

Heart Handbook

Your Heart Transplant

A basic overview of your daily
healthcare, medications, and monitoring



I T N S

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Introduction



Since the first human heart transplant was performed in December, 1967, in Capetown, South Africa, heart transplantation has evolved from being an experimental procedure to an accepted therapy for carefully selected patients with a diagnosis of congestive heart failure or an enlarged heart.

Anatomy and Function of the Heart

Structure and Function of the Heart

The heart is a muscular pump about the size of a fist located under the breastbone (sternum) between the lungs. There are four hollow chambers in the heart: the right and left upper chambers (atrium) and right and left lower chambers (ventricles). The heart muscle expands and contracts ("beats") and four valves open and close between the chambers and major blood vessels in an organized manner moving the blood continuously through the chambers and into the main circulatory system. Blood brings oxygen and nutrients to all the organs and removes waste products via the lungs, kidneys and liver.



Right and Left Atrium

Right and Left Ventricles

Causes of Heart Failure Leading to Heart Transplantation

The diagnosis of cardiomyopathy indicates that there is a disease process that has caused the heart muscle to enlarge. As a result, the heart cannot pump blood effectively to all of the organs and tissues in the body and fails (heart failure). Fluid backs up in the blood vessels, the lungs, liver, abdomen and legs. Because of the lack of oxygen and nutrients to the rest of the body, other organ systems can begin to fail also.

The major reasons for heart failure are the following:

1. You have a type of heart failure that causes the heart to get bigger and pump poorly. Some of these types of heart failure that may cause you to have what your doctor describes as a dilated heart or heart failure are:
 - Viral (infection)
 - Post-partum (period of time after pregnancy)
 - Alcohol (occurs in some chronic alcoholics)
 - Drug Abuse
 - Idiopathic (cause unknown)
2. If your heart has been damaged by a myocardial infarction, or heart attack, this may also cause your heart to pump poorly or may cause you to have severe or frequent chest pain (angina). This type of heart failure may be described as or can be a result of:
 - Ischemic (coronary artery disease, temporary loss of blood supply to the heart)
 - High blood pressure
3. If you were born with a heart that does not work well
 - Congenital



If your heart has become unable to pump correctly because it has become stiff or the ventricles are thick and unable to pump blood effectively to the rest of the body this type of congestive heart failure may be described as:

- Hypertrophic (enlarged heart)
- Restrictive

4. When your heart can no longer be helped with medicines or by other surgery your doctor may refer you to be evaluated for a heart transplant.

Pre-Heart Transplant Evaluation Process

The pre-heart transplant evaluation begins with the initial referral to a heart transplant center. The heart transplant coordinator's office will be responsible for the scheduling of the appropriate diagnostic tests and clinic visits with the patient and all of the transplant team members. This can be done in the hospital setting or the ambulatory care setting (outpatient) depending on how sick you may be at that time.

The Heart Transplant Team includes:

Patient and family/ caregivers

It is essential that you participate as a responsible member of the team to facilitate your own well being. Support from family, significant others or friends is an essential part of a successful transplant

Heart transplant coordinator

This transplant specialist acts as a liaison between you, family and the other members of the transplant team.

Staff nurse

This nurse works with members of the heart transplant team to coordinate the every day activities of your care during your hospital stay.

Heart transplant surgeon

The surgeon evaluates your former surgical history to determine if heart transplantation can be performed from a surgical standpoint. The surgeon will be the one performing the heart transplant.



**Heart transplant cardiologist**

The cardiologist reviews your cardiac history and other disease processes such as diabetes. This doctor maximizes the medications for heart failure and determines what specific tests may be necessary to complete the transplant evaluation.

Social worker

The social worker examines you and your family's psychosocial and emotional needs. These may include financial issues and concerns related to housing, medications and caregiver problems.

Nutritionist

The nutritionalist meets with you and your family to determine your ideal body weight and teaches you about the dietary restrictions with heart failure as well as heart transplantation. These may include low-fat, low salt, and diabetic restrictions. There may also be specific fluid restrictions.

Clinical pharmacist

The clinical pharmacist educates you and your support persons regarding the required medications you will be taking for a lifetime after your transplant.

Financial counselor

The financial counselor reviews your insurance coverage and clears you for the initial visit with the transplant team. He/she provides information to the you and your family on what expenses to expect for the future, and what supplemental fundraising options you may be required to do prior to being listed for your transplant.

Pre-Heart Transplant Evaluation Tests**Laboratory Tests**

Many tubes of blood will be drawn to obtain blood and tissue typing. Tests will be run to rule out exposure to hepatitis, HIV and other disease processes as well as anemia, bleeding problems, kidney and liver studies.

Chest X-ray

An X-ray of the chest will be obtained to determine the size of the heart and any abnormalities seen on the lungs.

Electrocardiogram

A 12 lead EKG will be obtained to determine if you have any abnormal heart rhythm disturbances that can or may need to be corrected

Echocardiogram

This test provides information on heart wall motion, how the valves work, and the size of the different chambers of the heart. It describes the pumping function of the heart and is usually called the ejection fraction and is stated as a percentage.

Left Heart Catheterization (angiogram)

This is an invasive test where dye is injected into one of the large arteries in the groin, to find out if there are any blockages in the coronary arteries of the heart. Left ventricular heart function can also be determined.

Right Heart Catheterization

This can be done at the same time as the left heart catheterization or separately. This gives the physician information on the pressures in the heart and lungs. These measurements help the physician make



recommendations and suggestions on medications you may be taking and whether you are a heart transplant candidate.

Pulmonary Function Tests

This tests your lungs ability to carry oxygen to the rest of your body.

Carotid Doppler Studies

This is an ultrasound of the carotid arteries in the neck which carry the blood to your brain. If blockages are present, the patient could suffer a stroke during surgery.

Peripheral Doppler Studies

This is an ultrasound of the legs. The surgeon needs to know if there are blockages in the arteries to the legs. Large catheters are put into the large veins and arteries in the groin for the heart-lung machine that is used during the heart transplant operation.

Abdominal Ultrasound

This is an ultrasound of the organs in the abdomen, liver, gallbladder, pancreas, spleen, and kidneys. This test looks for any abnormality that might interfere with a successful heart transplant surgery and outcome.

Vaccinations

This includes T.B. skin testing and immunizations for influenza, pneumonia, and hepatitis.

Females: Mammogram and Pap Smear, flexible sigmoidoscopy or colonoscopy.

Males: Prostate exam, flexible sigmoidoscopy or colonoscopy.

Other testing: individualized depending on patient's other diseases (i.e. Diabetes mellitus, history of cancer)

Selection of Patients for Heart Transplantation

The heart transplant team meets on a regular basis to discuss patients who have been evaluated for heart transplantation. A decision is made whether or not to offer the patient a heart transplant based upon the evaluation and the recommendations of all the heart transplant team members. If the patient is not a suitable candidate he/she will be referred back to their referring physician for continued medical management.

The following selection criteria for potential cardiac transplant candidates are often used as a basis for judgement. Each transplant center, however, may have specific policies and procedures for transplant candidate selection. Criteria include:

- End-stage heart failure refractory to medical management
- Other medical and surgical options exhausted
- Absence of contraindications:
 - Fixed pulmonary hypertension
 - Ongoing malignancy
 - Irreversible hepatic, renal, or pulmonary dysfunction
 - Active infection
 - Age > 65 - 70 years
 - Diabetes mellitus with vascular complications
 - Advanced peripheral or cerebrovascular disease
 - Morbid obesity
 - Cachexia
 - Active substance abuse
 - Inability to comply with medical regimen



Listing the Patient on the United Network for Organ Sharing (UNOS) List

The patient is placed on the national transplant list, which is managed by the United Network for Organ Sharing (UNOS). Information needed to list the patient appropriately for a suitable donor heart is the following:

- Last name and first initial
- Social Security Number
- Date of Birth
- Weight range for the donor
- Blood type
 - Need for a crossmatch (a blood test to determine if the donor recipient area match)

Status for listing according to the UNOS policies:

1A (intensive care)

1B (in hospital or at home on continuous IV medication)

2 (at home)

7 (inactive)

The following information describes the UNOS policy for listing patients for transplant.

Status 1A:

The patient is hospitalized with at least 1 of the following therapies:

- Mechanical circulatory support
- Ventricular assist device for < 30 days
- Total artificial heart
- Intra-aortic balloon pump
- Extracorporeal membrane oxygenator
- Mechanical circulatory support for > 30 days with device-related complications
- Mechanical ventilation
- Continuous infusion of intravenous (IV) inotropes with hemodynamic monitoring.

This is valid for 7 days with a one-time renewal for each occurrence of a Status 1A listing of the same patient

- The patient does not meet criteria specified in 1,2,3, or 4, but is admitted to the hospital with a life expectancy of < 7 days

Status 1B

The patient may be in or out of the hospital with the following therapies:

- Ventricular assist device for > 30 days
- Continuous infusion of IV inotropes

Status 2

The patient is outside of the hospital and does not meet the criteria for Status 1A or 1B.

Status 7

The patient is temporarily unsuitable to receive a heart transplant, or your doctor has determined your condition has improved to the point that heart transplant is not indicated at the present time.

Who Will Be Your Donor?

Once you have been placed upon the UNOS waiting list, your wait for the donor heart begins. You will be matched to a potential donor based upon your blood type (A, B, AB or O) and your body size (height and weight). Keep in mind that you may have other specifics that your doctor may consider at the time of selecting a donor that best meets your needs. Such other items that may be discussed with you are antibody issues, higher blood pressure in your lungs that may require you to receive special medicine at the time of the transplant, and being a back up to someone else. If there are any changes that need to be discussed with you prior to transplant, your doctor will discuss them with you.



You will not be given any personal information about your donor. It will be up to your transplant center about what type of information they tell you. You will be encouraged to write an anonymous letter to the donor family thanking them for your second chance at life. This is not mandatory. Your transplant coordinator can help you to determine what to say in your letter and will deliver the letter to the organ procurement agency who will send it to the donor family.

Waiting for a Donor Heart

The period of waiting for a suitable donor heart can be very difficult physically and emotionally. You may wait at home or in the hospital, depending on the treatment needed such as IV medications and other devices that aid in supporting your heart. The goal of the heart transplant team is to maximize the patient's medical treatment and enhance the patient's quality of life during this period. Since the timing of the heart transplant is important, you may be asked to move temporarily near the hospital in order to insure that you can be at the hospital when a donor heart has been identified for you.



Preparing for the hospital and Heart Transplant Surgery

If you are waiting at home, you may need to be ready to leave your home quickly after receiving the call. The following is a list of items to have ready in preparation for the call for a heart transplantation.

- a. Overnight bag packed with necessary toiletry and other personal items you may need (i.e. eyeglasses to sign consents)
- b. Identified drivers for your ride to the hospital
- c. Insurance information
- d. List of medications and allergies
- e. List of family members names and numbers you will need to contact while you are in the hospital

You will be asked about when your last meal was, and be asked to not eat or drink anything until after you get to the hospital, in preparation for your pending operation.

