease may worsen slowly over time. It may be treatable but is usually not reversible.
- Chronic Rejection** Slow failure of the transplanted organ.
- Coagulation** The process of blood clotting. Many factors are required for the blood to clot normally. Clotting ability is assessed by several blood tests including the prothrombin time (PT), partial thromboplastin time (PTT), and platelet count.
- Coagulopathy** Decreased ability of the blood to clot. This increases the risk of bleeding, particularly with surgery or any invasive procedures such as biopsies.
- Complete blood count** A blood test that measures many parts of your blood count, including the hemoglobin (Hgb), hematocrit (Hct), platelets blood count (FBC) (Plt), and the types of white blood cells (WBC).
- CT scan** Computed Tomography scan; a noninvasive radiologic study that shows a detailed cross-section of organ and tissue structure.

Creatinine	The creatinine level indicates health of kidney function. It is a waste product produced by the muscles and released into the blood stream. Creatinine levels may be increased with kidney disease. Abnormal creatinine levels can also be caused by some medications.
Crossmatch	This is a test that examines the compatibility of the transplant recipient's blood with that of the donor. A high positive crossmatch may indicate the need for higher levels of immunosuppression. A negative crossmatch means that there is no reaction between the donor and recipient.
Cytomegalovirus (CMV)	CMV is a type of herpes virus. Between 50 – 85 % of people in the United States have had a CMV infection by the time they are 40 years ago. CMV is mainly a problem for certain high risk groups such as organ transplant patients. CMV is a virus commonly seen following transplantation that can cause an infection in the gastrointestinal tract, blood, liver, lungs, and/or eyes.

D

Diabetes	Diabetes means that you have too much sugar in your blood.
Diastolic	This is the “bottom number” of blood pressure reading when the heart muscle is at rest, expanding and filling with blood.
Diuretic	A medicine that helps remove excess fluid from the body tissue by causing the body to excrete sodium. Furosemide (Lasix®) and spironolactone (Aldactone®) are diuretics. These drugs will increase urine output.

E

Edema	Swelling of tissue, particularly in the face, hands, legs, and ankles. Diuretics may help to decrease edema.
Electrolytes	The dissolved form of a mineral found in the blood that helps maintain bodily functions and fluid balance. Sodium, potassium, chloride, magnesium, calcium, and phosphorus are some of the electrolytes found in your body.
Enzyme	A protein made in the body that is capable of changing a substance from one form to another.

G

Gingival hyperplasia Swelling or enlarged gums. It is a side effect of cyclosporine and some seizure medications. Gum overgrowth may be controlled or decreased through good oral hygiene, surgical gum reduction, and changes in immunosuppression.

Glucose The body's primary source of energy takes the form of glucose. It is a type of sugar comes from digesting carbohydrates into a chemical that can be easily converted to energy. Glucose levels may vary with diet, medications, stress, and organ dysfunction.

H

Hematocrit A measurement of the amount of red blood cells in the blood.

Hematoma A collection of blood outside a blood vessel. For example trauma can cause blood to collect in the tissue.

Hemoglobin Hemoglobin is a protein in your red blood cells. Hemoglobin contains iron and protein. It carries oxygen from the lungs to the tissues and carbon dioxide from the tissues to the lungs.

Herpes A family of viruses that cause infection in humans.

Hirsutism Excessive hair growth. It is a common side effect of cyclosporine and is seen in both male and female transplant patients who receive cyclosporine. In women, increased hair growth is often seen as male-patterned growth such as facial hair.

Hyperlipidemia A high level of fats (triglycerides or cholesterol) in the blood. This can be caused by diet, genetic disorders, or medications.

Hypertension High blood pressure occurs when the force of the blood pushing against the walls of the blood vessels is higher than normal because the blood vessels have either become less able to stretch or have gotten smaller. High blood pressure causes the heart to pump harder to move blood through the body. High blood pressure can cause kidney failure and heart disease if not treated.

I

Immune system	A specialized system of cells and proteins that protect the body from organisms that may cause infection or disease. The immune system, which is made up of special cells, proteins, tissues, and organs, defends people against germs and microorganisms every day. In most cases, the immune system does a great job of keeping people healthy and preventing infections. But sometimes problems with the immune system can lead to illness and infection.
Immunity	The ability of the body to resist an organism to infection that causes infection or disease.
Immunization	Providing the body with protection from certain diseases through vaccinations. Immunizations help protect you from disease. They also help reduce the spread of disease to others and prevent epidemics. Most are given as shots. They are sometimes called vaccines, or vaccinations.
Immunosuppressed	Describes the immune system of a transplant patient which is weakened by certain medications. Drugs (such as cyclosporine, tacrolimus, and prednisone) are used to lower the ability of the immune system to attack foreign cells (the transplanted tissue). Immunosuppression will help decrease the body's ability to reject the transplanted organ.
Infection	Organisms such as bacteria, fungi, and viruses that invade the body and reproduce, causing a many symptoms.
Insulin	A hormone secreted in the pancreas by the Islets of Langerhans that regulates sugar metabolism. Insulin helps the body use sugar and other carbohydrates. As insulin is released in the body, the blood sugar level decreases.
Intravenous (IV)	Drugs and nutrients may be given directly into the veins.

