

A GUIDE TO YOUR HEALTH CARE

AFTER HEART TRANSPLANTATION



ITNS Heart Transplant Handbook

A Guide for Your Health Care after Heart Transplantation

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Table of Contents

Introduction	4	Your Lifestyle after Heart Transplant	62
Purpose	4	Sun exposure and skin cancer screening	62
Your Responsibilities	4	Travel.....	63
Your Transplant Team.....	5	Safe food handling	64
Medications	9	Drinking water.....	64
What you should know about your medications	9	Pets	64
Medication Guidelines	11	Plants and gardening	65
Commonly Prescribed Medications Following Heart Transplantation	13	Routine Screenings and Examinations	66
Medications to treat or prevent rejection.....	13	Medic-Alert identification	66
Medications to treat or prevent infection	25	Your local primary care physician (PCP).....	67
Gastrointestinal agents, antacids and acid inhibitors.....	28	Dental care	67
Medications to treat electrolyte imbalances.....	29	Eye care	68
Blood pressure medications	30	Sexual and reproductive concerns.....	69
Cholesterol-lowering medications.....	31	Prostate screening.....	72
Bone density medications	32	Colorectal screening tests	73
Over-the-counter medications	32	Bone density screening	73
Complications Following Heart Transplantation	35	Immunizations	75
Fever	35	Tetanus vaccine.....	76
Rejection.....	37	The influenza vaccine.....	76
The Denervated Heart.....	43	Other Health Concerns	77
Infection	44	Smoking.....	77
Taking Care of Yourself and Your Heart	48	Recreational/Illegal Drug Use.....	77
Transplant Clinic.....	48	Understanding Your Emotions after Transplant	78
Vital Signs.....	49	Glossary of Terms	79
Blood Tests	52	Vital Signs Form	87
Nutrition	58	Appointment Diary	88
Activity	60	My Transplant Team	89
Returning to work or school	61	My Local Healthcare Team	90
Driving	61		



Congratulations on your recovery following heart transplantation! This manual provides important information about your care as you and your family prepare for discharge from the hospital. As you are learning by now, heart 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 heart. You are the most important member of the transplant team and active participation in your care will lead to a successful recovery.

Purpose

This handbook is designed as a general reference for care after heart transplantation. Transplant centers often have different care routines, monitoring guidelines, and immunosuppressive routines following heart transplant. It is always 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 heart. 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.
- ✓ Have blood tests drawn and other tests and procedures completed routinely.
- ✓ Monitor your weight, blood pressure, and temperature.
- ✓ Maintain a healthy lifestyle that includes a balanced diet, regular exercise, and routine check-ups.

Your Transplant Team

Maintaining regular contact with your transplant team is important. Team members will continue to provide medical care, advice, and support for you and your family throughout the transplant process. Transplant centers have a variety of members on the heart transplant team, but usually 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 through clinic appointments and communicating with members of the team. Support from your family and friends is also helpful in your care and recovery.

Heart Transplant Surgeon

Heart transplant surgeons are medical doctors who specialize in surgery of the heart and in heart transplantation. The surgeons assess your heart condition and determine whether heart transplantation is the best treatment for your illness. The heart 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: _____

Cardiologist

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

My transplant cardiologist: _____

Office number: _____

Management varies by transplant center, so you may have follow-up care with a heart transplant surgeon or cardiologist. Your surgeon or cardiologist will be responsible for managing your medications and any medical issues directly related to your heart transplant. For health problems not related to your heart 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.

Heart Transplant Coordinator (RN, CCTC)

Transplant coordinators are usually licensed registered nurses (RN). They are experienced in the care and management of patients with heart disease who are waiting for transplant. The transplant coordinator will also help you prepare for discharge after transplant and will 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 heart 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 is usually 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. Your dietician will help manage your nutrition before and after transplant. This clinician determines your ideal body weight and will discuss any food restrictions you may have before transplant due to heart failure. The dietician will also teach you about nutritional guidelines after transplant such as low fat or low salt diets or fluid restrictions. 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: _____

MEDICATIONS



One of the most important responsibilities you will have after your transplant surgery is taking your medications correctly. Here are some things you should know 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 (non-branded) 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 an infection, your health care provider may order an antibiotic. Be sure to know how long you are to 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.

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.

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 heart transplant recipient.

Call your transplant coordinator if you:

- are unable to take your medicines because you are nauseated, feeling sick, or vomiting
- have diarrhea and are worried that your medication is not being absorbed
- have forgotten to take your medications or missed any doses
- notice 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, herbal medicine, or medication that you have not previously discussed with your doctor
- would like to take acetaminophen (Tylenol®)/paracetamol for fever
- are instructed to take any new medications by your local doctor or 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 Heart Transplantation

This section contains information about medications that are commonly prescribed following heart transplantation. This information is meant to be a general guide for the heart 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 heart transplant. Tacrolimus prevents rejection by inhibiting or suppressing the immune system so that the immune system does not attack the cells of the transplanted heart, causing rejection. Tacrolimus may be used by itself or in combination with other anti-rejection medications (immunosuppressants) to prevent rejection.

Dosage: Prograf®, the brand form of Tacrolimus, is available in 0.5 mg (yellow), 1 mg (white), and 5 mg (pink) capsules. Several generic forms of Tacrolimus are also now available. 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 heart 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 (neurotoxicities): High tacrolimus levels may cause headache, insomnia (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 (aphasia) 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 (*nephrotoxicity*):

Tacrolimus can cause the blood vessels that carry oxygen-containing blood in the kidneys to get smaller or constrict. When these tiny vessels (arterioles) 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 (an elevated blood urea nitrogen [BUN] and creatinine). 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, usually during the first three months after transplant. 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. This is called a *trough level* and is the lowest level of tacrolimus that is present in the blood. For example, if you take tacrolimus at 8:00 AM and 8:00 PM, your trough level should be drawn between 6:00 and 8:00 AM or 6:00 and 8:00 PM.
- 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.
- Your dose of tacrolimus may be increased if you are experiencing 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.



- Take your tacrolimus dose in the same way and at the same time every day to maintain a stable level.
- 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. A light breakfast or meal appears to have no effect on tacrolimus absorption. Again, being consistent in how you take this medication is most important.
- 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. 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. All forms of grapefruit and drinks containing a significant amount of grapefruit juice should be avoided

- if you are prescribed tacrolimus. An increased tacrolimus level increases your risk of infection and serious side effects. Seville oranges should also be avoided.
- Some medications should not be taken at the same time as tacrolimus.
 - Two hours from tacrolimus: sucralfate (Carafate®), Mylanta®, Tums®, magnesium oxide, magnesium gluconate (Magonate®)
 - Two to four hours from tacrolimus: sodium bicarbonate (Bicitra®, Polycitra®)
- 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, do not double the next dose. Contact the Transplant Team for instructions. Remember, it is best to stay on schedule with all your medications.
- 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 heart transplant. Cyclosporine prevents rejection by inhibiting or suppressing the immune system so that the immune system does not attack the cells of the transplanted heart, 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

(neurotoxicities): High levels of cyclosporine may cause headache, hand tremors, trouble sleeping (insomnia), 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 (*nephrotoxicity*):

Cyclosporine can cause the blood vessels that carry oxygen-containing blood in the kidneys to get smaller or constrict. When these tiny vessels (arterioles) 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 (an elevated blood urea nitrogen [BUN] and creatinine). 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, particularly during the first three months after transplant, and if you are being treated for rejection with increased immunosuppression.

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. This is called a trough level and is the lowest level of cyclosporine that is present in the blood. For example, if you take cyclosporine at 8:00 AM and 8:00 PM, your trough level should be drawn between 6:00 and 8:00 AM or 6:00 and 8:00 PM.
- 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.

- Your dose of cyclosporine 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 complications due to side effects of the medication.
- 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. Grapefruit, grapefruit juice, or the herbal product of grapefruit will increase cyclosporine levels. Patients who are taking cyclosporine may develop a very high level of their medication if grapefruit is taken at any time of day. All forms of grapefruit and drinks containing grapefruit juice should be avoided if you are prescribed cyclosporine. An increased cyclosporine level increases your risk of infection and serious side effects. Seville oranges should also be avoided.



- Some medications should not be taken at the same time as cyclosporine.
 - Two hours from cyclosporine: sucralfate (Carafate®), Mylanta®, Tums®, magnesium oxide, magnesium gluconate (Magonate®)
 - Two to four hours from cyclosporine: sodium bicarbonate (Bicitra®, Polycitra®)
- 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, do not double the next dose. Contact the Transplant Team for instructions. Remember, it is best to stay on schedule with all your medications.
- 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 and all 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. Although some patients require prednisone for life, many transplant recipients are being weaned from steroids within weeks to a few months after transplant. Some centers do not use prednisone unless it is needed to treat rejection.

Dosage: Prednisone is available in several strengths including 1 mg, 2.5 mg, 5 mg, 10 mg, and 20 mg tablets. 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.
- If prednisone is to be stopped, the dose should be decreased slowly over several weeks. If prednisone is stopped completely, serious complications may occur.
- Prednisone should be taken with food because this medication can cause stomach upset.
- If you miss a dose, do not double the next dose. Contact the Transplant Team for instructions. Remember, it is best to stay on schedule with all your medications.
- 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 transplant team 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 0.5 mg (tan), 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 insure 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. Since 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, 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. This is called a trough level and is the lowest level of sirolimus that is present in the blood. 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.
- 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.
- If you miss a dose, do not double the next dose. Contact the Transplant Team for instructions. Remember, it is best to stay on schedule with all your medications.

Azathioprine (Imuran®)



Purpose: Azathioprine is used to help prevent or treat rejection in organ transplant recipients. Azathioprine is a “helper” immunosuppressant and may be given with tacrolimus, cyclosporine, and/or prednisone.

Dosage: Azathioprine is available as a tablet and a liquid. It is usually prescribed once daily and should be given 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 (LFTs). It can cause an inflammation of the pancreas (pancreatitis).