If you are waiting in the hospital, a doctor or coordinator will tell you about the pending transplant. Please bring all the names and phone numbers of family and friends you will need and want to contact while you are in the hospital. Keep in mind depending upon where they live and how long it takes for them to get to the hospital, you may not see them before you are taken to the operating room for your surgery.

Getting ready for your transplant

Whether you are waiting at home or in the hospital, you will have baseline lab work done, a chest X-ray and may be given the first doses of your (anti-rejection medicine) prior to the surgery.



Transplant Surgery

Before Surgery

When a donor heart becomes available, the transplant coordinator acts as the link between the donor recovery team and the heart transplant surgery team. Preparations for your surgery will take place according to the time set by the heart transplant surgeon and the donor team. Even though you may be moved to the operating room and anesthesia given, you will not undergo surgery until the donor team actually visualizes and manually inspects the heart and gives the final approval. Once that happens, the doctors and nurses in the operating room can then begin the life-saving heart transplant surgery.

During Surgery

During the heart transplant operation, most of your old heart will be taken out of your body. The doctors will leave in a small piece of the top of the heart (atria) and back in order to sew the new heart into place. You will have new coronary arteries and valves. The operation usually lasts between 5-6 hours from beginning to end, but can last longer if you have had previous open heart surgery or have a left ventricular assist device in place.

During the transplant surgery, the transplant coordinator or nursing supervisor may be in touch with your family to give them an update on your condition. This policy may vary depending on the surgeon. You should clarify this before surgery. Your family will be placed in the surgery or intensive care waiting area. Once the operation is over, the surgeon will be able to meet with your family to inform them about your transplantation.

Congratulations on Your Heart Transplant!

Post-Operative Care

Intensive Care Unit (ICU)

After the surgery, you will be taken directly to the intensive care unit to recover from your operation. You will be watched very closely by the doctors and nurses who have been trained to recognize any problems you could have with your new heart. The following are the usual policies and procedures your family can expect in the ICU:

- a. Everyone who enters your room will need to wash their hands. Depending upon your transplant center, other protective garments such as gloves, booties or gowns may be required. This protects you from potential infections due to the anti-rejection medication.
- b. For the first 24-48 hours you will be on a breathing machine until the effects of anesthesia wear away and you begin to breath on your own effectively. You will be asked to communicate with your nurse and family by nodding your head and/or writing messages on a tablet.
- c. A special tube or catheter will be in one of the big veins of your neck so the doctors can measure the pressures in your new heart. You may also have other IV catheters in your arms to receive IV medications and fluids if necessary.



- d. You will also have a catheter in your bladder to drain your urine. It is very important to monitor your urine output in order to make sure your kidneys are functioning normally. The doctors will remove this tube within the first 24-48 hours after surgery.
- e. You will have 2-3 chest tubes coming out of your chest that will be draining fluids from your chest cavity from the operation. Once the fluid that is collected in the container decreases or stops, the doctors will order these tubes to be removed.
- f. You will have a bandage over the chest incision for the first 24 hours. If there is no drainage, the bandage will be removed. You may have staples (wire) or suture (thread) on your incision, depending on the surgeon's preference.
- g. You will have two wires below the chest incision coming through the skin. They may be attached to a temporary pacemaker if your new heart needs the help. These wires will be removed before your discharge from the hospital.
- h. You will get out of bed and sit in a chair the next day after your surgery depending on how well you are doing. If you have pain and are uncomfortable, don't be afraid to ask for pain medication. Reducing your immediate pain will allow your body to move more easily and help you recover faster.
- i. You will have blood drawn each day in the ICU in order to adjust the dosages of the anti-rejection medications and to monitor kidney, liver and other bodily functions after your transplant.

Cough and Deep Breathing

After you are breathing on your own, you will learn to use a hand held breathing exercise machine (incentive spirometer) to help prevent you from getting pneumonia. It will be important for you to use this machine and to cough and deep breath every hour. It may be an uncomfortable exercise the first few days after surgery but practicing will make it easier.

Your doctors may order chest X-rays every morning to determine how your lungs are doing. It is not unusual to be short of breath after the surgery. Remember, you received a lot of fluids, medications and blood products during the operation. As you begin to move, your body will naturally get rid of the extra fluid so you may need to urinate frequently.





Denervation and its effects

Your new heart is dependent upon circulating catecholamines (hormones) for your heart rate. The surgically denervated heart responds differently to physiologic demands and has a delayed response to exercise. You will be instructed to have a warm-up period before any exercise as well as a cool-down period so your heart rate can slowly return to normal since the nerves were cut during surgery. You may also experience a slight light-headed feeling when you make abrupt changes in position.

Most heart transplant recipients achieve near normal function despite cardiac denervation. Most recipients are able to exercise normally, and some have eventually become capable of athletic achievements. Patients generally report good functional capacity and life satisfaction.

- Make sure you have healthy daily habits that include a good diet and regular exercise.
- Follow your medication schedule **STRICTLY**.
- Check your weight, temperature, blood pressure, and pulse as instructed.
- Communicate to your transplant team regularly.
- Keep to your schedule for lab tests, checkups and follow-up appointments.
- Make sure all of your doctors, your dentist and your pharmacist know about your medications and your care.

Your Transplant Coordinator

Once you leave the hospital, your transplant coordinator will be your main contact with your transplant team. The coordinator is a highly trained person (most are registered nurses) who will teach you how to care for

your general health and will answer most of your questions. Your transplant coordinator is involved in most aspects of your care and will put you in touch with other team members, who can provide, any other services you may need.

Information About Your Heart

Exercise

You will be encouraged to get up and out of bed as soon as the breathing tube has been removed in the ICU. You will gradually increase your activity level each day. We



anticipate you will be walking without assistance by the time you are ready to go home. Some people need additional assistance depending upon how ill you may have been pre-transplant.

You will be encouraged to enroll in a cardiac rehabilitation program within the first 3 months after your surgery. They will be able to help you become physically stronger in a monitored setting as you become more comfortable with your new heart and how your body deals with exercise. Take it easy and pace your self. Always remember to warm up and cool down, as well as to keep yourself well hydrated with water during exercise. After the initial post-operative period we have no limitation in your exercise.



Complications

Complications after surgery

There are a number of complications that can take place after your surgery. Your transplant team will do their best to reduce your chance of having complications and to treat any problems or difficulties right away. Following instructions carefully and keeping your transplant team informed of any problems you think you may be having or are concerned about, will help you return quickly to a normal, active life.

Infections

Antirejection medications interfere with your body's natural ability to fight off infections; therefore, you will be more likely to get infections after your transplant surgery. The following are some of the most common infections

Viral Infections:

Cytomegalovirus (CMV)

CMV is one of the viral infections that occur most often in transplant patients. The risk of CMV is highest in the first months after transplantation. Signs include fatigue, fever, night sweats, aching joints, headaches, nausea, vomiting, diarrhea and shortness of breath. You may need to be admitted to the hospital, and you may have to take medicine intravenously through a special IV inserted in your arm. Even after you are discharged from the hospital you may need to take a pill or continue the IV for several weeks or months.

Herpes-simplex virus type 1 and 2

These viruses most often infect the skin but can also turn up in other areas like the eyes and lungs. Type 1 causes cold sores and blisters around the mouth, and type 2 causes genital sores. Herpes is an infectious disease and can be transmitted sexually. Herpes infections in transplant patients, however, are not necessarily transmitted sexually.

Most herpes simplex infections are mild, but sometimes they can be severe. Although there is no cure for herpes, it can be treated. Depending on the severity of the infection, the treatment is either by mouth (pill form), on the skin ointment and creams, or intravenously.

Symptoms of herpes include feeling weak and having painful, fluid-filled sores in your mouth or genital area. Report any pain with swallowing. Women should also watch for any unusual vaginal discharge. Contact your transplant team right away if you think you may have herpes.

Precautions:

- Keep the sore areas as clean and dry as possible.
- Wash your hands with soap and water after touching the sore.
- Wear loose-fitting clothing to avoid irritating the sores and spreading the virus.
- Avoid kissing or having oral sex with someone who has a cold sore.
- Avoid having intercourse with someone who has genital lesions.

**Herpes zoster (shingles)**

Shingles appears as a rash or small water blisters, usually on the chest, back or hip. The rash may or may not be painful and may occur in people who have had chicken pox. Call your transplant team immediately if you have this kind of a rash.

Varicella zoster (chicken pox)

Chicken pox may appear as a rash or small blisters and usually occurs in childhood, giving immunity to further infection. Call your transplant team immediately if you have been exposed and have not had chicken pox previously - do not wait to see if you are going to get sick.

Fungal Infections:**Candida (yeast)**

Candida is a fungus that can cause a variety of infections in transplant patients. It usually starts in the mouth and throat but may also be in the surgical incision, eyes, respiratory and urinary tracts. Candida is most severe in the bloodstream.

If the fungus is seen in the mouth or throat, it is called thrush. Thrush causes white, patchy lesions (raw areas), pain, tenderness, a white film on the tongue, and difficulty swallowing.

Candida can also infect the tube from the mouth to the stomach (esophagus) or, in women, the vagina. Vaginal infections usually cause an abnormal discharge that may be yellow or white and is often itchy. Call your transplant team if you think you have a yeast infection. Treatment of severe fungal infections may include hospitalization where you may receive an IV medication.

Bacterial Infections:**Wound Infections**

Bacterial wound infections happen at the surgical site. If you have a fever or notice redness, swelling, tenderness, or drainage oozing from your incision, call your transplant team. After a test for bacteria is taken, you will be given an antibiotic if you have an infection.

**Pneumocystis carinii**

Pneumocystis carinii is a germ that is a lot like a fungus, and it is normally found in the lung. In people whose immune systems are suppressed (such as transplant patients), it may cause a type of pneumonia. Early in the illness, you might have a mild, dry cough and a fever. If you think that you have a cold or flu-like illness that does not get better, contact your transplant team right away. Some transplant programs provide treatment to prevent this infection.



REJECTION

Signs and Symptoms

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

Rejection is an attempt by your immune system to attack the transplanted heart and destroy it. To prevent rejection, you must take anti-rejection medications, 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 at least one rejection episode within the first year, even though these people are taking anti-rejection medications. The first episode often happens within the first 6 months of surgery. Rejections are usually controlled by changing the dosages of your anti-rejection medications or by adding a new one temporarily. Rejection does not necessarily mean your new heart is going to fail. Most episodes of rejection can be successfully reversed with anti-rejection medications.

If they are detected early, most rejection episodes can be reversed successfully. You should look for the signs of rejection and call your transplant team promptly if you have the following:

- Fatigue/weakness
- Fever of 100.5°F degrees or higher
- Shortness of breath
- Fast heartbeat or skipping some beats (irregular rhythm)

- Swelling of your hands or feet
- Sudden weight gain
- Drop of your blood pressure
- Not feeling "quite right" or flu-type aches and pains
- A feeling that you are sick to your stomach

You will need to let the transplant team know if any of these happen to you. **DO NOT** attempt to treat your symptoms at home or wait until you are scheduled for a return visit to report these symptoms to your coordinator. Let the transplant team decide about what to do about these symptoms. If you are concerned about something it is a reason to let your transplant team know.