L

Lymphocytes	Cells produced by the lymph glands defend the body against infection and foreign substances by making antibodies and other substances.
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M

Magnesium A mineral required for normal bodily function. Magnesium is involved in nerve, skeletal muscle, heart, and cell function. It is also involved in blood clotting and the metabolism of carbohydrates and proteins. It helps maintain normal muscle and nerve function, keeps heart rhythm steady, supports a healthy immune system, and keeps bones strong. Magnesium also helps regulate blood sugar levels, promotes normal blood pressure, and is involved in energy metabolism and protein synthesis. Dietary magnesium is absorbed in the small intestines. Magnesium is excreted through the kidneys.

N

Nephrotoxicity Kidney damage, usually as a result of medications or other substances.

Nonadherence Failure to follow instructions for medical care. This may include not taking medications as directed, not getting labs as instructed, or missing clinic appointments and tests. Nonadherence is a significant post-transplant issue that often results in rejection, infection, and loss of the transplanted organ.

P

Pneumocystis jirovecii pneumonia A bacterial fungal infection of the lungs that is more common in people who are immunosuppressed. Transplant patients are usually (PJP) given an antibiotic (Bactrim®/Septra®) to prevent this type of pneumonia.

Platelet A type of blood cell that is involved in the clotting process. Platelets help stop bleeding at the site of the injury by clumping and forming a clot. If the platelet count is low, there is an increased risk of bleeding.

Post-transplant lymphoproliferative disease—PTLD a wide spectrum of viral disorders associated with the Epstein Barr Virus (EBV) that may range from a self-limiting mononucleosis (“mono,” glandular fever) to a type of lymphoma, or cancer of the lymph nodes. PTLD is a complication of a suppressed immune system and occurs in only a small percentage of patients. Treatment includes lowering immunosuppression and giving antiviral medications.

Potassium A mineral required for normal body functioning. Potassium is important in helping the heart, nerves, and muscles function properly. Potassium also helps change carbohydrates into energy and in forming proteins. The kidneys excrete any extra potassium in the body. It is important to check potassium levels after transplant because some anti-rejection medications can cause an increase in the potassium level. If the potassium level is too high, there is a risk for abnormal heartbeat patterns (arrhythmias). Some diuretics can cause low potassium levels.

Prophylactic Antibiotics or antivirals that are given to prevent certain infections in a group of patients who are at a higher risk for these infections. For example, patients who are at risk for CMV may receive prophylactic (preventative) treatment with ganciclovir or valganciclovir.

R

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

Renal A term that refers to the kidney or having to do with the kidney.

S

Shingles A viral infection caused by the herpes zoster virus that usually affects an area by a nerve, resulting in fluid-filled blisters and pain. Shingles rash is most often seen on the neck, abdomen, and legs. The virus can also affect the nerves of the eye. Shingles can be very painful. Although shingles can occur anywhere on your body, it most often appears as a band of blisters that wraps from the middle of your back around one side of your chest to your breastbone. Shingles is caused by the varicella-zoster virus — the same virus that causes chickenpox. After you've had chickenpox, the virus lies inactive in nerve tissue near your spinal cord and brain. Years later, the virus may reactivate as shingles.

Sodium A type of salt found in the blood and required by the body to maintain the balance between electrolytes and water.

Steroids Corticosteroids; hormones secreted by the adrenal gland, located above the kidney. This hormone can also be manufactured. It is prescribed through medications such as prednisone/prednisolone. Steroids can help prevent rejection and may be prescribed in higher dosages to treat rejection.

Systolic The “top number” of blood pressure measurement. The systolic pressure measures the pressure as the heart muscle contracts to pump blood around the body.

T

T cells T cells are a type of lymphocyte, or white blood cell, that develop in the thymus gland which is located in the upper chest in front of the heart. T cells are associated with the ability of the body to fight an infection or foreign substance that it was exposed to in the past. T cells play a major role in the rejection process.

Thrush A fungal infection that looks like white plaques or spots in the mouth, throat, and on the tongue. Patients who are immunosuppressed are at greater risk for developing thrush.

U

Ultrasound A test that uses sound waves to display organs, blood vessels and ducts. For example an ultrasound of the heart is called an echocardiogram (ECHO). It may be obtained to examine the size of the heart and the valves, fluid in the sac around the heart, and the heart pumping function. Most ultrasound exams are done using a device outside of your body. There are some ultrasound exams that place a device inside your body.

V

Vital Signs (VS) The measurement of temperature, blood pressure, heart rate, and respiratory (breathing) rate.

W

Wean To slowly withdraw or reduce; Immunosuppression, particularly steroids, may be weaned slowly over time in patients who have not had rejection.

White blood cell A type of blood cell that fights infection.