Additional information:

- Do not change the dose of azathioprine or give 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.
- 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. Azathioprine and allopurinol can not be taken together.

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

Mycophenolate mofetil (Cellcept®)

Mycophenolate sodium (Myfortic®)



Purpose: Mycophenolate (MMF) is used to help prevent or treat rejection in heart 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 (enteric-coated) 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. The enteric-coated form of mycophenolate helps decrease GI side effects in some patients.

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.
- On days when you are having blood work, be sure to have your labs drawn before taking mycophenolate 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, do not double the next dose. Contact the Transplant Team for instructions. Remember, it is best to stay on schedule with all your medications.
- 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, 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 these viruses.

Everolimus (Certican[®])
Everolimus does not have FDA approval in the United States. It is currently used in European countries only.

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 disperses 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 25 ml (about one ounce) of water. Wait for about two minutes so the tablet can break up in the water. Then swallow the entire solution. Rinse the cup with another 25 ml (one ounce) of water and swallow that amount of water as well. The maximum dose of the dispersible tablet that can be dissolved in 25 ml of water is 1.25 mg. If your dose is greater than 1.25 mg, you will need more water to mix with the medication. 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.

- 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 losing 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 medications that you take to stop your body from rejecting your new heart 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 will prescribe one or more drugs to protect you from infection or to control infection. The following section includes some of the most commonly prescribed medications to prevent or treat infection following heart transplant.

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



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

Dosage: The dose and duration of treatment to prevent PJP varies by center. Some centers prescribe Bactrim[®] three times a week for the patient's lifetime, usually on Monday, Wednesday, and Friday. Other transplant centers prescribe a lower dose that is taken daily for three months post-transplant. Be sure to know your transplant center's plan for taking this medication. TMP/SMX is available as a tablet or liquid.

Side effects: Patients who are allergic to sulfa drugs may have an allergic reaction to TMP/SMX. These patients may develop a rash, itching, and hives. If you are allergic to medications containing sulfa, your transplant doctor will prescribe a different medication to prevent PJP. Pentamidine aerosols or dapsone are commonly used for patients who have a sulfa allergy.

Other side effects of TMP/SMX 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.



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

Purpose: Ganciclovir and valganciclovir are medications used to prevent or treat certain viruses 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 routines.

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 virus 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 virus.

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.

Side effects: 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 at least 3 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 will be discharged to complete the IV treatment at home with home care nursing support.
- Since ganciclovir/valganciclovir is eliminated by the kidneys, drink plenty of fluids while you are taking this medication. 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 coordinator if you have fever, chills, unhealed sores, or white plaques in your mouth.

Cytomegalovirus Immune Globulin (CytoGam®, CMV-IVIG)

Purpose: 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: 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 on the type of herpes infection being treated. The dose also depends on if the herpes infection is active or if it is being prevented. Patients with open herpes lesions (sores) are usually treated with intravenous (IV) acyclovir. When the lesions become crusted, the medicine is changed to acyclovir, which is taken by mouth 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.

Additional information: 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.

Antifungal Medications

Nystatin (Mycostatin®), Nilstat®) and Clotrimazole (Lotrimin®, Lotrisone®, Mycelex®)



Purpose: When you are taking anti-rejection 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.

Dosage: An antifungal medication is prescribed to treat fungus at the site of the infection. Nystatin, a liquid antifungal medication, is used to prevent or treat a fungus infection (thrush) that appears in the mouth. The liquid should be swished in the mouth for at least 30 seconds, like mouthwash, then swallowed. 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.

Side effects: Side effects are uncommon, but may include nausea, vomiting and diarrhea. Side effects of clotrimazole also include mouth irritation, a stinging sensation and increased liver function tests.

Additional information:

- Nystatin oral solution should be swished and held in the mouth for as long as possible (at least 30 seconds) before swallowing.
- The clotrimazole lozenge should be dissolved slowly in the mouth.
- Patients should not eat or drink for about 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.

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®)

Purpose: Following transplantation, patients are at risk for developing stomach irritation and ulcers. This can be caused by steroids and also stress which may increase the amount of acid in your stomach. You may be prescribed one or two GI agents and/or antacids after transplant. 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 the mechanism that produces acid 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 what 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®, Rolaids®, 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 that the antacid does not bind with phosphorus in the foods you eat. This can 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, a high level of 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 gluconate (Magonate®)	to treat or prevent low magnesium levels	diarrhea, abdominal cramping, muscle weakness, high magnesium level, low blood pressure
Fludrocortisone (Florinef®)	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 additionally have diabetes and/or poor kidney function will need to be treated for high blood pressure if their pressures are 130/80.

After heart transplant, patients who have had high blood pressure may need to continue their treatment for hypertension.

Sometimes, high blood pressure occurs after transplant in patients who previously had a blood pressure that was normal. 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 to control high blood pressure and any complications you may have.

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®) Isradipine (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, rapid swelling of the skin (angioedema)
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[®]), Fluvastatine (Lescol[®]), Pravastatin (Pravasine[®], Pravachol[®]), Rosuvastatin (Crestor[®]) and Simvastatine (Zocor[®])

Purpose: Patients may develop high cholesterol after heart transplantation. High cholesterol is a side effect of some anti-rejection 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 what cholesterol-lowering medication you are prescribed. Side effects may include mild stomach pain, gas, bloating, stomach upset, heartburn, nausea,

constipation, and skin rash. Muscle pain and tenderness or weakness with fever and dark colored urine are symptoms of muscle breakdown. This is a more serious side effect and is rare. Statin medications can also effect 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 can not 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.



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 prescribed alone or 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 30 minutes before drinking fluids other than water, eating food, or taking other medications.

Over-the-Counter (OTC) Medications

After heart transplant, patients may have complaints about common every day illnesses, just like the general population. 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 doctor knows when you are ill because your illness could be related to your transplant, rather than being a routine community-acquired illness.

Always contact your transplant center before starting any new medication.

• **OTCs for Diarrhea**

Diarrhea may occur after heart 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 by a fungus or bacteria 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 coordinator or physician. If you have diarrhea, your transplant medications may not be absorbed well in your intestine. This could result in unsuitable levels of immunosuppression. If your immunosuppression level is lower or higher than it should be, you could be at risk for complications.

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.

Contact your doctor and/or transplant coordinator 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) is a stool softener. It 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 doctor or transplant coordinator 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 doctor or transplant coordinator.

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. Although ibuprofen or naproxen may be appropriate medications to take for pain, be sure to talk to your doctor before using these medications.

• OTCs for Colds, Coughs, and the Flu

If you have cold or flu symptoms, particularly with fever, call your doctor or transplant coordinator. 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 heart transplant, you may be asked to come for a check-up and/or have labs drawn. If you have a common



community-acquired cold or flu, ask what OTC remedy you can take to relieve your symptoms. 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 coordinator for your center's recommendations.

- **Nutritional Supplements**

After heart transplant, some patients may be advised to take a daily multivitamin, vitamin supplements, and/or mineral supplements. This is usually because they had poor nutrition before transplant due to chronic disease or a difficult recovery after transplant. Your dietitian will give you guidelines for eating healthy



after heart transplant and will discuss your specific dietary needs. Always check with your doctor or transplant coordinator 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 recommend that transplant recipients 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 heart.

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 coordinator. Never take an herbal supplement without telling your physician or transplant coordinator. These products can interact with your medications and lead to significant problems with your heart transplant.

Complications Following Heart Transplantation

FEVER

What is fever?

Fever is an increase in body temperature that is above the normal body temperature of 98.6° Fahrenheit (F) or 37° Celsius (C). Fever is not an illness, but is a symptom of an illness. Fever can be caused by a minor illness as well as a serious infection. Fever is usually defined as a body temperature greater than 101° Fahrenheit (F) or 38.4° Celsius (C).

If you are taking prednisone, your body may not be able to show a high fever, so even a low fever, greater than 100° F or 38° C can be important. Discuss the fever temperature range with your doctor or transplant coordinator. Be sure you know what temperature is considered to be a fever for you.

Why would I get a fever?

In the general population, fever can be a symptom of a cold, the flu, or another type of infection. You may have a fever after your heart transplant. Remember that because you have had a heart transplant, your immune system is suppressed so that your transplanted heart will not be rejected. If you get a fever after heart transplant, it could be from a community-acquired cold or flu, as in the general population. But a fever after heart transplant can also be a symptom of rejection or a specific infection related to having a suppressed immune

system. A fever in the first several days after transplant can be an infection related to the surgery or a procedure. Sometimes a fever can even be a side effect of a medication.

What should I do if I have a fever?

It is very important to call your doctor and/or transplant coordinator if you have a fever. Check with your transplant coordinator about your center's guidelines on when to call if you have a fever. Be sure that you have a thermometer when you leave the hospital and that you are able to read it.



Digital thermometers are available if you have trouble reading a glass thermometer.

If you have a fever, most transplant centers recommend that you:

- Call your transplant coordinator or doctor immediately if your fever is 101° F (38.4° C) or higher.
- Do not take any medications to treat your fever until told to do so.

Depending on how high your fever is and any other symptoms, you may be told to take acetaminophen (Tylenol®) or paracetamol. Be sure to take the recommended dose at the appropriate time interval, usually every 4 to 6 hours. You may also be asked to have blood tests drawn or to go to your Transplant Clinic, physician’s office, or local Emergency Room for an examination.

Ibuprofen products (Motrin®, Advil®) are sometimes used to treat fever. You should not take these products unless advised to do so by your doctor. Although ibuprofen can treat high fevers effectively, this medication can also affect liver and kidney function. Ibuprofen also causes stomach irritation, ulcers and gastrointestinal (GI) bleeding.

My responsibilities in monitoring for fever:

- I must have a working thermometer that my caregiver or I can read before I leave the hospital.
- I should have a supply of acetaminophen (Tylenol®) or paracetamol on hand to take for fever if I am told to do so.