Biopsies

Presently the only way to diagnose whether you are having rejection is by having a heart biopsy done. Biopsies are scheduled routinely initially after transplant and vary from program to program. Often they are done weekly for the first four weeks, every other week for 3 months then monthly for 3 months and less frequently the farther you get out from your initial transplant date.

This test is done in the cardiac catheterization laboratory. The right side of your neck will be cleaned with a special liquid; you will feel a slight "pin prick" as your doctor gives you a numbing medication. After you are numb, a small cut will be made in the side of your neck where the doctor will advance a special catheter called a (bioprobe) into the large vein going down the side of your neck. This vein leads to the right side of your heart where the doctor will remove 4-5 small pieces of tissue from your heart.



The test takes between 15-30 minutes to complete. You might be uncomfortable during the procedure due to the pressure of the catheter, however most people tolerate it without any problem. You will be up and walking shortly after, and will be discharged to home within an hour after the procedure is over.

You may not have any symptoms, but your biopsy result may be abnormal, suggesting that rejection is happening. This is why getting routine biopsies done as scheduled is critical. Based on the results, your transplant team will decide the best treatment for you.

Treatment

Maximizing Medications

If there is evidence of rejection, the first step by your transplant doctor will be to make sure the doses of anti-rejection drugs are adequate. They may even increase the dosages temporarily.

Intravenous Medications for Rejection

There are specific drugs given intravenously (i.e. OKT3, ATGAM) for rejection. Usually, though, the first intravenous drug given will be Solu-Medrol (IV form of Prednisone). You might be hospitalized for this depending on your transplant center's policy.

Oral "Pulse" of Prednisone

Prednisone is often given for rejection with an increased amount prescribed for 3 days and then tapered back to the original dosage. For example, the doctor might order Prednisone 50mg twice per day for 3 days, then taper to 40mg twice per day for 2 days, 30 mg twice per day for 2 days and so on. A repeat heart biopsy, right heart catheterization and echocardiogram will be scheduled after 1-2 weeks of treatment.

Plasmapheresis

This is used as a treatment for a type of rejection called "humoral rejection".

Graft Coronary Artery Disease

One of the late limiting factors of heart transplantation is a very aggressive type of coronary artery disease or blockages in the heart. Annual left heart catheterizations are done to determine if this disease is present. sometimes stents and/or balloons can be used to open blockages but many of the transplanted heart blockages are at the ends of the arteries and cannot be reached by a catheter.

Limiting cardiac risk factors is important. Managing diabetes, high blood pressure, obesity, high cholesterol and stopping smoking and alcohol are ways of controlling this disease.

Anxiety And Depression

A serious operation such as the one you have had can put a lot of stress on you and your family. It is common for transplant patients to have anxiety and perhaps depression after their surgery. This can happen during their stay in the hospital, and/or upon return home. There are counseling services to help you adjust to life at home and to your return to work or school. Ask your transplant team for information about these services.



Diabetes

Some of the antirejection medications, particularly prednisone, may cause diabetes. Diabetes is an increased level of sugar in your blood.

Signs of diabetes may include increased thirst, increased urination, blurred vision, and confusion. Call your transplant team if you have any of these signs. Early detection can result in reversal or reduction of this medication-induced diabetes. Blood sugar can also be reduced by weight loss, careful diet, and exercise. You may need an oral diabetes drug or insulin injections for a short time while your early doses of anti-rejection medications are higher. If you get diabetes, you will be given special teaching about how to deal with this problem.



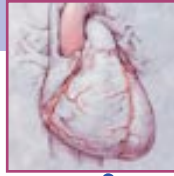
If you were a diabetic prior to surgery, you may have more problems controlling your blood sugar after transplantation.

High Blood Pressure

High blood pressure is a side effect of some of the medications you will be taking. You may need to take another medication to control your blood pressure or your transplant doctor may make a change in your anti-rejection medication.

There are many different types of drugs available to control high blood pressure. You may need to try several different medications before you find the right one. Your transplant team or local healthcare provider will choose the one that works best for you.

You may also be given a water pill (diuretic) to lower your blood pressure, increase your urine output, and remove extra fluid.



Information About Medications

You are responsible for taking the medications that have been prescribed for you. Talk to your doctor, pharmacist, transplant nurse, and/or coordinator so you understand:

- The name and purpose of each medication
- Dose of medication
- When to take each medication
- How to take each medication
- How long to continue taking each medication
- Main side effects of each medication
- What to do if you forget to take a dose
- When to order more medication so you do not run out
- How to get your medication
- What you should avoid (such as drinking alcohol or driving) while you are taking medications

When you return home, you will continue taking most of the medicines you began taking in the hospital after your surgery.

Your immune system recognizes your new heart as foreign and will try to reject it. Therefore, your immune system must be controlled with antirejection medications. You probably will have to take one or more of these drugs for the rest of your life, in addition to other medications.

REMINDER: Never stop taking your medications or change the dosage without your transplant team's approval.

General Guidelines For Storing Your Medications

1. Keep medications in the original container, tightly capped. If you use a special container to hold your pills, keep the container tightly sealed.
2. Store in a cool, dry place away from direct sunlight.
3. Do not store medications in the bathroom - moisture and heat can cause them to lose their strength.
4. Do not allow liquid medications to freeze
5. Do not store medications in the refrigerator unless your pharmacist advises you to do so.
6. Keep all medications away from children.





Before You Take Your Medications

1. Ask your nurse, transplant coordinator, or pharmacist to help you choose the best times to take your medications.
2. Try to take each medication at the same time every day.
3. Follow a written schedule.
4. **DO NOT** cut or crush a tablet unless your are advised to do so.

Notify Your Transplant Team If You...

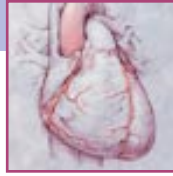
- Cannot take your medicines by mouth because of illness.
- Have a period lasting no more than 36-48 hours of (nausea, vomiting, diarrhea).
- Think the directions on the label may be different from what you were told.
- Have trouble removing child-resistant caps - contact your pharmacist first.
- Have a reason to take aspirin, Advil® (ibuprofen), other pain relievers, cold remedies, or diet pills.
- Feel you are having a reaction to your medications.
- Have had a change in health or eating habits.
- Have a new prescription from your local doctor or a change in a current prescription.
- Experience any unusual symptoms or side effects, since they may be related to the medication you are taking.

Information About Specific Medications

This section is a general guide to each medication's function, proper use, dosage, precautions, and side effects. **The information does not cover everything about each medication and does not replace your doctor's advice.** It is just an overview. Always follow the instructions given to you by your transplant team. Not all of the medications talked about in this handbook will be prescribed by your transplant doctor.

You probably will not experience all of the side effects listed for each medication. Also, side effects usually decrease with time.





ANTI-REJECTION MEDICATIONS

Cyclosporine (Sandimmune®, Neoral®, Gengraf®, Eon®)

NOTE: Sandimmune®, Neoral®, Gengraf® and Eon® should not be substituted for one another except under the direction of your transplant team.

Purpose:

Cyclosporine is used to prevent rejection of a transplanted heart. You may have to take it for the rest of your life.

How to take:

- Capsules - 25 mg, 50 mg, and 100 mg. If you take cyclosporine twice daily, doses should be 12 hours apart. You may be given intravenous cyclosporine for the first few days after your transplant.
- Liquid - 100 mg per ml (milliliter). The liquid form will taste better if you mix it with milk, chocolate milk, or orange juice. Mix it with a room-temperature liquid in a glass or hard plastic container and stir it with a metal spoon. Do not use a plastic foam container.
- Your transplant team will determine your dosage based on your weight, your blood levels, other laboratory tests, the possible side effects of cyclosporine and other medications you are taking.
- Cyclosporine is usually taken with:
 - Corticosteroids, such as prednisone (Deltasone®)
 - Azathioprine (Imuran®), mycophenolate mofetil (CellCept®) or Sirolimus (Rapamune®)

Precautions:

- You will probably have frequent lab tests during the first few months to keep watch on the effectiveness and side effects of cyclosporine.
- On a day when your cyclosporine level is to be measured, do not take your morning dose until your blood has been drawn. After your blood is drawn, take your prescribed medications.
- Store cyclosporine capsules below 77°F, store liquid below 86°F. Do not leave cyclosporine in your car or store it in a refrigerator or bathroom medicine cabinet or exposed to direct light. Good places to store this drug include the kitchen or your bedroom - away from heat, cold, moisture, and children.
- An open bottle of liquid cyclosporine is good for 2 months. You should not remove a capsule from a wrapper until you are about to use it.
- **Cyclosporine interacts with many commonly used drugs including those purchased over the counter. Check with your transplant team before starting any new medications or any herbal remedies.**
- The benefits of taking this medication if you are pregnant or breastfeeding must be weighed against the possible danger to you, your unborn baby, or your infant. Call your transplant team immediately if you think you are pregnant.

Main side effects:

These include, but are not limited to, headaches, tremor, abnormal kidney function, high blood pressure, high blood sugar, high





cholesterol, infection, elevated potassium level in your blood, excessive hair growth, trouble sleeping, swelling or overgrowth of the gums, need for gum surgery.

Switching drugs:

Your transplant team may decide to give you tacrolimus (Prograf®) instead of cyclosporine, or the other way around, because of side effects or rejection. If this happens, follow the instructions of your transplant team.

NOTES

Tacrolimus (Prograf®, FK506)

Purpose:

Tacrolimus is used to prevent or treat rejection in people who have received a transplant. You may have to take it for the rest of your life. It is used to prevent rejections by blocking certain white blood cells involved in rejection.

How to take:

- Capsules - 0.5 mg, 1mg (milligram) and 5mg. If you take tacrolimus twice daily, doses should be 12 hours apart. Either oral or intravenous tacrolimus may be given to you immediately after your transplant.
- Your transplant team will determine the right dosage for you based on your weight, your blood levels, other lab tests, and the possible side effects of tacrolimus.
- Tacrolimus should be taken regularly to keep drug levels steady. Do not take with grapefruit juice.

Tacrolimus is usually taken with:

- **Corticosteroids, such as prednisone (Deltasone®)**
- **Azathioprine (Imuran®) or mycophenolate mofetil (CellCept®)**
- **Sirolimus (Rapamune®)**

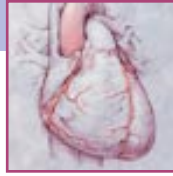
Precautions:

- You will probably have frequent lab tests during the first few months to keep watch on the effectiveness and side effects of tacrolimus.
- On a day when your tacrolimus level is to be measured, do not take your morning dose until your blood has been drawn. After your blood is drawn, take your prescribed dosage.
- Store tacrolimus at room temperature (59° to 86°F) and away from children.
- **Tacrolimus may interact with some commonly used drugs including those purchased over the counter. Check with your transplant team before starting any new medications or taking any herbal medications.**
- The benefits of taking this medication if you are pregnant or breastfeeding must be weighed against the possible danger to you, your unborn baby, or your infant. Call your transplant team immediately if you think you are pregnant.