Ask your transplant coordinator to fill in the blanks below:

- After I am discharged from the hospital, I should take my temperature every _____

_____.
- I should call my transplant coordinator or primary doctor if my temperature is greater than or equal to _____° F or _____° C.
- If I am told to take acetaminophen (Tylenol®) or paracetamol my dose is:
_____mg or _____ tablets
every _____ hours as needed
for a fever greater than or equal to _____.
I should not take more than _____ doses in a 24 hour period.
- I should not take any ibuprofen products, such as Motrin® or Advil® unless told to do so by my doctor.

REJECTION

What is rejection?

Your body's immune system protects you from infection by recognizing and destroying certain foreign objects like bacteria and viruses. Unfortunately, your immune system "sees" your new heart as a foreign object also.

Rejection is an attempt by your immune system to attack your transplanted heart and destroy it. To prevent rejection, you must take anti-rejection medications (drugs), as prescribed, for the rest of your life.

In spite of all precautions, rejection can occur. Up to half of all heart transplant patients will have rejection at least once during the first post-transplant year, even though they are taking their anti-rejection drugs. The first rejection episode often happens within the first 6 months after the transplant. Rejection does not necessarily mean that your new heart is going to fail. Most rejection episodes can be successfully treated with anti-rejection drugs.

There are two types of rejection. The most common type is "acute cellular rejection". With this type of rejection, your T-cells (a certain type of white blood cells) "see" your heart as foreign and attack the cells of your heart. This type of rejection occurs most often during the first few months after transplant and decreases over time. However, it can occur at any time.

The second type of rejection is called "humoral" or "vascular" rejection. This type of rejection involves antibodies, which are proteins that your body makes to protect itself. These antibodies injure your blood vessels. This results in decreased blood flow and damage to your coronary arteries.

(Coronary arteries are the major blood vessels that supply blood to your heart). Humoral rejection occurs far less often than cellular rejection.

If I have rejection, do I need another heart transplant?

Rejection does not usually mean that you need another heart transplant. By having regular heart biopsies and knowing the symptoms of rejection, you can help avoid serious problems.

What are the symptoms of rejection?

You should look for symptoms of rejection and call your transplant team promptly if you have any of the following:

- Feeling tired or weak
- Fever of 100.5 degrees F (38 degrees C) or higher
- Shortness of breath at rest or with light to moderate activity
- Fast heartbeat or irregular heartbeat (skipping some beats)
- Swelling of your hands, feet, or ankles
- Sudden weight gain (such as 4 lbs [2 kg] within 24 hours)
- Drop in your blood pressure
- Not feeling "quite right" or flu-like aches and pains, chills, dizziness, headache
- Loss of appetite
- Feeling that you are "sick to your stomach"

What should I do if I have these symptoms?

You should call your transplant team right away if you have any of these symptoms. DO NOT try to treat these symptoms at home or wait until your next scheduled clinic visit to report these symptoms. Let your transplant team decide what to do about these symptoms. Your being concerned about something is reason

enough to call your transplant team. If most rejection episodes are caught early, they can be successfully treated.

Can rejection occur without any symptoms?

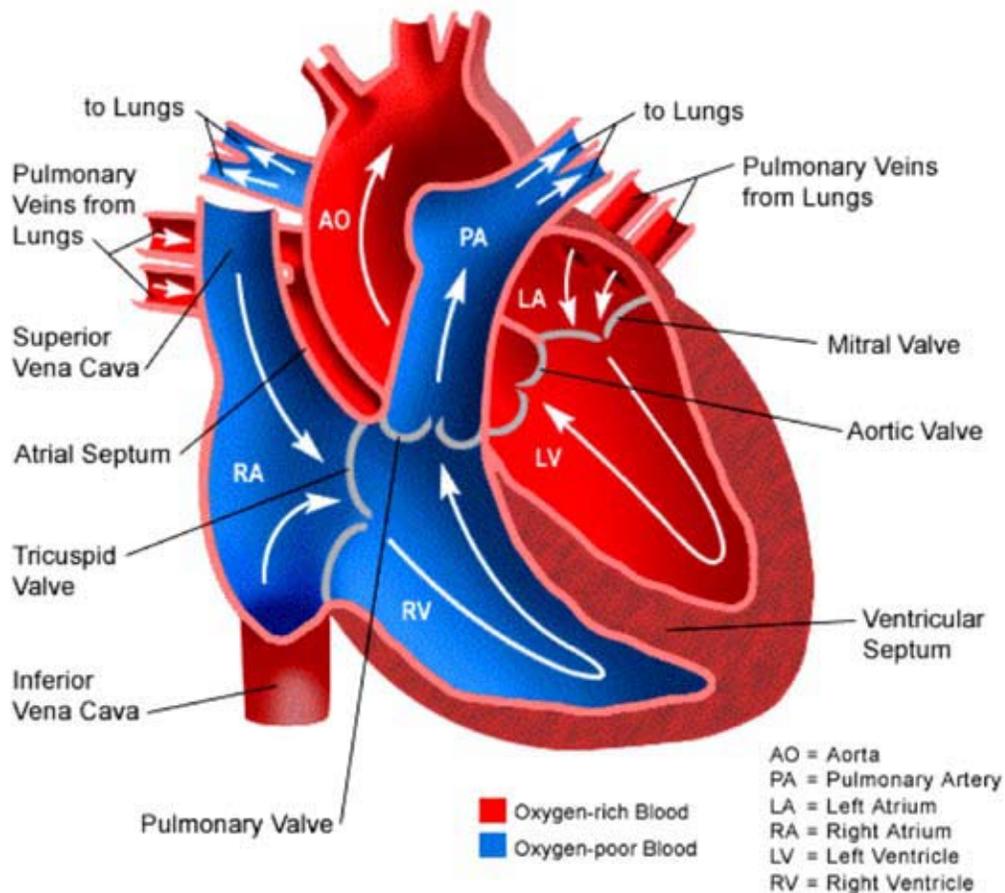
Yes. Sometimes rejection happens without any symptoms. That is why you have routine follow-up visits with your transplant team. These visits include an exam, lab tests, a review of your transplant log book (blood pressure, weight, etc) and tests to check for rejection.

What tests are used to check for rejection?

There are two tests for rejection: a heart biopsy and a gene expression blood test (AlloMap®). Your transplant team will tell you which test is best for you.

What is a heart biopsy?

A heart biopsy is a test to find out if you have rejection. This test often is done in the cardiac catheterization (“cath”) lab or a “special procedures” room. The right side of your neck will be cleaned with a special liquid. You will feel a slight “pin prick” as your doctor numbs your neck. After your neck is numb, a small cut will be made in the side of your neck. The doctor will insert a special probe (catheter) called a biptome into a large vein in the side of your neck. This vein leads to the right side of your heart, where your doctor will remove 4 to 6 very small pieces of tissue from your heart. These tissue samples are placed into a special liquid and taken to the lab where a pathologist will look at them under a microscope. The biopsy is done under X-ray or echocardiogram guidance so that your doctor can watch the probe as it



moves into your heart. If your neck vein has a lot of scar tissue, a groin vein (the femoral vein) can be used for the biopsy.

The biopsy takes about 15 to 30 minutes. During this test, you might feel a little pressure in your chest; this pressure is caused by the catheter. However, most people do not have any problems during or after the biopsy. You will be up and walking soon after the test and can go home within an hour or so after the test is over. (Some transplant centers do a chest X-ray after the biopsy to make sure that no problems have occurred).

Your biopsy results will be ready either later that day or within 24 to 48 hours. Someone from your transplant team will call and tell you:

- If you have rejection
- If you have to change your medications in any way
- When your next biopsy will be done



How often are biopsies done?

Biopsies are done often in the first few months after the transplant. The timing varies from program to program. Often they are done weekly for the first few weeks after the transplant, then every other week for a few months, and then monthly for awhile. Biopsies are done less often the farther out you get from the time of your transplant. Some transplant centers stop routine biopsies after patients are 2 to 5 years posttransplant.

Can my biopsy show rejection even if I don't have any symptoms?

Yes. You may not have any symptoms, but your biopsy result may still be abnormal, suggesting that you have rejection. This is why you must get your biopsies done as scheduled. If you do have rejection, your transplant team will decide the best treatment for you.

If I do have rejection, how is it treated?

Treatment for rejection depends on many factors, such as:

- How severe the rejection is
- How the rejection is affecting your heart
- Whether or not you have had any prior rejection episodes
- Any symptoms you may be having
- The anti-rejection drugs you are currently taking
- The type of rejection you are having

What is the treatment for cellular rejection?

There are many ways to treat cellular rejection. For mild to moderate rejection, your doctor may:

- Increase the dose and/or frequency of one or more of the anti-rejection drugs that you take by mouth or
- Change the drugs that you take by mouth or

- Give you “pulse” doses of prednisone by mouth for a little while. A “pulse” dose means that a higher dose is given for a few days and then the dose is slowly decreased down to your original dose. For example, your doctor might order prednisone 50 mg twice a day for 3 days, followed by 40 mg twice a day for 2 days, then 30 mg twice a day for 2 days, and so on.

For more severe rejection, your doctor may give you stronger drugs through a vein (intravenously). Often, the first drug that is given this way is SoluMedrol[®], which is the form of prednisone that is given through a vein (IV). There are other anti-rejection drugs that your transplant team may prescribe for you, such as antithymocyte globulin. These drugs are given IV in the hospital and patients are closely watched to make sure that the rejection is getting better. If the rejection gets worse despite this treatment, the patient may need to have another heart transplant.



What is the treatment for humoral (vascular) rejection?

Plasmapheresis (pronounced “plaz ma fur eee sis”) is used to treat humoral rejection. Plasmapheresis is a process that filters the blood and removes the harmful antibodies that cause humoral rejection. This process is also called a “plasma exchange”. These plasma exchange sessions are completed over a two to three week period. Echocardiograms and lab tests are done to see if this treatment is working. Patients with humoral rejection may also be given some heart failure drugs to improve any heart failure symptoms they may have. These heart failure drugs may be similar to those given before the heart transplant.

What happens after I am treated for rejection?

A repeat heart biopsy, lab work, a right heart “cath” or echocardiogram might be ordered after 1 to 2 weeks of treatment for rejection. If rejection persists, more treatment is required. If rejection is going away and your heart is getting better, the extra doses of anti-rejection drugs may be decreased or stopped. The dose of your main anti-rejection drug (for example, tacrolimus or cyclosporine) may also be decreased. Your transplant team’s goal is to have you on the lowest amount of anti-rejection medication as possible, so that you do not reject your heart and have good heart function. Lower doses of anti-rejection drugs also help to decrease your risk of infection and other side effects of higher doses of these drugs.

What is the AlloMap[®] test?

The AlloMap[®] test is a blood test that tells how your immune system is reacting to your new heart. The purpose of this test is to find out your chances of NOT HAVING a moderate or severe rejection episode at the time when your blood for the AlloMap[®] test was drawn.

Who can have the AlloMap® test?

This test can be used only with stable patients who:

- Are between 2 months and 5 years after transplant
- Have a low risk of having a rejection episode.

Where is the AlloMap® test done?

The AlloMap® blood test may be done at your transplant center or at a special blood drawing center. You do not need to fast before having your blood drawn for this test.

When will I get the results of my AlloMap® test?

Your doctor will have your AlloMap® test score about two days after your blood has been drawn.

What does my AlloMap® test score mean?

In general, the lower your score, the less the chance that you are having moderate or severe rejection.

How often is the AlloMap® test done?

The timing of the AlloMap® test varies from program to program. Often, this test is done monthly during the first year after transplant and then every 3 to 4 months.

If I have the AlloMap® test, do I need a heart biopsy?

If there is an increase in your AlloMap® score, you may need to have a biopsy done. Your doctor will examine you, review your health record, and decide whether a biopsy should be done.

Do all transplant centers do the AlloMap® test?

Right now, many, but not all, heart transplant centers do the AlloMap® test.

Will I always have to worry about rejection?

Although the risk of rejection goes down over time, it can still occur at any time. Your transplant team will always discuss your test results, anti-rejection drugs, and treatment plan with you. Talking with your transplant team and following your care routine are key factors for a good outcome after heart transplant.

What is coronary artery vasculopathy?

Coronary artery vasculopathy (CAV) is a form of chronic rejection in which changes occur in the transplanted heart over a period of weeks or months. These changes affect the coronary arteries, which supply blood to the heart itself. As blood supply to the heart decreases, the heart muscle becomes “stiffer” and weaker. This can lead to heart failure.

Treatment for CAV includes stronger anti-rejection drugs, and, for some patients, angioplasty, stenting, or bypass surgery. Retransplantation is the only definitive cure for CAV.

If you have CAV, it is very important for you to:

- Eat a heart healthy diet
- Maintain a healthy weight
- Keep your blood pressure in the normal range
- Keep your cholesterol levels in the normal range
- Avoid the use of all tobacco products
- Avoid excessive amounts of alcohol

What is coronary artery disease?

Coronary heart disease in the transplanted heart occurs when plaque, made up mostly of fat, cholesterol, and calcium, builds up inside the coronary arteries. This build-up of plaque causes the arteries to be narrowed. The coronary arteries carry

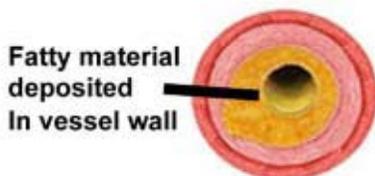
oxygen-rich blood to the heart. When the arteries become narrowed, less oxygen-rich blood can get to the heart muscle. Blood clots can also form and block blood flow.

Heart transplant centers recommend regular intravascular ultrasounds (IVUS) or left heart catheterizations to check for coronary artery disease. Sometimes the arteries can be opened with balloon angioplasty or stents. Arteries, however, cannot be opened if the blockages occur at the ends of the arteries where the catheter cannot reach them.

The risk of coronary artery disease can be decreased by living a heart healthy lifestyle. You should eat a heart healthy diet, maintain a healthy weight and normal blood pressure, control your blood glucose (blood sugar) levels and cholesterol, and avoid tobacco and excessive use of alcohol.

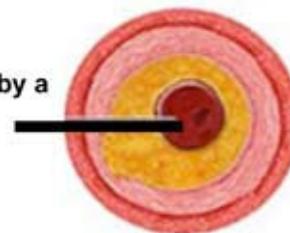


Normal coronary artery



Fatty material deposited in vessel wall

Narrowed artery becomes blocked by a blood clot



What should I do to decrease my risk of rejection and other complications?

It is important for you to:

- Know, understand, and check yourself for the symptoms of rejection
- Take all of your drugs exactly as prescribed (the right dose at the right time and in the right way)
- Make certain that you always have a good supply of your drugs
- Check your weight, temperature, and blood pressure as ordered by your transplant team
- Stay in contact with your transplant team for any changes in your anti-rejection drugs
- Keep all scheduled clinic and office visits
- Have all of your labwork and other tests done on time
- Have your heart biopsies or AlloMap[®] tests done as scheduled
- Follow-up on your blood test results with your transplant team
- Call your transplant team if you are having any symptoms of rejection or if you do not feel well
- Live a healthy lifestyle by eating a heart healthy diet and getting regular exercise
- Avoid all tobacco products, recreational/illegal drugs, herbal remedies or supplements, and excessive use of alcohol

(Source of Pictures: www.cdc.gov/heartdisease/coronary_ad.htm)

THE DENERVATED HEART

What is a denervated heart?

Your transplanted heart is said to be *denervated*. When the heart is removed from the donor, the nerves to the heart are cut and the nervous system is “disconnected.” During transplant surgery, it is not possible to reconnect the nervous system in the donor heart to the recipient’s nervous system. Although the transplanted heart will beat adequately, there is no connection to external nerves that will affect the heart rate. The heart transplant recipient is said to have a denervated heart.

What happens if the heart is denervated?

Although most heart transplant recipients have near normal function of the transplanted heart, there are some differences when the heart is denervated.

- Heart transplant recipients usually do not have chest pain (angina) if the blood flow through the coronary arteries is decreased. Instead of chest pain, they may have extreme tiredness or fatigue, shortness of breath, and not be able to tolerate exercise or activity.
- Heart transplant recipients have a faster resting heart rate, approximately 100 beats per minute.
- The heart rate of a denervated heart will not increase as quickly with exercise. The denervated heart responds differently to your body’s needs and does not respond to exercise and activity the way that your own heart would respond. Some patients may become mildly light-headed or dizzy if they move around or change positions quickly. Because your transplanted heart is denervated, you will need to take some time to warm up before exercising. This will help to gradually



increase your heart rate. Likewise, you will need to take several minutes to cool down after exercising. This will help your heart rate slowly return to normal. It may also be helpful to pump your legs and rotate your ankles several times before getting out of bed or out of a chair. The recommendations for warm up and cool down vary by center, so be sure to talk to your doctor or transplant coordinator about your center’s guidelines.

Ask your transplant coordinator to complete these instructions for you:

- Before I begin to exercise, I should warm up for _____minutes.
- When I am done exercising, I should do cool down exercises and stretches for _____minutes.

INFECTION

Why am I at risk for getting infections?

Heart transplant recipients require anti-rejection medications to suppress their immune system so that the transplanted heart is not rejected. Because the immune system is suppressed by these medications, transplant recipients are always at risk for infection. This risk is highest in the first three to six months after transplant. Infections can also occur when higher levels of immunosuppression are needed to treat rejection.

If you are doing well, have good function of your transplanted heart, 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 minimize your risk of infection.

How can I decrease my risk of infection?

There are many ways to stay healthy after heart transplant and avoid infections. The following guidelines are commonly recommended for transplant recipients. Discuss how you can prevent the risk of infection with your transplant team. Know your center's specific guidelines.

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 convenient 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, and after playing with pets.
- Encourage any family and friends who are in contact with you to practice good hand washing techniques.
- Wash your hands well before caring for any wounds or doing any dressing changes. Report any changes in the wound (increased redness, swelling, or drainage) to your transplant coordinator.
- Avoid putting your fingers or hands in or near your mouth, particularly if you have not washed your hands recently.

Contacts:

- 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 or when you are highly immunosuppressed.
- Do not share eating utensils, cups, glasses or toothbrushes with others since many viral illnesses are spread through saliva and mucus.
- Do not share razors, nail clippers or other manicure equipment.



Pets:

- If you have pets, be sure that they are healthy and have had all recommended vaccines.
- Do not handle animal waste. Do not clean bird cages, fish or turtle tanks, or change cat litter.
- 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.

Gardening:

- Wear gloves when working in the garden and in soil.
- Wash your hands frequently when gardening.
- Some transplant centers request that gardening be avoided for three to six months after transplant until the patient's immunosuppression level is lower.
- Avoid compost piles, wet leaves, and rotting organic matter. These materials can carry mold which can cause significant respiratory infections in immunosuppressed patients.

Swimming

- Heart transplant recipients may swim in chlorinated pools after their incision and wounds are healed and they are able to exercise.
- 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.

Sexual Activity

- To avoid sexually transmitted diseases (STDs), practice safe sex and use condoms.

What are some common signs of infection?

Some symptoms that may be related to infection include:

- body temperature (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, chills, or cold symptoms
- changes in wound appearance: increased drainage, redness, foul odor, and/or pain and tenderness around the incision site

It is important to contact your doctor and/or transplant coordinator 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 usually 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 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 determine where the infection is 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 recipients 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 Infections

Cytomegalovirus (CMV) is a common community-acquired virus and is not a serious illness for most people who are healthy. CMV is of more concern to people who are taking immunosuppressive medications.

CMV is the most common viral infection that occurs following heart transplantation, usually within two to three months after transplant. Some patients are more at risk for CMV than others. The patients who are at highest risk are those who:

- are CMV-negative (meaning they never had CMV) and have received a CMV-positive heart or CMV-positive blood products
- have received high levels of immunosuppression

Because CMV is such a common infection, transplant centers usually prescribe medication to prevent this infection, particularly in patients who are considered to be at high risk for getting the virus. Most CMV prevention plans include treatment with ganciclovir or valganciclovir. Some centers continue preventative treatment for up to three months after transplant. Using these treatments to prevent CMV has decreased 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 include fever, a low white blood cell count and a low platelet count. 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 intestine tissue to determine if the virus has infected those organs.