Main side effects:

These include, but are not limited to headaches, high blood pressure, nausea, diarrhea, high blood sugar, tremors, hair loss, trouble sleeping, infection, numbness and tingling of your hands or feet, elevated potassium level in your blood and abnormal kidney function.





Switching drugs:

Your transplant team may decide to give you cyclosporine (Sandimmune®, Neoral®, Gengraf®) instead of tacrolimus (Prograf®), because of side effects or rejection. If this happens, follow the instructions of your transplant team.

NOTES:

Prednisone (Deltasone®) - prednisolone

Purpose:

Prednisone helps prevent and treat rejection of the transplanted heart. Prednisone is a steroid and is used to fight rejection. When you go home and with each biopsy, your prednisone dose might be lowered if you remain rejection free post-transplant. We will lower the amount of this medication you are taking. We will not decrease your dose if you have rejection, and in fact may increase it or stop decreasing your dose altogether. You may also have to take it for the rest of your life.

How to take:

- Tablets come in several different strengths; your transplant team will decide the best tablet strength; liquid - 1mg per ml; and injectable forms are also available.
- It is best to take prednisone with food because it decreases stomach upset.
- If you take prednisone once a day, you should take it in the morning - ask your transplant team for specific directions. Your transplant team will determine the right dosage for you according to your weight, how well your transplant is

functioning, and the length of time since your transplant.

- Missing doses may cause serious side effects.

Precautions:

The benefits of taking this medication if you are pregnant or breastfeeding must be weighed against the possible danger to you, your unborn baby, or your infant. Call your transplant team immediately if you think you are pregnant.

Main side effects:

These include, but are not limited to:

- High blood sugar
- Weight gain
- Hunger
- Puffy cheeks and a round face
- Infections
- Pimples on the back or face
- Purple or red marks (bruising) easily
- Osteoporosis
- High cholesterol
- Mood swings
- Night sweats
- Anxiety
- Stomach irritation (which can lead to ulcers)
- Blurry vision (cataracts)
- Slow growth and high blood pressure in children.

Special instructions to keep in mind while taking prednisone include: good skin care, active exercise, keep to a good diet low in concentrated sweets, be alert for infections and report these signs and symptoms to your transplant team, black tarry stools or abdominal pain can be an early warning sign for an ulcer.





NOTES

Azathioprine (Imuran®)*Purpose:*

Azathioprine is given to you with other drugs to help prevent rejection of your new heart. You may have to take it for the rest of your heart's life.

How to take:

- Tablets - 50 mg; liquid - 10 mg per ml. Intravenous Azathioprine may be given to you for the first few days after transplantation.
- Your transplant team will determine the right dosage for you based on your weight and white blood cell count.

Precautions:

- Azathioprine may lower some of your blood cell counts such as your white blood cells, which fight infection, and your platelets, which help your blood clot. You should report any unusual bruising or bleeding to your transplant team.
- Azathioprine may interact with some medications. Check with your transplant team before starting any new medications or herbal remedies. Check with your transplant team before taking any anti-gout medications such as Allopurinol®.
- The benefits of taking this medication if you are pregnant or breastfeeding must be weighed against the possible danger to you, your unborn baby, or your infant. Call your transplant team immediately if you think you are pregnant.

Main side effects:

These include, but are not limited to, nausea, vomiting and infection. Report any rashes, yellowing of your skin or whites of your eyes.

NOTES

Mycophenolate mofetil (CellCept®, RS, MMF, MPA)*Purpose:*

Mycophenolate mofetil is given to you with other medications to help prevent or treat rejection of your new heart. You may have to take it for the rest of your life.

How to take:

- Capsules - 250 mg, 500 mg. If you take mycophenolate twice daily, doses should be 12 hours apart.
- Your transplant team will decide the right dosage for you based on your laboratory values and kidney function.
- May be taken with food if causes stomach upset or discomfort.

Precautions:

- Mycophenolate mofetil may lower some of your blood cell counts such as white blood cells, which fight infection. It might also lower your platelets, which help your blood to clot. You should report any unusual bruising or bleeding to your transplant team.
- Mycophenolate mofetil should not be used by pregnant women unless the possible benefits justifies the possible danger to





the unborn baby. Women of childbearing age should use effective contraception before beginning CellCept®, during the time you are taking CellCept®, and for 6 weeks after you have stopped taking CellCept®. Call your transplant team immediately if you think you are pregnant.

Main side effects:

These include, but are not limited to, heartburn, stomach discomfort, infection, nausea, vomiting, and diarrhea. These side effects may decrease with dose reduction, as directed by your transplant team.

NOTES

Antithymocyte globulin (Atgam®, Thymoglobulin®)

Purpose:

Antithymocyte globulin may be given to you after your heart transplant to prevent "acute" rejection. It may also be used later for chronic "acute" rejection.

How to take:

- This medication is given only intravenously. You will need to have a central IV line inserted to receive this medication such as a midline or a PICC line. It takes 4 to 6 hours to administer this medication.
- To reduce side effects, you may receive Tylenol® and/or Benadryl® before you are given Antithymocyte globulin.
- Most often, you will be hospitalized to receive this medication. Your transplant

team will decide the right dosage based on your weight, how your transplant is functioning, your white blood cell count, and the possible side effects of Antithymocyte globulin.

Precautions:

- Your transplant team may change the dosages of your other medications while you are taking Antithymocyte globulin.
- The benefits of taking this medication if you are pregnant or breastfeeding must be weighed against the possible danger to you, your unborn baby, or your infant. Call your transplant team immediately if you think you are pregnant.

Main side effects:

Report any side effects to your nurse as soon as possible. These include, but are not limited to, difficulty breathing, fever, chills, rash, nausea, vomiting, diarrhea, muscle aches, infection and pain during infusion. Your platelet and blood cell levels may lower.

NOTES





OKT3 (Orthoclone OKT®3, Muromonab-CD3)

Purpose:

OKT3 may be given to prevent rejection. It may also be used later on to treat chronic rejection.

How to take:

- This medication is given only intravenously. It is generally given once a day for 5 to 14 days. It will be given over a few minutes.
- To reduce side effects, you may receive Tylenol® and/or Benadryl® before you are given OKT3.
- Your transplant team will decide the right dosage for you based on your weight, how your transplant is functioning, your white blood cell count, your platelet count, and the possible side effects of OKT3.

Precautions:

- Notify your transplant team at the first sign of wheezing, difficulty breathing, rapid heartbeat, difficulty swallowing, rash or itching. Most patients have some mild adverse reactions to OKT3 with the first three doses.
- Your transplant team may change the dosages of your other medications while you are taking OKT3.
- The benefits of taking OKT3 if you are pregnant or breastfeeding must be weighed against the possible danger to you, your unborn baby, or your infant. Call your transplant team immediately if you think you are pregnant.

Main side effects:

These include, but are not limited to, wheezing, difficulty breathing, chest pain, fever, chills, nausea, vomiting, diarrhea, tremor, headache, infection, fast heart rate, and muscle stiffness. The most uncomfortable side effects generally happen only during the first few doses or in the first 1 to 4 days. You may be able to finish this therapy without staying in the hospital.

NOTES

Sirolimus (Rapamune®)

Purpose:

Rapamune® is given to you with some of your other medications as an anti-rejection medication. You may begin taking this immediately after transplant or your doctor may prescribe this medicine, if you have been treated for rejection.

How to take:

Capsules are available in 1 mg. The standard dose is 2 mg so you will be taking 2 tablets. Rapamune® is also available in a liquid form, 1 mg of liquid = 1ml/cc of medicine.

Your transplant team will decide upon the right dose for you depending upon your weight, laboratory values and kidney function.

Rapamune® should be taken with orange juice or water.





You will take Rapamune® once a day 4 hours after your cyclosporine. Tacrolimus may be given at the same time as Rapamune®.

Precautions:

Rapamune® should not be taken at the same time as the other immunosuppression. You should be instructed to take your medicine 4 hours apart from your cyclosporine.

Main Side effects:

These include but are not limited to, infection, peripheral edema, high blood pressure, elevated BUN and creatinine, elevated lipid profile, diarrhea and nausea, tremors, headache, indigestion and heartburn. These side effects are often related to the dose of the medication you are taking. Please inform your transplant team if you feel you are having an adverse reaction to this medication. DO NOT stop taking any medication unless first directed by your doctor.

Daclizumab (Zenapax®)

Purpose:

Daclizumab is a medication that suppresses the immune system and prevents acute rejection. Tacrolimus or cyclosporine is usually given with prednisone and CellCept®.

How to take:

It is available only in injection form and is given intravenously at the time of transplant. It is then given up to four more times at 2 week intervals. It is usually given in combination with cyclosporine and prednisone. When you are discharged from the hospital, you will be given instructions

on where to receive additional doses. The most common side effect of this drug is nausea but generally this drug is very well tolerated.

Precautions:

Since it is unknown if daclizumab is safe in pregnancy, women of childbearing age should use effective birth control before, during, and for four months after completion of therapy.

Basiliximab (Simulect®)

Purpose:

Basiliximab is a medication that suppresses the immune system and prevents rejection. Tacrolimus or cyclosporine is usually given with prednisone and CellCept®.

How to take:

This medication is given intravenously at the time of transplant and once again four days later. The most common side effect is nausea and some of the other same side effects of cyclosporine and prednisone.

Precautions:

As with the other anti-rejection medications, notify your transplant team of any signs of infection. It is not known if there are long term side effects on your body's response to bacteria, fungi, or viruses.

Since it is unknown if basiliximab is safe in pregnancy, women of child-bearing age should use effective birth control before, during, and for two months after completion of therapy.





INFECTION-FIGHTING DRUGS

The medications you take to stop your body from rejecting your new kidney also reduce the normal ability of your body to fight bacteria, viruses, and other germs. As a result, you are in more danger of getting an infection. Your doctor may prescribe one or more drugs to protect you from infection or to control infection.

The following are some of the most commonly used antibiotics (antibacterial drugs), antiviral drugs, and antifungal medications.

Trimethoprim/sulfamethoxazole or TMP/SMX (Bactrim®, Septra®, Co-trimoxazole, Cotrim® - also available under other names)

Purpose:

TMP/SMX is used to prevent and/or treat pneumocystis carinii pneumonia and other infections. Transplant patients have more risk of getting this type of pneumonia because of the drugs taken to avoid rejection, which reduce their body's ability to fight infection.

How to take:

- This medication is taken by mouth and is available in pill or liquid form.
- Your transplant team will decide the right dosage and length of time for you to take TMP/SMX.
- Take plenty of fluids with this medication - check with your transplant team about the amount.

Precautions:

- Do not take TMP/SMX if you are allergic to sulfa. In that case, your transplant team may give you another drug.
- The benefits of taking TMP/SMX if you are pregnant or breastfeeding must be weighed against the possible danger to you, your unborn baby, or your infant. Call your transplant team immediately if you think you are pregnant.