CMV is treated with anti-viral medications that can be given orally or IV. In some cases, immunosuppression may be lowered during the infection to help the immune system fight the virus.



Epstein-Barr Virus (EBV) and Post-Transplant 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 commonly 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.

Heart transplant recipients who are at a higher risk for developing EBV:

- are EBV-negative (never had EBV before) and have received a EBV-positive heart
- have received high levels 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 complications are monitored 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 protocols for EBV and PTLD vary by transplant center, but usually include 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.

Taking Care of Yourself and Your Heart

TRANSPLANT CLINIC

After discharge from the hospital, you will be followed as an outpatient at your center’s transplant clinic. Most patients are seen one to two times a week for about a month, then less frequently as they improve and return home. Although clinic routines vary by center, long-term patients who have good heart function may be seen once or twice a year. Blood tests are also obtained routinely to check for any complications.

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

Clinic routines vary by center. Discuss the following questions with your coordinator before you leave the hospital.

- When is my first clinic appointment?

- Where is clinic?

- What should I bring with me to clinic?
 - a list of my medications
 - my medications
 - my Heart Handbook
 - a record of my blood pressure measurements
 - a record of my daily temperatures
 - a record of my fluid intake
 - a record of my urine output

- a record of my blood sugar levels (for patients with high blood sugar)
- a family member or caregiver
- _____
- _____

What is the usual Clinic routine?

What will happen in Clinic?

Every transplant center has a slightly different clinic routine. Patients are usually examined by a physician, blood tests are obtained, the plan of care is reviewed, and questions or concerns are discussed. For a typical routine for a clinic appointment you may be instructed to:

- report to the Transplant Clinic and register for your appointment
- have your blood tests drawn before taking your morning dose of tacrolimus, cyclosporine, sirolimus, everolimus, or mycophenolate.
- have a physical examination by the transplant physician or another physician on the transplant team.
- review your blood test results and medications with your physician
- meet with your transplant coordinator to:
 - review your medical care
 - answer questions or concerns
 - be aware of and understand any changes in care or medications
 - get prescriptions or have any new medications or medication changes ordered
- schedule or report for any additional procedures or tests (biopsy, X-ray, ECHO, etc.) that might be needed
- meet with other members of the transplant team as needed (social worker, clinical nurse specialist, dietician, pharmacist)
- attend support group meetings

VITAL SIGNS

When you leave the hospital, you may be asked to regularly check your temperature, pulse, and blood pressure - your vital signs. Understanding what each vital sign means and what your normal range is for each vital sign is important.

If you experience difficulty breathing or any chest pain or pressure, call Emergency Services (911 in the United States) and ask to be taken to the nearest Emergency Room. If you have these life-threatening symptoms, never try to drive yourself or have a caregiver take you to the hospital. You may require care as soon as possible and your caregiver may not be able to help you if he/she is driving. Always call Emergency Services in this case.

I should call _____ in the event of an emergency.

Blood pressure

Blood pressure is the measure of force in your arteries. It is a measure of two types of pressure, the systolic and the diastolic. The blood pressure measurement is written as two numbers, for example: 120/80. The systolic blood pressure is the “top number” of blood pressure measurement and measures the force of muscle contraction of the heart as blood is pumped out of the chambers of the heart. The diastolic blood pressure is the “bottom number.” It measures the pressure when the heart muscle is at rest between beats, expanding and filling with blood.

If you are asked to record your blood pressure, you and your caregiver will be taught how to take your blood pressure before you leave the hospital. Your center will provide you with a blood pressure cuff

or instruct you on where you can purchase one. Cuffs may be manual (you pump them yourself) or digital (automatic). If you have a digital cuff, be sure to measure how accurate it is with the blood pressure cuff used by your nurse in the hospital or clinic. Accuracy varies in some of the digital pumps.

Since blood pressure changes throughout the day, measurements should be taken at the same time of day and on the same arm. Take your blood pressure at the times recommended by your doctor, usually immediately after waking but before breakfast and in the early evening. You may also be instructed to take your blood pressure before taking any blood pressure medications.

High blood pressure (hypertension) may occur early on after heart transplant and is usually related to side effects of some medications or kidney problems. It can often be managed well with blood pressure medications and/or some adjustments in your diet, such as a low sodium diet.

What you should know about your blood pressure:

- A normal blood pressure for me ranges from a low of _____/_____ to a high of _____/_____.
- I should take my blood pressure _____ times every day and before I take blood pressure medicine. I will be taking my blood pressure at:
 - _____ AM
 - _____ PM
 - or as needed every _____ hours
- I should call my coordinator if my blood pressure is greater than _____/_____ or less than _____/_____.
- I should record my blood pressure measurements and bring this record to clinic.

Temperature

Normal body temperature is 98.6° F or 37° C. If your temperature is rising, you may feel hot or cold, achy, and/or develop chills or sweat. Fever is an important symptom and can occur with rejection or infection.

What you should know about your temperature:

- How often should I take my temperature?

- I should call my transplant coordinator or physician if my temperature is _____° F or _____° C or higher.
- If I am told to take acetaminophen (Tylenol®) or paracetamol my dose is:
_____mg or _____ tablets
every _____ hours as needed
for fever greater than or equal to _____.
I should not take more than _____ doses in a 24 hour period.
- I should not take any ibuprofen products (Motrin®, Advil®, Nuprin®, Midol®, Brufen®, Nurofen®) or naproxen products (Naprosyn® or Aleve®) unless instructed to do so by my doctor.

Pulse

Your pulse is created by your heart beat. When you take your pulse, you are feeling the pressure of your blood in an artery from the beating of your heart. The pulse rate is the number of times your heart beats in a minute, for example 72 beats per minute (bpm). Your pulse can be felt in your wrist or neck. You can also listen to your pulse with a stethoscope over your heart. You may be advised to take your pulse when you take your blood pressure or if you feel like your heart is beating too fast or “racing.” You may also be asked to take your pulse if you are on certain heart medications that affect your heart rate.

What you should know about your pulse rate:

- My normal pulse when resting is:
_____.
Remember that because the transplanted heart is denervated, you will have a higher resting heart rate.
- My normal pulse when active is:
_____.
- I should call my coordinator if my pulse is greater than _____ or less than _____ beats per minute.



Weight

You may be asked to weigh yourself daily or two to three times a week to monitor for any losses or gains. Your weight will also be monitored at every clinic visit. When you are home, you should check your weight as often as instructed on the same scale at the same time each morning. After you go to the bathroom, but before you eat breakfast is a good time. You may be asked to record your weight so that your doctor can follow any changes in your weight. Gaining or losing weight, particularly if this happens suddenly, can be a sign of problems in your recovery. A sudden weight gain could mean that you are holding on to (retaining) fluids. This could be a side effect of medications or a sign that your kidneys or heart are not working well. A sudden

weight loss could mean you are dehydrated which can be harmful to your heart and kidneys. Call your transplant coordinator with any sudden weight changes.

What you should know about your weight:

- My ideal body weight is _____lbs/kg.
- My weight at discharge from the hospital is _____lbs/kg.
- I should call my doctor or transplant coordinator if I have a sudden weight gain of greater than _____lbs/kg within _____ days.



BLOOD TESTS

Monitoring blood tests is another way your transplant team follows your recovery and checks how your transplanted heart and other important body systems are functioning. Your medications may be adjusted based on your test results.

Blood tests are done frequently after transplant while you are in the hospital to monitor your recovery and progress. As you improve, your blood tests will be checked less often. Your blood tests may be repeated more frequently if you have rejection, infection, recent changes in your medications, or have other complications. When you return home, you will have your blood tests done locally. Depending on your transplant center, it may be your responsibility to arrange this. Your coordinator will advise you on where to go and how to have your results sent to the transplant center. You may also want to keep a record of your results to help follow your care.

What I should know about my blood tests:

- When should I get my labs drawn?

- When I am at the transplant center, where will I get my labs drawn? _____

- When I am at home, where will I get my labs drawn? _____

- My lab results should be faxed to:

- Who should I call to be sure my lab results have been reviewed?

- If a tacrolimus (Prograf®), cyclosporine, or sirolimus (Rapamune®) level is being drawn, I should have my labs drawn one to two hours before taking the morning or evening dose. I should not be more than one hour late in taking my dose. What time of day should I have my labs drawn?

- Special instructions about my labs:



Measurement ranges of blood tests vary by center. **Adjust the normal ranges in the following tables to your center's guidelines.** If your blood test results are out of the normal range, your physician or transplant coordinator will discuss the results with you. Some abnormal lab values may be acceptable as you recover from transplant or a related complication and should improve over time.

(Lab values are US and UK measurements.)

To help you read the charts below:

- ↑ An arrow going up indicates that the lab value being discussed is increased, or greater than the desired levels. For example, when discussing the BUN, ↑ *kidney dysfunction* means that if the BUN is **increased**, the kidneys may not be working well.
- ↓ An arrow going down indicates that the lab value being discussed is decreased or less than the desired level. For example: when discussing creatinine, ↓ *muscle wasting* means that when the creatinine level is low or decreased, there may be symptoms of muscle wasting.



Tests that Monitor Kidney Function and Electrolytes

The tests used to monitor kidney function and fluid balance are listed on the following page. Anti-rejection medications can sometimes effect how well your kidneys work, so it is important that kidney function tests are checked regularly. If your kidneys are not working well, you may also have abnormal levels of your electrolytes. Your physician will treat any problems with adjustments in your immunosuppression and/or other medications to correct electrolyte imbalances.