Main side effects:

These include, but are not limited to, nausea, rash, itching, and increase risk of sunburn.

Ganciclovir (Cytovene®)

Purpose:

Ganciclovir is used to prevent or treat CMV, a viral infection, which may cause pneumonia or infect your GI tract.

How to take:

- Ganciclovir is given intravenously or orally. The first few doses are generally given in the hospital.
- Your transplant team will decide the right dosage and length of time you should take ganciclovir.
- Take plenty of fluids with this medication - check with your transplant team about the amount - and take with food to reduce stomach upset.

Precautions:

- Ganciclovir may lead to more risk of infection
- The benefits of taking ganciclovir if you are pregnant or breastfeeding must be weighed against the possible danger to





you, your unborn baby, or your infant. Call your transplant team immediately if you think you are pregnant.

Main side effects:

These include, but are not limited to, nausea, vomiting, diarrhea and lowering of your white blood cell count.

Acyclovir (Zovirax®)

Purpose:

Acyclovir is used to prevent or treat herpes simplex and shingles. Acyclovir will not get rid of the herpes virus, but it will lessen the pain and help heal the sores. Acyclovir is also used to prevent and decrease the severity of CMV infection.

How to take:

- Capsules - 200 mg; tablets - 400 mg and 800 mg; liquid - 200 mg per 5 ml; and ointment. If you are taking acyclovir by mouth, you should take it with food and plenty of water to reduce stomach upset.
- Your transplant team will decide the right dosage and length of time you should take acyclovir.

Precautions:

- Acyclovir will not prevent you from spreading herpes to others. It is best not to have sex if either partner has any symptoms of genital herpes. Condoms may help prevent the spread of genital herpes, but vaginal jellies and diaphragms will not.
- The benefits of taking acyclovir if you are pregnant or breastfeeding must be weighed against the possible danger to you, your unborn baby, or your infant.

Call your transplant team immediately if you think you are pregnant.

Main side effects:

These include, but are not limited to, nausea, vomiting and lowering of your white blood cell count.

Valganciclovir (Valcyte®)

Purpose:

Valganciclovir may be given to help prevent or treat infections that are caused by a virus called Cytomegalovirus (CMV). The CMV virus is present in about 50% of the population. This virus is generally experienced in the form of a common cold or flu and most people are unaware that they have had this virus.

However, when a donor kidney with CMV is transplanted into a recipient who has not had CMV, the recipient is at risk for becoming infected with the CMV virus. If you acquire the CMV virus after your transplant, you are at risk for infection because you are taking anti-rejection medication.

By taking Valganciclovir, you are protecting yourself against the CMV virus and thus protecting yourself from infection.

How to take:

- It is given orally in 450 mg tablets. It is generally given once daily in the morning.
- Take this medicine with food.
- Swallow whole - Do not break, crush, or chew the tablet before swallowing.
- Your transplant team will advise you on how long to take this medication, generally 3-6 months.



*Precautions:*

This medication may reduce your number of platelets; platelets are the blood cells, which are necessary for clotting. This medication can also reduce the number of white blood cells and the number of red blood cells. Your transplant team will be monitoring your blood counts to make sure you are not having potential side effects.

Valganciclovir has caused birth defects in animals and may impair fertility. Since it may cause birth defects, both women and men of childbearing age should use effective birth control during and for 90 days following the use of Valcyte. If you suspect you are pregnant, contact your transplant team immediately.

Main side effects:

Side effects that may occur, but are not limited to, while taking this medication are: dizziness, nausea, diarrhea, and decrease red blood cell counts, platelets, and white blood cell's.

ANTIFUNGAL DRUGS

The lowered ability of your body to fight infection puts you in more danger of getting a serious fungus infection. This may take the form of thrush, or, in women, vaginal yeast infections.

Purpose:

Various drugs, such as AmBisome, are used to treat or prevent fungus infections.

Nystatin (Mycostatin®) and **clotrimazole (Lotrimin®, Lotrisone®, Mycelex®)** and **Amphotericin (AmBisome®)** are the most commonly used. Other antifungal drugs may be used as well but may interact with your antirejection drugs, so an adjustment will have to be made in your medications when you start and stop taking the antifungal drugs.

How to take:

- Liquid - swish and swallow.
- Troche or lozenge - dissolve in your mouth. Do not chew.
- The liquid or the lozenge should be taken after meals and other medications to allow liquids and lozenges to work in your mouth. Do not drink anything for at least 30 minutes.
- Vaginal suppository or cream - used as directed.
- Severe fungal infections may require hospitalization and the use of intravenous antifungal drugs.
- Your transplant team will decide the right dosage and length of time for you to take antifungal medications.

Precautions:

The benefits of taking these medications if you are pregnant or breastfeeding must be weighed against the possible danger to you, your unborn baby, or your infant. Call your transplant team immediately if you think you are pregnant.

Main side effects:

These include, but are not limited to nausea, vomiting, diarrhea and unpleasant taste.





DRUGS THAT PROTECT YOUR DIGESTIVE SYSTEM

Because some medications you take can cause stomach ulcers, you may need to take other medication to help protect your digestive system. These drugs will be prescribed by your transplant team when necessary.

Antacids/Antiulcer Medications

Ranitidine (Zantac®), famotidine (Pepcid®), omeprazole (Prilosec®), and sucralfate (Carafate®) are medications used to prevent and sometimes treat stomach ulcers.

How to take:

- It is important to follow instructions about meals and other medications when taking any of these drugs.
- Your transplant team will decide the right medication, dosage, and length of treatment time for you.

Precautions:

- Do not take these drugs with other medications unless your transplant team has told you to do so.
- Do not make changes to dosage on your own.
- Call your transplant team immediately if you think you are pregnant.

Main side effects:

These include, but are not limited to, headache, nausea, vomiting, diarrhea, constipation, and gas.

OVER THE COUNTER MEDICATIONS

The following is a list of common complaints and recommended over the counter medications that you can take for these problems. Please check this list before taking any over the counter medication. The addition of any other medications or change in your current medications must be made through your transplant center.

Constipation

Metamucil®, Fiber-Con®, Senekot®, Colace® are medications that you may take. Increase fluids in your diet and increase fiber in your diet (bran, fresh fruits and vegetables). If constipation remains a problem, be sure to report to your transplant center.

Diarrhea

Imodium®, Kaopectate®, Donnagel® are medication that you may take. Increase fluids to prevent dehydration until diarrhea goes away. If diarrhea persists for more than 2 days, please notify your transplant center.





Headache, Muscle Aches, other Aches and Pains

If headaches persist or accompanied by fever, please notify your transplant center immediately. Tylenol®/Acetaminophen, Aspirin are medications that you may take.

DO NOT TAKE:

IBUPROFEN, MOTRIN-IB®, ADVIL®, NUPRIN®, MENADOL®, MIDOL®, GENPRIL®, KETOPROFEN®, ORUDIS-KT®, ACTRON®, NAPROXEN®, ALEVE®. These medications interact with your anti-rejection medications and may harm your kidneys.

Allergy, Cold Symptoms

Over the counter medications should be cleared by your transplant team.

Indigestion/Heartburn

You can take Zantac 75®, Axid AR®, or Pepcid AC®

Nutritional Supplements

Your transplant team may recommend that you take vitamin and/or mineral supplements in case your diet is not providing enough of the nutrients you need. Check with your transplant team before taking any nutritional supplement, including herbal preparations.

CAUTION: HERBAL PRODUCTS OR TEAS

Since there is little information about drug interactions between herbals and anti-rejection drugs, it is recommended that transplant patients do not take herbal products.

Herbal products are not regulated by any government agency. This means that they are not tested for safety, side effects or drug interactions. St. John's Wort, for example, is an herbal known to increase the risk of rejection by decreasing the amount of the anti-rejection drugs in your blood. Other products that may "enhance your immune system" may lead to rejection as well.

Blood Sugar Monitoring And Insulin

Monitoring of blood sugar (glucose) after transplant is done to detect high levels of sugar in the blood called hyperglycemia. If you were taking insulin prior to transplant, you will continue to take insulin after transplant. If you were taking pills to control your blood sugar before transplant, you may need to take insulin after transplant for a time. Unless you receive a pancreas transplant, your surgery will not replace the need to control your blood sugars.

Some of the drugs that you will be taking to prevent rejection may cause an increase in your blood sugar. Your blood sugar levels may return to normal as the doses of your medications are decreased. If your blood sugar remains high when you are ready to go home, you will be taught how to check your blood sugar, how to give yourself insulin, and how to change your diet to help control your blood sugar.

NOTES



Going Home:



A Practical Guide for the Heart Transplant Patient

Keeping Your New Heart Healthy at Home

Now that you have received a new heart and are about to go home, it is important to understand that having a new heart brings new responsibilities.

Your transplant team will continue your post-transplant care. At this point, though, the most important member of the team is YOU! Without your active support, the team's best efforts cannot succeed. As the lifetime caretaker of your new heart, you will need to:

After you leave the hospital, you will be asked to measure your:

- Temperature
- Pulse
- Blood pressure
- Weight

Temperature

Check and record your temperature any time you feel cold, hot, achy, or ill. Sometimes you may not have an actual high temperature but will experience other symptoms, such as chills or sweats. This may be a sign of infection.



WARNING: DO NOT USE Tylenol®, Advil®, aspirin, or other such products unless your doctor tells you to, as these drugs may cause further symptoms or interact with your other medications. If your temperature is higher than 100.5F degrees at any time, notify your transplant team or your doctor immediately. This is considered an emergency, because a high temperature could mean you have a serious infection or rejection.

Pulse

If you are taking medication that affects your heart rate, your nurse or coordinator will teach you how to check your pulse at home. **Notify your doctor or transplant team if your pulse is:** faster than _____ or slower than _____.

Blood pressure

Your nurse or transplant coordinator will teach you how to measure your blood pressure, if necessary. The top number (systolic) is noted at the first sound you hear and the bottom number (diastolic) is noted when the sound changes (not stops). If you use a digital cuff, have the readings checked by your transplant coordinator against manual cuff readings. It is important that you know your normal blood pressure, normal changes, and when you should be worried.

You should notify your transplant team or doctor if your blood pressure is:

Systolic - more than _____ or less than _____
Diastolic - more than _____ or less than _____

Note: If you have chest pain or difficulty breathing, call 911 for an ambulance and go to the nearest emergency room. **DO NOT** try to drive yourself or have someone drive you.



Weight

You may be asked to weigh yourself on a standard bathroom scale at the same time every morning (after going to the toilet). Write your weight on the chart in this handbook. If you gain more than 2 pounds a day, you could be retaining fluid. Report this to your transplant team or doctor.

Clinic Visits

When you leave the hospital, you will receive a schedule of follow-up clinic visits for lab tests, heart biopsies, echocardiograms and other tests. The reason for these visits is to track your progress and find complications as early as possible.