Test	Name	Result	Normal Range (US)	Normal Range (UK)
BUN, Urea	Blood urea nitrogen	<p>↑ kidney dysfunction, dehydration, high protein diet, side effect of some anti-rejection medications</p> <p>↓ liver disease; over-hydration, malnutrition</p>	8-25 mg/dl	3.4-8 mmol/L
Cr	Creatinine	<p>↑ kidney dysfunction, side effect of some medications, dehydration</p> <p>↓ muscle wasting</p>	<p>Males: 0.6-1.3 mg/dl</p> <p>Females: 0.5-1.2 mg/dl</p>	134-146 mmol/L
Alb	Albumin	↓ malnutrition	3.5-5. g/dl	9-40 u/l
Na	Sodium	↓ side effect of diuretics; kidney dysfunction, side effects of other medications	135-145 mEq/L	3.4-5.2 mmol/L
K ⁺	Potassium	<p>↑ side effect of medications; kidney dysfunction</p> <p>↓ side effect of diuretics; decreased intake, vomiting</p>	3.5-5.0 mEq/L	<p>60-126 umol/L</p> <p>3.4-5.2 mmol/L</p>
Mg ⁺⁺	Magnesium	<p>↑ kidney dysfunction, high doses of magnesium supplements</p> <p>↓ diarrhea; side effect of medications</p>	1.8-3.0 mg/dl	0.70-0.95 mmol/L
Glu	Glucose	<p>↑ diabetes, problems with the pancreas, side effect of some medications</p> <p>↓ occurs in liver disease or with thyroid problems; side effect of treatment for diabetes</p>	70-115 mg/dl (fasting)	3.5-6.0 mmol/L
Ca ⁺⁺	Calcium (total)	<p>↑ high intake of calcium often caused by taking too many antacids; bone disorders, thyroid problems, problems with the parathyroid</p> <p>↓ kidney dysfunction, over-hydration, problems with the pancreas, severe malnutrition</p>	8.5-10.5 mg/dl	2.10-2.60 mmol/L
TP	Total protein	↓ malnutrition, kidney dysfunction	6-8.4 g/dl	60-80 g/l
Phos	Phosphorus	<p>↑ kidney dysfunction, high doses of phosphorus supplements</p> <p>↓ problems with the parathyroid gland</p>	3.5-5.5 mg/dL	0.8-1.4 mmol/L (phosphate)

Tests that Monitor Liver Function

Liver function tests (LFTs) may be monitored in some patients to check how well the liver is working and to watch for any signs of infection in the liver or side effects of medications. Some cholesterol-lowering medications may cause the liver function tests to increase.

Test	Name	Result	Normal Range (US)	Normal Range (UK)
Bili	Total bilirubin	↑ bile duct obstruction, infection	0.1-1.2 mg/dl	7-330 u/l
Alk Phos	Alkaline phosphatase	↑ bile duct obstruction ↓ malnutrition	Adults 20-140 IU/l	1-22 umol
ALT	Alanine aminotransferase	↑ liver injury	1-30 u/l	5-41 u/l
AST	Aspartate aminotransferase	↑ liver injury	0-35 u/l	5-43 u/l
GGTP	Gamma-glutamyl transpeptidase	↑ liver injury, bile duct obstruction	Males: 11-50 u/l Females: 7-32 u/l	Males: 11-50 u/l Females: 10-40 u/l
Alb	Albumin (serum)	↓ malnutrition	3.5-5. g/dl	9-40 u/l
TP	Total protein	↓ malnutrition, chronic liver dysfunction	6-8.4 g/dl	60-80g/l

Complete Blood Count (CBC) or Full Blood Count (FBC)

The Complete Blood Count (CBC) or Full Blood Count (FBC) will be monitored with your routine labs to check for infection, effects of anti-rejection drugs, a low red blood cell count (anemia), and to make sure you have the normal range of each type of blood cell.

Test	Name	Result	Normal Range (US)	Normal Range (UK)
WBC	White blood cell count: cells that fight infection; also involved in the rejection process	↑ may indicate bacterial and viral infections ↓ may be a side effect of some medications, stress	4.5-11 WBC/mm ³ x 1000	4.0-10 x10 ⁹
Hct	Hematocrit: measures the percentage of oxygen-containing RBCs	↑ may cause blood clotting ↓ can be a sign of anemia	Males: 40-54% Female: 37-47%	0.37-0.47
Hgb	Hemoglobin: the oxygen-containing part of the RBC	↑ may indicate dehydration or a blood disorder ↓ can be a sign of anemia	Males: 14-18 g/dl Female: 12-16 g/dl	Males: 14-18 g/dl Female: 12-16 g/dl
Plt	Platelets: component of blood that helps stop bleeding	↑ can make your blood “thick” and lead to clotting ↓ may be a sign of liver disease, bleeding, anemia	150,000-350,000	150,000-350,000

Immunosuppression Levels

The level of anti-rejection medicine in your blood is monitored very closely after transplant. It is important that you have a level that is high enough to prevent rejection, but not so high that you develop infections easily.

The level of your anti-rejection medicine is highest during the first three to six months after transplant. If you do not have rejection and if your heart is working well, your level will be decreased slowly over time. If you have rejection, your immunosuppression level will be increased.

The doses of your anti-rejection medications may change frequently depending on if you are experiencing rejection or infection. Be sure that you always know your dose of these medications and the level that your doctor is trying to maintain.

Anti-rejection medication	My dose	My level
Cyclosporine (Sandimmune®, Neoral®, Gengraf™)		
Tacrolimus (Prograf®)		
Mycophenolate mofetil (Cellcept®, Myfortic®)		
Sirolimus (Rapamune®)		
Everolimus (Certican®)		

Immunosuppression levels vary greatly depending on transplant center protocols, the length of time after transplant, and the presence of infection or rejection. Talk to your doctor or transplant coordinator about the level that is right for you.

NUTRITION

A healthy diet is one that is made up of fruits, vegetables, whole grains, and low fat or fat free milk and milk products. It also includes lean meats, poultry (chicken, turkey), fish, eggs, nuts, and beans. A healthy diet should be low in saturated fats, trans fat, salt, added sugar, and cholesterol.

Good nutrition is an important part of a complete recovery following heart transplant. As you recover, your body has increased nutritional needs for wound healing, to regain any weight you lost due to heart disease and the stress of surgery, and to help your body fight infection. After heart transplant, patients need a diet high in calories and protein to rebuild muscle tissue and restore protein levels. Dietary requirements are different for everyone, so your dietician will meet with you after transplant to discuss your specific nutritional and caloric needs and any dietary restrictions you may have. For a while after surgery, most patients will need to increase calories as well as calcium and protein intake.

During the first few weeks after transplant, some patients have trouble eating due to loss of appetite, feeling full or nauseated, or because they have changes in taste. This is quite common and will resolve over time as patients recover and activity increases.

Here are some helpful hints if you are having trouble eating:

- If you have a poor appetite, try to eat several small meals a day, snack between meals on high calorie and high protein foods, and/or drink higher calorie liquids such as milk or juice rather than water. Your dietician can help you plan your meals and snacks.



- If you feel full or bloated, try to eat frequent small meals, avoid foods that may cause additional gas, eat foods that are high in carbohydrates and proteins rather than fats, or sip on fluids between meals instead of during meals.
- If you are nauseated, foods high in carbohydrates such as pasta, cereal, bread, pretzels, and fruit may help. Nausea may also be decreased by drinking ginger ale and lemon-lime sodas. Spicy and fatty foods should be avoided if you are nauseated. If you continue to have problems with nausea, your physician may order a medication to help decrease this feeling.
- If you are experiencing changes in taste, try using seasonings and spices to enhance the flavors of your food. Marinating meat, poultry, or fish can also be helpful. If you seem to always have a bad taste in your mouth, drinking cold fluids or sucking on hard candies may also help.

After transplant, most transplant recipients have few restrictions or limits in what they are allowed to eat. Your dietary guidelines are much the same as for any person who is trying to eat healthy. If you have other health problems, such as high blood sugar or high blood pressure, your transplant team will give you special instructions about your diet. Fad diets, diet supplements, and herbal products should be avoided.

The level of some anti-rejection medications is affected when taken with grapefruit or grapefruit juice. For patients who take cyclosporine or tacrolimus, all transplant centers and pharmacists recommend avoiding all forms of grapefruit and any drinks that contain a significant amount of grapefruit juice if they are taking cyclosporine or tacrolimus. Seville oranges should also be avoided.

While it is important to regain lost weight and rebuild your protein stores, your weight should stay within your appropriate weight range. Being overweight contributes to heart disease and diabetes.

Patients often have high potassium levels in their blood following transplant. An increased potassium level (hyperkalemia) could be due to anti-rejection medications or kidney dysfunction. High levels of potassium may cause the heart to beat irregularly. If your potassium level is high, it will be controlled by a medication called fludrocortisone (Florinef[®]) and/or dietary limits of high-potassium foods. You may also be asked to limit or avoid foods that are high in potassium. Your dietician will advise you on how many servings of these foods you may have daily if your potassium level is high.

Foods That are High in Potassium

apricots
bananas
cantaloupes
dates
dried fruits
figs
honeydew
kiwi
nectarines
oranges
prunes
raisins
artichokes
beans
Brussel sprouts
lentils
peas
potatoes
pumpkin
spinach
squash
tomatoes
ketchup
cocoa
coffee
nuts
cereals with fruits and nuts
salt substitute

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 disease (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 or even doing housework counts as exercise! Staying active is key to living a full and healthy life.

It is common to feel tired or weak as you recover from heart transplant. If you have been hospitalized for a long time before or after your transplant, you may have lost some muscle mass 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 recipients should discuss how to start an exercise program with their doctor and 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. Your team can help develop a plan that is right for you. 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 organize and start a simple exercise routine.

Cardiac rehabilitation can be very helpful following heart transplant. These programs help heart transplant patients gradually and

safely increase their activity level. Cardiac rehabilitation programs teach patients how to exercise safely after heart transplant and can also help increase a patient's confidence in their ability to exercise. Talk to your transplant coordinator or physical therapist about a cardiac 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 intensive exercise programs. Check with your coordinator and physician for your center's guidelines. The best activity in the first few weeks after transplant is walking. Remember that you will also need several minutes to warm up and cool down because the transplanted heart is denervated. 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 heart 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 recipients 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 the type of work that is done. Most patients are ready to return to work or school within three months after transplant. When possible, it can be helpful 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 coordinator. They can help you decide on the time that is best for you based on your workplace and responsibilities.

Driving

Most transplant recipients can resume driving within four to six weeks after transplant, depending on their recovery period, complications, and medications. 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 doctor and coordinator 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. If you are still sore, padding your chest with a towel or small pillow will help cushion your incision from the seat belt. The seat belt will provide a safe restraint in case of an accident.



YOUR LIFESTYLE AFTER HEART TRANSPLANT

Sun Exposure and Skin Cancer Screening

Transplant recipients 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 recipients 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 meds you have taken, how long you have taken anti-rejection 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 detected early. Transplant recipients 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. 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, you may be asked to see a dermatologist regularly. Transplant recipients should always use a sun screen with a sun protection factor (SPF) of at least 30 to protect their skin from light rays that are damaging to the skin. Sunscreen should be used on all exposed areas of skin. It is also important to wear sunglasses, a broad-rimmed hat, and protective clothing. 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 recipients should not use tanning booths.



Travel

As you recover and return to a more normal routine, you may consider traveling or going on a vacation. Check with your transplant coordinator for your center's guidelines on traveling early on 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 a few weeks 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 airline to see if there are any restrictions on taking your medications on the plane.

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.

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. Additionally, 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. 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 includes 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 salad bars or buffets due to possible contamination by others and unsafe food temperatures.
- Do not eat food purchased from street vendors.



Drinking Water

It is safe for you to drink treated municipal tap water after your heart 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 recipients to boil well water if they are using it for brushing teeth, washing fresh fruits and vegetables, or for 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 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 animals 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.
- Be sure that your pet is healthy, has regular check-ups, and has received its required immunizations. If your pet is ill, have him examined by your veterinarian as soon as possible.



- 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 clean the area well with a disinfectant.
- Do not let your pet lick your face.
- Do not change your cat's litter box. The litter and liner should be replaced frequently. 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 wash your hands after you are done.
- Contact your transplant coordinator immediately if you are bitten by any animal.
- Avoid stray or sick animals.
- Some pets should be avoided by transplant recipients. The following animals are considered high-risk animals by the Centers for Disease Control for people who are immunosuppressed:
 - Reptiles, including lizards, snakes, and turtles
 - Baby chicks and ducklings

- Exotic pets, including monkeys
- Some transplant centers also recommend that amphibians (frogs), hamsters, guinea pigs, and caged birds are not 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 gloves whenever you are working in the soil. It is also helpful to wash your hands every so often while gardening. Avoid working around compost piles, wet leaves, and rotting organic matter when possible. These materials may contain mold which can cause significant respiratory infections in immunosuppressed patients. Check with your transplant coordinator for your center's guidelines about gardening.



Routine Screenings and Examinations

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

Medic-Alert Identification

Many centers recommend that patients wear a Medic-Alert necklace or bracelet that identifies them as a transplant recipient 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 internationally. 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 coordinator can provide you with information about Medic-Alert 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 heart transplant, allergies, your current medications, and other health conditions that will be included in your file.



Your Local Primary Care Physician (PCP)

Your local physician may be an internal medicine physician (internist) or a cardiologist 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. You may be asked to see this physician within the first month of returning home.

Your transplant coordinator should have the contact information for your local physician before you leave the transplant center. The coordinator will forward information to your local physician about your transplant surgery, any complications you may have had after transplant, and your current care. Your coordinator will also describe the transplant center's role in your care and how the physicians can work cooperatively to be sure you do well. Your local physician 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 coordinator.

Dental Care

Maintaining healthy teeth and gums is an important part of your care after transplant. As in the general population, 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 also develop infections more easily because your immune system is suppressed. Bacteria that are commonly in the mouth can cause infection.

It is important to 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 regularly and call your physician 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. This is called infection *prophylaxis*. 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 examinations are important for everyone. Vision screenings (checking how well you see) can be completed regularly by a health care professional to detect problems. The need for a *dilated* eye examination 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 examination can detect serious problems such as glaucoma, cataracts, diabetes, infection, and cancer.

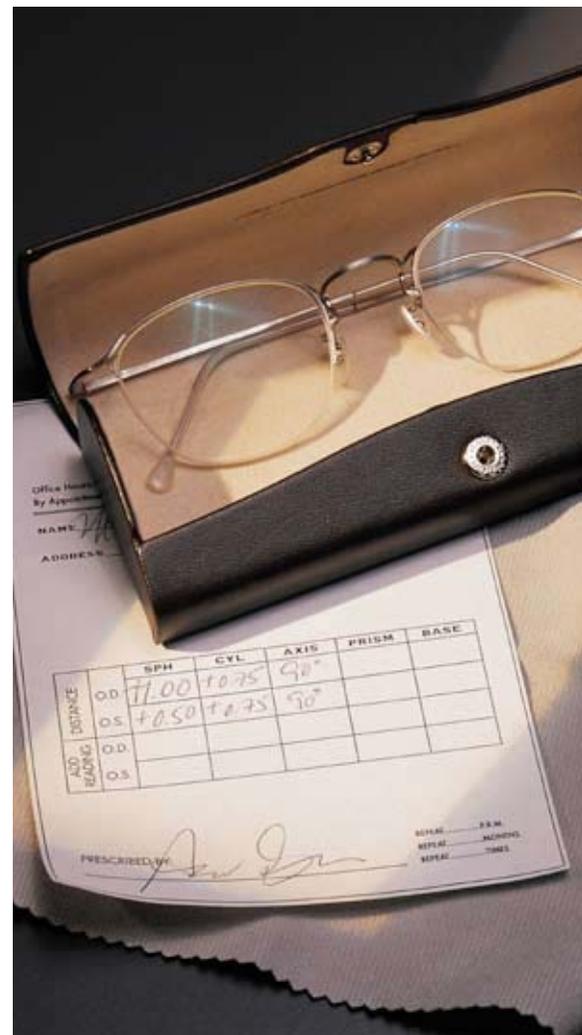
Transplant recipients may have an increased risk of developing eye problems because their immune systems are suppressed. Eye problems can also be a side effect of some medications. Discuss the risk of developing eye problems with your transplant physician or transplant coordinator. Some transplant centers recommend ophthalmology exams every year for those at risk. You and your doctor should decide on the frequency of an examination by an eye doctor that best meets your needs as a transplant recipient. 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 anti-rejection protocols and treatments to prevent infection.

Call your primary care physician 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



SEXUAL AND REPRODUCTIVE CONCERNS

Gynecologic Examinations

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

Many transplant centers advise their female transplant recipients who are 18 years of age or older and/or are sexually active to have a gynecologic examination every year. This examination is the same as for the general population and should include a pelvic exam to detect any abnormalities of the uterus, a breast examination to evaluate changes in the breast tissue, and a Papanicolaou's smear (Pap smear) to detect any abnormalities of the cervix. Women ages 18-39 should have a professional breast exam every three years, or as needed, and should perform monthly breast self-examinations. Women 40 years of age and older should also have a yearly mammogram and perform monthly breast self-exams. Physicians 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.

Sexual activity

Sexual activity is an important part of adult life. Before transplant, many patients experience a decreased desire (libido) to have sex or are unable to have sex (impotence) because of health problems and activity limitations. After transplant, both men and women often find that their 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 doctor or coordinator when it is medically safe for you to have sex.

There are many reasons why patients can have problems with sexual activity. Difficulties could be from complications related to their original cardiac disease, medications, or problems in their relationship with their partner. 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 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 recipients 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
- avoiding anal sex

Birth control and pregnancy

When you resume sexual activity after transplant, an appropriate 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 sexually transmitted diseases. Some transplant centers have approved the use of low-dose oral contraception (“the pill”). However,



oral contraceptive pills place the transplant recipient 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 oral contraception. Additionally, 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 following transplant to become pregnant. This allows for a reasonable amount of time to be sure that the transplanted organ is healthy and functioning well. Immunosuppression levels should be stable and at a maintenance level.

When considering pregnancy, female heart transplant recipients should have:

- stable function of the transplanted heart
- stable level of immunosuppression
- good kidney function
- normal blood pressure or well-controlled high blood pressure
- normal blood glucose levels or well-controlled diabetes
- overall good health

If you are thinking about getting pregnant after your heart 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 heart, and your medications.

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

Pregnancy outcomes of transplant recipients 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 additional information. Your transplant team can discuss the findings of this group in greater detail with you if you are considering 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>



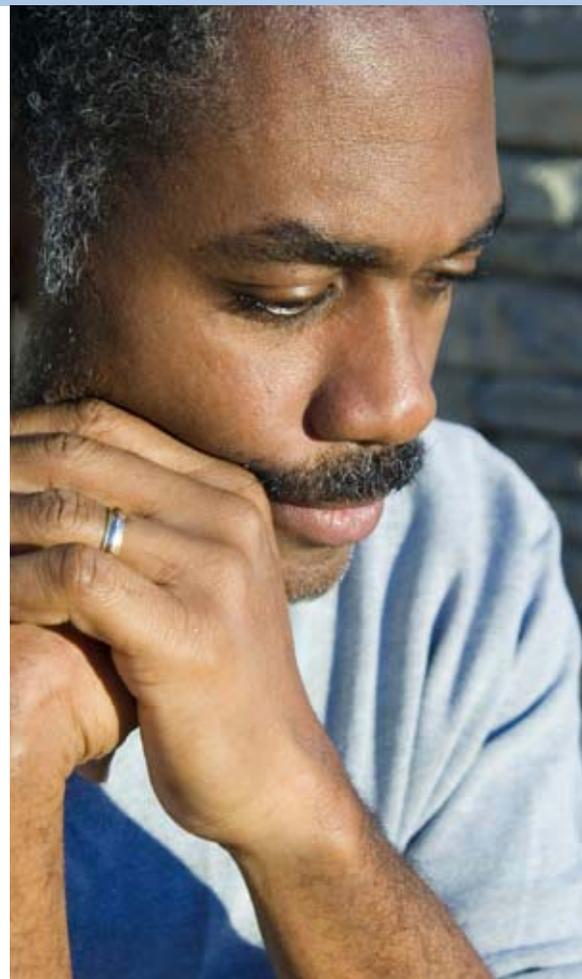
Prostate screening

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 Caucasians.