Follow-up visits

On days when you are scheduled for follow-up visits, bring your medication list and this handbook with you. You will be told about routine lab work (to keep track of your blood count, kidney and liver function, medication levels, etc) or special tests that you might need.

Lab Tests

You will be given some lab tests each time you go for a checkup. These can include blood and urine tests. Some of the things the tests look for are:

- 1) Your white blood cell count, which can indicate whether you have an infection or side effects from medication
- 2) How well your blood can clot (to avoid too much bleeding if you are injured)
- 3) How well your kidney and liver are working
 - **Creatinine** and **BUN** tell how well your kidney works by measuring levels of creatinine and blood urea nitrogen, waste

products normally removed from the blood by the kidneys.

- **Bili** measures the level of bilirubin. The liver removes bilirubin from the blood and excretes it in the bile. When the liver is not functioning normally, bilirubin levels can increase, often resulting in jaundiced (yellowed) skin and eyes.
 - **Alk Phos** measures alkaline phosphatase, which is made in the bones, liver, pancreas, and intestines and removed from the blood by the liver.
 - **AST, ALT, and GGTP** test enzymes that are made in the liver. These tests tell how well your liver is working.
- 4) Whether you have enough minerals in your body
 - **Ca** measures calcium, which is necessary for strong bones and teeth, blood clotting, and heart and nerve function.
 - **PO4** measures phosphate, which works closely with calcium to strengthen bones.
 - **Mg** measures magnesium, which is necessary for normal functioning of muscles and for blood clotting.
 - **K** measures potassium, which is needed for normal heart and muscle function.
 - **Na** measures sodium, which helps maintain the balance of salt and water in the body.
 - 5) How much medication is staying in your bloodstream and for how long
 - Drug levels will be collected to check whether specific immunosuppressants are too high or too low in your body. High levels could lead to toxicity or over-immunosuppression, and low levels may lead to rejection.
 - 6) How much sugar (glucose) is in your blood
 - 7) How much cholesterol and lipids are in your blood



Additional Tests And Procedures

Your transplant team may perform one or more of the following tests to keep watch on your transplant.

Echocardiogram (ECHO)

This test is an ultrasound "sound wave" of your heart. It uses sound waves to check the size, shape and motion of the heart and its valves, the heart pumping function and can detect fluid in the sac around your heart (pericardial effusion). A gel is applied to the chest and a wand with a ball on the end of it will be placed on your chest and moved around to get the pictures of your heart.

Cardiac Catheterization (Cath)

Right Heart Cath (RHC)

A right heart catheterization will be done to check the pressures in the heart. After numbing the area, a catheter will be inserted into a vein in the neck and advanced into the right side of the heart. Pressures will be measured of the heart chambers, main blood vessels, and valves. A Swan Ganz catheter is used to document these pressures in your heart.

Left Heart Cath (LHC)

A left heart catheterization is usually done yearly to check for blockages in the arteries in your heart. A catheter will be inserted into the blood vessel (artery) in the groin or arm and advanced to the left side of the heart. Dye will be injected to look at the arteries and the pumping function of the heart. This procedure is done in the Cath Lab.

Electrocardiogram (EKG)

This test checks your heart rhythm and checks to see if you have had a heart attack, or if your heart is in an abnormal rhythm. This test was used in the early days of heart transplantation to determine rejection by measuring the voltage of the QRS complexes.

Ultrasound

This test is performed to make sure all the main blood vessels leading to the organs in your abdomen are functioning normally. This test is also used to check for amounts of fluid around the kidney, and to check for blockage of the kidney. The test consists of placing a cool gel on your abdomen, over which a wand is moved to transmit sound waves. These are converted into images of your kidney or other organs and projected onto a television screen.

Magnetic resonance imaging (MRI)

This is another type of test that produces an image. Somewhat like a CT scan (another imaging method), it also allows your kidney to be viewed from different angles and in three-dimensional images. A MRI shows soft tissues, such as the kidney, more clearly than a CT scan does.

Bone Density Scan (DEXA Scan)

This test will check your bones for osteoporosis, which is calcium loss in your bones from taking steroids.

NOTES:



Resuming Normal Activities

Avoiding Infection

Because anti-rejection medications interfere with your body's defenses, you need to make sure to protect yourself from infection after your surgery by taking the following precautions:

- Wash your hands often.
- Keep your hands away from your face and mouth.
- Stay away from people with colds or other infections.
- Ask friends to visit only when they are well.
- If you have a wound and must change your own dressing, wash your hands before and after.
- Wash your hands after coughing or sneezing, and throw tissues into the trash immediately.
- If someone in your family becomes ill with a cold or flu, have that individual follow normal precautions (using separate drinking glasses, covering their mouth when coughing, frequent hand-washing, etc.)
- Avoid handling animal waste and avoid contact with animals that roam outside. Do not clean bird cages or fish or turtle tanks or cat litter. The cat litter box should be covered and taken out of your home before it is changed. The feces of some animals contain parasites and can cause infections. Fish tanks can develop fungus as well and can be infectious. All of these organisms can infect you after your transplant.
- Avoid vaccines that have live viruses such as Sabin oral polio, measles, mumps, German measles, yellow fever, smallpox and chicken pox. If you or any family member needs to receive any vaccinations, tell your transplant team or doctor.

SPECIAL WARNING TO PARENTS OF CHILDREN WHO HAVE HAD TRANSPLANTS:

Ask the school nurse or other official to call you immediately if there are any communicable diseases (for example, measles or chicken pox) that may be going around in your school.

Food Safety

Food can carry bacteria, viruses, fungi and parasites. What may be safe to eat for the healthy person can be a risk for an immunosuppressed person. Specific guidelines can be followed to prevent contamination. The following is a list of suggestions that you should follow to prevent infections from the foods that you eat. Again, your hospital stay is a good time to meet with your transplant nutritionist to review your individual nutrition guidelines.

Dairy

Drink only pasteurized milk, use only pasteurized milk products.

Eggs

Yolks and whites should be cooked firm, pasteurized egg substitutes may be a better choice.

Meat and Poultry

Avoid raw meats and poultry, juices from all meats should run clear.

Fruits and Vegetables

Wash fruits and vegetables using scrub brush and chlorinated water, even when not eating the peel.

Avoid Cross-contamination

Thoroughly clean counter tops and dishcloths.



Suggestions for Dining Out

Order meat, seafood, poultry cooked to "medium". If animal flesh has any pink, send it back for additional cooking. Make sure shellfish is well cooked and firm.

Diet And Nutrition

Eating right is an important part of your recovery. A nutritionist can help you develop an eating plan that provides a balanced diet to meet your needs. The number of calories you need will be based on whether you need to gain, maintain, or lose weight and on your level of activity.



During the first weeks after your transplant, your body will require extra calories and protein. Meeting your increased nutritional needs will help your body to heal, fight infection, and gain back any weight you may have lost. Even if your appetite is not good after surgery, it is still important to eat. Think of food as another medicine to help you get well. The following are some tips to help you increase calories and protein in your diet.

- Try eating 5-6 small meals a day.
- Ask your nutritionist about adding high calorie, high protein supplements and/or snacks with or between your meals. Good snack choices include:
 - Instant Breakfast
 - Low fat yogurt
 - Low fat cheese and crackers
 - Low fat peanut butter and crackers
- Choose high calorie drinks such as juice or milk rather than water.

Use of salt, sugar, and fat

A low-fat, low-sugar diet will help control your weight and blood sugar. Eating right will help keep you at a healthy weight and in the best shape. Certain medications you take may cause your blood pressure, blood sugar, cholesterol and weight to increase. To help regulate these things, it is important for you to limit your daily intake of saturated fat, salt and sugar. Your use of salt may be restricted to help limit the amount of fluid your body holds and to control blood pressure and blood sugar. Consult your nutritionist about using salt, sugar, and fat in your diet. Your diet should include a variety of foods, such as:

- 5 fruits and vegetables per day
- Whole-grain cereals and breads
- Low-fat or non-fat milk and dairy products or other sources of calcium
- Lean meats, fish, and poultry or other sources of protein; avoid/limit fried foods
- Egg whites or egg substitute
- Sugar free beverages and limit concentrated sweets
- Limit processed, "convenience" or canned foods; good salt free seasonings to choose include garlic & onion powder, pepper, vinegar and herb mixtures



Electrolytes

Levels of potassium, phosphorus and magnesium

Your medications may also affect the levels of potassium, phosphorus, and magnesium in your body. You may need to restrict or supplement your intake of these things to keep them in a desirable range. The following are examples of foods high in each category.

<u>Potassium</u>	<u>Phosphorous</u>	<u>Magnesium</u>
Cantaloupe	Milk	Shrimp
Oranges	Cheese	Peanuts
Orange juice	Yogurt	Beets
Broccoli	Whole grains	Spinach
Potatoes	Raisins	Tofu
Tomatoes		
Bananas		

Caring For Your Bones

Research has shown that transplant patients are in more danger than other people for having bone fractures. The feet and ankles seem to be particularly vulnerable, but other bones can break too.

To lower your fracture risk, make sure you are getting enough calcium and vitamin D in your diet (unless your doctor says not to). Here are a few good dietary sources of calcium:

- Yogurt
- Ricotta cheese, part skim
- Skim or low-fat milk
- Provolone cheese
- Mozzarella cheese, part skim
- Sardines with bones, canned
- Salmon with bones, canned
- Calcium-fortified orange juice

Exercise

After transplant surgery, exercise is very important to your mental health and physical well being. Physical activity also helps

decrease the effects of prednisone, which causes muscle weakness. Your transplant team will provide a referral to physical therapy or cardiac rehabilitation depending on how weak you may be. It is important to remember that your sternum is wired and needs to heal over a period of 6-8 weeks. You should not lift more than 5 lbs. during this time. Also, you will need to obtain a clearance from your transplant team before driving.



WARNING: If you have any of the following symptoms, stop your exercise until you talk to your doctor.

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

Returning To Work Or School

Returning to work or school must be discussed with your transplant team; they will help you to determine your readiness to return. The time frame will depend upon many factors including your recovery and the type of work you perform.



Sexual Activity

You may resume sexual activity after your transplant surgery. How quickly you feel ready will depend a lot on your recovery progress. Your sexual functioning may be affected by your transplantation and/or certain medications. Some people avoid sexual activity because they are afraid of rejection or of infection. If you have any of these fears, you may want to check with your transplant team. If you are sexually active and do not have a steady sexual partner, you must use condoms to reduce the risk of sexually transmitted diseases such as AIDS, syphilis, herpes, hepatitis, or gonorrhea. You must use contraception to prevent unplanned pregnancy also. You should discuss this during your clinic visits.

Skin And Hair Care

You will not need any special skin care unless you develop acne or dry skin. Generally, you should shower or bathe as often as necessary to keep your skin clean. Most soap is generally okay to use.

Call your transplant team if you discover any unusual skin growths, rash, or discoloration.

Sun exposure

Transplant patients have more chance of developing skin and lip cancers. Since the risk gets bigger with time, you must always protect your skin from the ultraviolet rays of the sun that cause skin cancer.