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.

The screening recommendations for prostate cancer based on scientific studies are unclear. Some physicians who support regular screening believe that the research shows that finding and treating prostate cancer early may save lives. These physicians 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. However, some physicians do not recommend regular screenings because they believe that finding and treating prostate cancer early may not save that person's life. They believe that the side effects of treatment are worse than the possible benefits because most prostate cancers grow very slowly and may never affect the man's life.

It is important that you discuss prostate screening with your physician. 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)
- the appearance of blood

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: Caucasian 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 contribute to osteoporosis.
- Medications: Certain medications, such as steroids, 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 recipients are at an increased risk for developing 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 developing osteoporosis depends on your general risk factors as well as the amount of immunosuppression and length of time you are prescribed high levels of these medicines.

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 on the amounts and types of foods that are right for you, particularly if you have additional 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. Recommendations for having this test are based on your age, risk factors, and any recent fractures. A BMD measures the density of your bones, or bone mass, and is painless and safe.
- Medications may be helpful in some people. Although osteoporosis can not be cured, there are several types of medications that treat this condition.

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 discontinue 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. Adult transplant recipients have usually received all required immunizations before transplant but infants and young children may not because of their age or being too ill. If a transplant recipient needs immunizations, there are some important exceptions. Transplant recipients can not receive immunizations that contain a live vaccine. Receiving a live vaccine may cause serious health complications because a transplant recipient could develop the virus that he/she is being immunized against. This is because live vaccines contain a small amount of the live virus that is weakened.



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 that is given to provide immunity against the polio virus (*poliomyelitis*). 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. 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. Transplant recipients who have infants should be sure that their child receives the Salk injection.
- **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.
- **Varivax®** (chickenpox or varicella vaccine): This is a live vaccine given to children at one year of age to immunize them against chickenpox (varicella). People who are immunosuppressed should not receive this vaccine. Some centers advise transplant recipients to avoid close contact with a child who has received the Varivax® injection. Check with your coordinator for your center’s guidelines.

Tetanus Vaccine

The general public is advised to get a tetanus 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 vaccine.

The Influenza Vaccine (“flu shot”)

The flu shot or injection is an inactivated (killed) vaccine that contains three influenza strains (types) that are expected to be seen most often in 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 recipients are usually advised to get the flu shot every year. Ask your transplant team for your center's recommendations. 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. Most transplant centers recommend that caregivers and other people in the household who have close contact with the transplant recipient 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
- Guillain-Barré Syndrome (a disease that results in muscle weakness and sometimes paralysis)

Check with your transplant team about getting the flu shot or any other vaccine if you are within the first three months after transplant or if you have recently been treated for rejection. You should not get the influenza vaccine if you have a fever when you visit the doctor's office for your shot. 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 can not get this form of the flu vaccine. The nasal spray flu vaccine contains weakened live influenza viruses instead of killed viruses. This live vaccine may place them at high risk for complications from the flu.

Other Health Concerns

Smoking

Smoking is a risk to everyone's health with both active and passive contact. Smoking can cause cancer, heart disease, and lung disease. Additionally, smokers may have prolonged respiratory infections because of the effect of smoke on the lungs. Transplant recipients who smoked before transplant are strongly encouraged to stop smoking. Since nicotine is broken down or metabolized by the liver, there is a possibility that some medications, particularly tacrolimus and cyclosporine, may not be metabolized well in people who smoke. Levels of these medications may be lower in smokers.

Your transplant coordinator or social worker can help you 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 additional information and support. If you are interested in using any medications to help you stop smoking, discuss this first with your coordinator to check on your center's recommendations.

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. Additionally, marijuana is known to carry a mold or fungus called *Aspergillus* which can cause a serious, life-threatening illness in people who have a suppressed immune system.

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 coordinator, social worker, or counselor. 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 recipients experience more emotional difficulties and stress before transplant when they are waiting for a heart 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 recipients can experience a variety of emotions including anger, frustration, guilt, and depression.

These feelings can affect you for different reasons and in different ways. What is emotional or stressful for you may not be as stressful for another person. Some common symptoms people experience 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, or being unable to fall asleep
- mood changes
- changes in appetite

Feeling emotional can also be related to side effects of medications or even an underlying medical problem. Talk to your doctor and transplant team about how you feel. They will consider how you are feeling emotionally when reviewing your blood tests, medications, physical examination, and reports from procedures. 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 strategies to deal with your emotions and feelings after transplant. Some things you can do to help yourself include:

- Exercise regularly and be as active as possible.
- Participate in social activities with friends and family at home and in your community.
- Eat a healthy diet.
- Establish a good sleeping routine. Take naps if needed and get adequate rest.
- Find a way to relax through music, social activities, arts and crafts, yoga, and/or meditation and deep breathing.
- Recognize and understand 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 and any 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 that is visualized through a special dye that is infused in the blood stream.

B

B cells	B cells are a type of lymphocyte, or white blood cell, that develop in the spleen and are responsible for the body’s immunity. B cells produce antibodies which help fight infection and foreign substances.
biopsy	A biopsy is a procedure that removes a small amount of tissue from an organ, tumor, bone, or other tissue from the body to find out more information about that organ or tissue. A heart biopsy is performed to examine heart tissue. A tiny cylinder of tissue, showing heart cells and how they are arranged, is removed. This tissue is examined under the microscope by a pathologist to look for any evidence of rejection or infection in the transplanted heart.
Blood Urea Nitrogen (BUN)	A test that indicates kidney function. The BUN is a product of protein breakdown, or waste product, normally excreted by the kidney.

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 administer 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	Having a disease for a long period of time. Chronic disease may worsen slowly over time. It may be treatable but is usually not reversible.
coagulation	The process of blood clotting. A variety of factors are necessary for the blood to have a normal clotting ability. 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 which increases the risk of bleeding, particularly with surgery or any invasive procedures such as biopsies.
complete blood count (CBC)/ full blood count (FBC)	A blood test that measures many parts of your blood count including the hemoglobin (Hgb), hematocrit (Hct), platelets (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.
congestive heart failure	a disease of the heart muscle causing enlargement and weakening of the heart.
creatinine	The creatinine level is an indication 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; a virus commonly seen following transplantation that can cause an infection in the gastrointestinal tract, blood, liver, lungs, and/or eyes. CMV is a type of herpes virus.

D

- diabetes** A disease originating in the pancreas related to insulin production that causes high levels of glucose (sugar) in the blood.
- diastolic** This is the "bottom number" of blood pressure measurement 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 medications will increase urine output.

E

- Echocardiogram (ECHO)** An ultrasound of the heart that uses sound waves to check the size, shape and motion of the heart. It also checks the heart valves and the heart pumping function. An ECHO can detect fluid in the sac around your heart (pericardial effusion). The radiology technician or radiologist applies a gel to the chest. A wand with a rotating ball is placed on the chest and gently moved around the area to take pictures of the heart.
- 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.

Electrocardiogram EKG/ECG	A noninvasive test that records the electrical activity of the heart.
enzyme	A protein made in the body that is capable of changing a substance from one form to another.

G

gingival hypertrophy	Swelling or enlargement of the gums. Gingival hypertrophy 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	A type of sugar in the blood that supplies energy to the cell. 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 bruise with swelling caused by the accumulation of blood in tissue.
hemoglobin	A substance in red blood cells that gives blood its characteristic red color. 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. Hirsutism is a common side effect of cyclosporine and is seen in both male and female transplant recipients who receive cyclosporine. In women, increased hair growth is often seen as male-patterned growth.
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.

I

immune system	A specialized system of cells and proteins that protect the body from organisms that may cause infection or disease.
immunity	The ability of the body to resist a specific disease.
immunization	Providing the body with protection from certain diseases through vaccinations.
immunosuppressed	Describes the immune system of a transplant recipient which is weakened or inhibited by certain medications. Specific medications (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 variety of 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 glucose level decreases.
intravenous (IV)	Within the blood stream; fluids and medications may be given intravenously as well as by mouth (PO).

L

lymphocytes	Cells produced by the lymph glands that are responsible for immunity and defend the body against infection and foreign substances by producing 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.
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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 prescribed, not obtaining labs as instructed, or missing clinic appointments and tests. Nonadherence is a significant post-transplant issue that often results in rejection, infection, an ultimately loss of the graft.

P

- Pneumocystis jirovecii pneumonia (PJP)*** A bacterial infection of the lungs that is more common in people who are immunosuppressed. Transplant recipients are usually prescribed 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.
- PTLD** Post-transplant lymphoproliferative disease; 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 administering 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 follow 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 medications Antibiotics or antivirals that are prescribed to prevent certain infections in a specific 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 are most commonly seen on the neck, abdomen, and legs. The virus can also affect the nerves of the eye.

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 also 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 acquired immunity, or 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 (oral mucosa), throat, and on the tongue. Patients who are immunosuppressed are at greater risk for developing thrush.

U

ultrasound A test that displays internal bodily organs, blood vessels, and ducts using sound waves. An ultrasound of the heart, often called an echocardiogram (ECHO), 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.

V

vital signs 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.

MY TRANSPLANT TEAM

My Transplant Center: _____

Address: _____

Phone: _____

Fax: _____

Website: <http://www>_____

	NAME	PHONE	EMAIL	FAX (if needed)
Transplant Coordinator				
Transplant MD				
Clinical Nurse Specialist				
Nurse Practitioner/PA				
Cardiologist				
Social Worker				
Pharmacist				
Physical Therapist				
Psychologist				
Dietician				