- Avoid midday (10 a.m. to 3 p.m.) sun, when ultraviolet rays are strongest.
- Wear a hat, long sleeves, and slacks when outdoors unless you are using a sunscreen.
- Use a sunscreen lotion with skin protective factors (SPF) rated at least 15.
- Use a sunscreen lotion and lip balm every day (rain or shine) and put them on any

areas that are not covered, especially your face, neck and hands.

NOTE: Remember that sunscreen lotions wash off. Put the lotion on again as needed, especially after swimming.

Dry skin care

If you have problems with dry skin, use a mild soap and put on body lotion after bathing.

Cuts and scratches

Recommend electric razor to avoid cuts while shaving. Wash minor cuts and scratches daily with soap and water. For large cuts, see your doctor right away.

Hair care

Prednisone will probably change the condition of your hair. Permanent hair dyes, tints, wave lotions, and bleach may cause your hair to become brittle and to break. It is recommended that you wait until the prednisone dosage is lower than 10 mg a day before having a permanent or coloring your hair. Tell your hairdresser that you are taking prednisone and use a good conditioner on your hair.

Unwanted hair growth

If you get more facial hair, use a hair-removal cream (depilatory). Be sure to follow directions carefully to avoid eye or lip irritation. Another way is to bleach extra hair growth with 50% peroxide solution. You might consider waxing or electrolysis to remove extra hair. Even if there is a lot hair growth, do not alter your medication. Call your transplant team about ways to deal with this problem.



Alcoholic Beverages

Drinking beer, wine, and liquor may damage your liver. Medications such as tacrolimus, cyclosporine, azathioprine, mycophenolate and TMP/SMX are broken down by the liver and, if combined with alcohol, could harm your liver. Call your transplant team for advice.

Smoking

The Surgeon General of the United States has determined that active and passive smoking can be harmful to your health. If you are a smoker, you may wish to join a stop-smoking group in your area. Look in the yellow pages of your telephone book. In the United States call the American Heart Association, American Lung Association, or American Cancer Society to find a local group.

Pregnancy

Pregnancy after heart transplantation is considered a high-risk condition. You need to carefully consider this risk to your life and the baby's life. You should discuss children and birth control options with your transplant team.

Men with heart transplants have been able to father children. Because of the medications that you take, it is important to discuss the possible risks to the baby with your transplant team.

Vacations And Travel

If you are planning a trip to a foreign country, it is important to talk to your transplant team. Some countries may require vaccinations for smallpox, measles, German measles, or certain other diseases. Your transplant team will decide which vaccinations you cannot have and can send a letter to your local

passport bureau indicating that you cannot receive these vaccines. Because you cannot receive these vaccines, however, travel to these countries may not be safe for you.

As you travel to places that have time differences, you will need to take this into account, when you take your medications. You may find that you will be taking your medications at times that you don't normally take your medications at home. It is important to adjust to the new time change but remember to space your medication times as you had at home. For example, if you take your anti-rejection medicine every 12 hours at home, you will need to take your anti-rejection medicine in a new time zone every 12 hours.

Also, diet and hygiene in some countries may be an issue. Discussions with your transplant team and infectious disease team can help you make wise decisions.

ALWAYS KEEP YOUR MEDICATIONS WITH YOU! Your transplant team can provide a letter verifying you are a transplant patient and that you will need these medications with you.

Vaccinations

The use of immunizations of organ transplant recipients is one that causes many questions. LIVE vaccines should not be given to transplant recipients due to the risk of infection that could be associated with the risk of viral replication of the virus given during the injection.

Some types of LIVE viruses include Measles, Mumps, Rubella, oral polio and yellow fever. Vaccinations for pneumonia,



(Pneumovax) and the flu shot (Influenza) do not contain live viruses and therefore can be given without any potential complication or harm to you.

Pets And Plants

Certain types of household pets such as birds and cats carry organisms, which can be problematic and infectious to patients that are immunocompromised. Birds can carry parasitic organisms such as psittacosis. Cats and other farm animals can carry toxoplasmosis. You should avoid contact with the feces of these animals. For example if you have a cat, you should not empty the litter box yourself, but rather have someone else in your family take care of it.

You should eat all of your meat and fish cooked and avoid eating raw meat.

Exposure to live plants and soil within the first few months after transplant should be avoided due to the many organisms that grow and live in the soil. If you are a gardener or have gardening as a hobby, you should always wear protective hand gloves while digging in the dirt and planting.

Driving

You will be given the permission to drive approximately 6-8 weeks following transplantation. Your sternum will need a chance to heal prior to your return to driving a car. If you should be in an accident you could cause serious harm to yourself and new heart if you should hit your chest and new incision on the steering wheel, or air bag. Also, you may find yourself extremely tired and de-conditioned due to your wait for transplant. Your reflexes and your

attention to driving may not be up to normal immediately post-transplant. When you have gained your strength and feel up to driving, and have been given the permission to drive, start out with small distances gradually increasing your distance and length of time behind the wheel.

Dental Care

Please inform your transplant coordinator if you need to have dental work done. You may now need to be given an antibiotic prior to getting any dental work done. An important part of your health maintenance following transplant is to see your dentist regularly. Small things such as a toothache, or an abscessed tooth can be a major complication now that you are taking your anti-rejection medications.

Routine Health Care

You will need to re-establish contact with your family or internal medicine doctor once you have had your transplant. You will need to have a yearly physical at the transplant center, but you also need to have someone you can see on a regular basis close to home for regular health care and screening examinations. You should make an appointment with this physician within the first 3-6 months post-transplant so they can get to know all that has happened to you since transplant and have the ability to review your medical records.

Please inform the transplant center who this physician may be and they would be happy to arrange getting them all the required information they will need to help keep you health and happy for the rest of your life.



Communication

With Your Healthcare Team

Having a transplanted heart and taking the medication needed to prevent rejection put you at risk for a number of problems. It is important for you to follow the instructions that will help prevent or lessen these problems.

One of your most important jobs is to make sure that all members of your healthcare team - your family doctor, dentist, local pharmacist, and any other healthcare professionals you see - are aware of your transplant, the medications you take each day, and the precautions you must follow to stay healthy. Give each of your local healthcare providers the telephone number of your transplant team. Ask them to call the transplant center for information.

Signs To Watch For

While the main things for you to avoid are infection and rejection, many other problems, such as colds or flu, your doctor can handle changes in other medication, and minor infections. You need to take precautions yourself, however, and learn to watch for signs of infection and rejection so you can call your doctor or transplant team right away. These include:

- Less urine output
- A fever that continues for more than 2 days
- Fluid retention - a bloated feeling
- A cough that produces a yellowish or greenish substance
- A dry cough that continues for more than 1 week
- Nausea, vomiting, or diarrhea for a long time
- An inability to take prescribed medication
- Bleeding, bruising, black stools, or red or rusty-brown urine
- A rash or other skin change

- Vaginal discharge or itching
- Burning discomfort when you urinate
- Exposure to mumps, measles, chicken pox, or shingles
- Unusual weakness or light-headedness
- Emergency-room treatment or hospitalization

Dental Care

Precautions for dental care - If you have dental pain, call your dentist immediately. Before you have dental work done (including cleaning and polishing), check with your transplant team to see if you need to take antibiotics.

Cyclosporine has been known to cause gum hyperplasia (overgrowth) in some patients. Make sure your dentist knows you are a transplant recipient and which medications you are taking.

Routine Healthcare

Immunization and medical and dental checkups are necessary for your continued well being.

NOTES



Glossary

A

ANESTHETIC

Medication that reduces pain by dulling sensation or causing the patient to sleep.

ANTACID

A drug that relieves heart burn and digestive discomfort.

B

BACTERIA

Small organisms (germs) that can cause disease.

BLADDER

A saclike structure that stores urine.

BUN

Blood urea nitrogen.

C

CATHETER

A drain placed into the bladder to empty urine. Or, a small needle with a hollow tube inserted into a vein used to give medication or fluids.

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.

CMV

(CYTOMEGALOVIRUS)

A virus infection that is very common in transplant patients; it can affect the lungs and other organs; a member of the family of herpes viruses.

CONGESTIVE HEART FAILURE

Congestive heart failure is a disease of the muscle of the heart causing enlargement and weakening of the heart.

COAGULATION

Blood clotting.

CORTICOSTEROID

A category of anti-rejection medications that includes prednisone and prednisolone.

CREATININE

A substance found in blood and urine; it results from normal body chemical reactions; high blood creatinine levels are signs of depressed kidney function.

D

DETOXIFY

To change a harmful substance into a safer form.

DIABETES

A disease in which patients have high levels of sugar in their blood.



E**EDEMA**

Too much fluid in body tissues; swelling of the ankles, for example, is a sign of edema.

ELECTROCARDIOGRAM (ECG)

A recording of the electrical activity of the heart

G**GALLBLADDER**

A muscular sac attached to the liver; stores bile.

H**HEMATOCRIT (HCT)**

A measure of separating solids from plasma in the blood.

HERPES

A family of viruses that infect people; herpes simplex causes lip and genital sores; herpes zoster causes shingles.

HYPERTENSION

High blood pressure.

I**IMMUNE SYSTEM**

The system that protects the body from invasion by foreign substances, such as bacteria and viruses, and from cancer cells.

IMMUNITY

Being able to resist a particular infectious disease.

IV, OR INTRAVENOUS

Refers to giving medication or fluids directly through the vein.

O**ORALLY**

By mouth.

P**PCP**

Pneumocystis carinii pneumonia, a type of pneumonia seen mainly in patients whose immunity is lowered by illness or drugs.

PLATELET

A small blood cell needed for normal blood clotting.

POTASSIUM

A mineral essential for body function.

R**REJECTION**

An attempt by the body to reject or destroy what it recognizes to be a "foreign" presence (for instance, a transplanted kidney).

RENAL

Refers to the kidney.



S

SHINGLES

A herpes virus infection (herpes zoster) that usually affects a nerve, causing pain in one area of the body.

SODIUM

A component of table salt (sodium chloride); the main salt in blood.

T

THRUSH

A fungus infection in the mouth.

U

URETER

A tube that transports urine to the bladder from the kidneys.

URINARY TRACT INFECTION (UTI)

An infection of one or more parts of the urinary tract.

V

VIRUS

A very small germ that causes infection - differs from bacteria.

W

WHITE BLOOD CELLS

Cells in the blood that fight infection.



Sources For More Information

American Heart Association (AHA)
National Center 7272 Greenville Avenue
Dallas, TX 75231-4596
1-800-242-8721
www.americanheart.org
(Local and national AHA and the AHA
Cookbook are good sources of nutritional advice)

**Transplant Recipient International
Organization (TRIO)**
2117 L Street NW, #353
Washington, DC 20037
Phone: 1-800-TRIO-386
Fax: 703-820-3948
Email: triointl@aol.com

National Kidney Foundation
30 East 33rd Street, Suite 1100
New York, NY 10016
Phone: 1-800-622-9010
Local: 212-889-2210
Fax: 212-689-9261
Email: info@kidney.org

**United Network for Organ Sharing
(UNOS)**
1100 Boulders Parkway, Suite 500
P.O. Box 13770
Richmond, VA 23225-8770
GET from KIDNEY BOOK
Web page: <http://www.unos.org>

International Transplant Nurses Society
1739 E. Carson Street
Box 351
Pittsburgh, PA 15203
Phone: (412) 343-ITNS (4867)
Fax: (412) 343-3959
Web page: <http://www.itns.org>
Email: itns@msn.com

American Society of Transplantation
1700 Commerce Parkway Suite C
Mt. Laurel, NJ 08054
www.a-s-t.org

Fujisawa Healthcare, Inc.
www.fujisawausa.com



Useful Forms

You may want to make extra copies of some of these forms before you fill them in.

PHONE DIRECTORY OF YOUR HEALTHCARE TEAM

Transplant team office phone number: _____

	<u>Name</u>	<u>Phone Number</u>
Primary Nurse:	_____	_____
Clinical Nurse Specialist	_____	_____
Transplant Coordinator	_____	_____
Nurse-Practitioner	_____	_____
Transplant Doctor	_____	_____
Transplant Surgeon	_____	_____
Social Worker	_____	_____
Nutritionist	_____	_____
Hospital Pharmacist	_____	_____
Physical Therapist	_____	_____
Psychiatrist or Psychologist	_____	_____
Other (_____)	_____	_____
Other (_____)	_____	_____

OTHER MEMBERS OF YOUR HEALTHCARE TEAM

Family Doctor	_____	_____
Dentist	_____	_____
Local Pharmacist	_____	_____
Laboratory	_____	_____
Other (_____)	_____	_____
Other (_____)	_____	_____

Patient's name _____

Pharmacy _____

Allergies _____

Pharmacy phone number _____

Drug	Strength	Directions	Number of Tablets/Capsules						
			Morning	Midmorning	Afternoon	Evening	Bedtime		

NOTES ON ADDITIONAL MEDICATIONS _____

FOLLOW-UP APPOINTMENT SCHEDULE

Patient's name

Date	Time	Type of appointment: lab or clinic	Location	Instructions on what to bring/do before appointment

RECORD OF LAB VALUES

Patient's name _____

Normal Values

Date									
WBC (White Blood Cell)									
HCT (Hematocrit)									
PLT (Platelet)									
PT (Prothrombin Time)									
BUN (Blood Urea Nitrogen)									
CREAT (Creatinine)									
Ca (Calcium)									
PO4 (Phosphorus)									
Mg (Magnesium)									
Na (Sodium)									
K (Potassium)									
GLU (Glucose)									
Cholesterol									
Tacrolimus									
Cyclosporine									
Other (_____)									

QUESTIONS FOR YOUR TRANSPLANT TEAM

YOUR NOTES AND COMMENTS



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Sincerely,

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Your Heart Transplant: The Pediatric Recipient Addendum

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Approved by the Patient-Parent Education
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Your Heart Transplant: The Pediatric Recipient

Introduction

Your child has had heart transplant surgery and will be getting ready to leave the hospital soon. During the time you have been at the hospital, you have become familiar with your child's care. Some of that care will need to continue after you leave the hospital. The purpose of this educational booklet is to help prepare you to take your child home and to serve as a source of information for any questions that you may have after you leave the hospital. The transplant team will be available to answer your questions. The phone numbers are listed under the section "Whom To Contact In An Emergency".



A Review: Transplantation, Immune System and Rejection

The body has a special system, called the Immune System, whose function is to protect it from infection and disease. White blood cells and antibodies are part of this system. They attack bacteria, viruses, fungi and other organisms they recognize as being harmful to the body. The immune system also mistakenly identifies a transplanted heart as something foreign and harmful too. The immune system reacts to the transplanted organ by attacking it. This process is called rejection.

The medications used to control rejection are called immunosuppressive medications. Some of these include tacrolimus (Prograf®, FK 506), cyclosporine (Neoral®), and prednisone. These medicines work on the body's immune system to make rejection less likely to occur. However, immunosuppressants also make your body's ability to fight off infection lower.

Medications



General Guidelines for Medications

When your child is transferred to the floor and are ready for discharge, you will typically be given a medication card. Record the name, dose and time of all medications on the medication card. Please write on this card **ONLY** in **PENCIL**. Many changes will be made in the first few weeks following transplant and corrections can be made easily to the card if written in pencil.

Please bring this card with you to all clinic visits. It is also important to carry this card with you to other doctor appointments, as it is an easy way to show them what medications your child is taking.

When a child is taking several medications at different times during the day it can be difficult to remember whether the doses were given. Please follow your medication card. Any system that you decide on to keep track of your child's medication is fine with the transplant team as long as it is working for you. If you know that you have missed a dose of immunosuppressive medications, please call the transplant office for instructions. **DO NOT** repeat a dose of medication unless specifically told to by the transplant team.

If your child vomits a dose of medicine, resume his normal schedule at the next medication time. **NEVER** try to make up for a missed dose by giving your child a double dose or a larger dose than what has been prescribed by your transplant physician.

Always have the prescriptions filled 1 week or more before they are empty. This allows enough time for the pharmacy to order a new supply of the medicine if they need to or call the physician if a new prescription is required. **DO NOT** wait until you take the last dose of medication before calling for refills or new prescriptions. Please be responsible for your child's medications and keep them up to date **AT ALL TIMES**.

Several doses of Tylenol® may be given to your child; however, you **MUST** inform the transplant office if your child has a cold or fever. A fever higher than 100.5°F orally or 101.5°F rectally must be reported to the transplant office. Any low grade temperature 99.5°F that lasts for longer than 24 hours must also be reported to the transplant office.

Do not medicate your child with Advil®, Pedia-profen® or Motrin®. Use of these medications especially while taking tacrolimus (Prograf®, FK506) or cyclosporine (Neoral®) may alter liver or kidney function and interfere with blood levels of the immunosuppressive medications.

Do not give any other over the counter medications to your child unless you first check with the transplant team. These include aspirin, antacids, laxatives, anti-diarrheal, and cough or cold medications. These may also interact with the medications your child is already taking or mask serious symptoms of infection your child may be developing.



Immunosuppressive Medications

After your child is discharged from the hospital, he/she will continue to take several medications. Some of them may be stopped later by your transplant physician.

However, your child will need to take the immunosuppressive medications tacrolimus (Prograf®, FK506) or cyclosporine (Neoral®) for the rest of their lives. Both of these medicines are used for immunosuppression. They help to weaken the body's immune system so that the transplant organ will not be rejected.

The amount of each medicine that the doctor prescribes is based on your child's weight and condition. As your child gains weight or his condition changes, the doctor will prescribe a different amount of medicine that takes these changes into consideration.



Tacrolimus (Prograf®, FK506)

Tacrolimus is a powerful immunosuppressant that inhibits the effectiveness of a certain type of cell in the immune system.

Prograf® is made in powder form and dispensed in a capsule or a liquid suspension.

It may be taken by swallowing the capsule whole or opening the capsule and sprinkling the powder onto a spoonful of food. If your child takes the liquid suspension, it may be easier to take at meal times. It is usually given twice a day, each dose approximately 12 hours apart. Food affects how the body absorbs tacrolimus. Therefore, to maintain consistent blood levels, your child should always take this medicine the same way WITH or WITHOUT food.

Special Facts about Tacrolimus

Tacrolimus capsules may be used one year after they have been manufactured. Check the expiration date on the container before using. The liquid suspension of tacrolimus is only good for 30 days after it has been mixed up by the pharmacy. Please plan accordingly for refills and when you are getting low on your supply.

Common side effects of tacrolimus (Prograf®)

- Headaches
- Flushing or burning sensation of the hands or feet
- Insomnia (difficulty sleeping)
- Hair loss
- Rash
- Tremor (shaking of the hands or feet)
- Diarrhea
- Decrease in normal kidney function
- Increased potassium level in the blood
- Increased blood sugar

Tacrolimus interacts with many different medications. Please call the transplant office if any other doctor prescribes a medication for your child to take. Do not take this medication until it is cleared by the transplant office first.



Cyclosporine (Neoral®, Sandimmune®, Gengraf®)

Cyclosporine is a powerful immunosuppressant that works by inhibiting a certain type of cell in the immune system. It is available in liquid or capsule form. It is usually given twice a day, each dose 12 hours apart. Food affects how the body absorbs cyclosporine. Therefore, to maintain consistent blood levels your child should always take Neoral the same way, either with food or without.

Mixing and Taking Liquid Cyclosporine

The liquid medication is in an olive oil base. It needs to be mixed with juice when it is given. Mixing improves the taste, prevents sticking to the container and helps with absorption to the body.

When your child is in the hospital you will be taught how to measure and mix the cyclosporine. These instructions will help you to remember the proper way to give your child the liquid medicine.

Draw up the proper amount of cyclosporine in the syringe.

NOTE: You may find it helpful to place a piece of clear tape over the markings on the syringe because they often wear out after handling the syringe.

Put the medication into a GLASS container for mixing. First pour the juice you will be mixing with into the glass, then add the Neoral. **DO NOT USE STYROFOAM OR PLASTIC** because it will absorb the medication and your child will not be getting the accurate dose.

Stir well and have your child drink it at once before it starts to clump.

To make certain that your child is receiving the full dose, add more juice to the glass swirl it around and have your child drink the remaining liquid from the glass.

After using, dry the outside of the syringe; do not rinse with water or other cleaning agent.

NOTE: Cyclosporine should be taken immediately after it is drawn up. If your child is going away from home, you may draw it up in the syringe one or two hours ahead of time. Wrap the pipette in a plastic bag and a brown paper bag (to protect it from light) so that it can be mixed and taken at the proper time.

Special Facts about Cyclosporine (Neoral®)

- The shade of yellow of Liquid Neoral® may vary. However it should be clear. Do not use if it is cloudy and return to your pharmacy.
- Record the date the bottle of liquid was opened on the label. When the bottle has been opened for longer than 2 months, the medication should no longer be used. Discard any remaining medication.
- Liquid Neoral® should be stored only in its original amber (brown) colored container that protects it from light.
- Keep liquid Neoral® in temperatures below 86°F (30°C). It should not be stored in the refrigerator.
- Neoral capsules may be used for three years after they are manufactured. Check the expiration date on the container before using. They do not need to be refrigerated.



Common Side Effects of Neoral®

- Increased blood pressure
- Tremors (shaking of the hands and feet)
- Excessive hair growth
- Swelling of the gums
- Decrease in normal kidney function
- Abdominal discomfort
- Diarrhea
- Flushing or burning of hands, feet, mouth, or tongue.

Some of these side effects will decrease as the dose of Neoral is decreased. The dosage may be decreased gradually after surgery, depending on your child's condition.

Excessive hair growth can be controlled by the use of hair removal products such as NAIR. They can be purchased at most pharmacies. Consult the transplant office if your child is having any questions about their body image and physical changes that are being caused by the medicines they are taking.

Prednisone

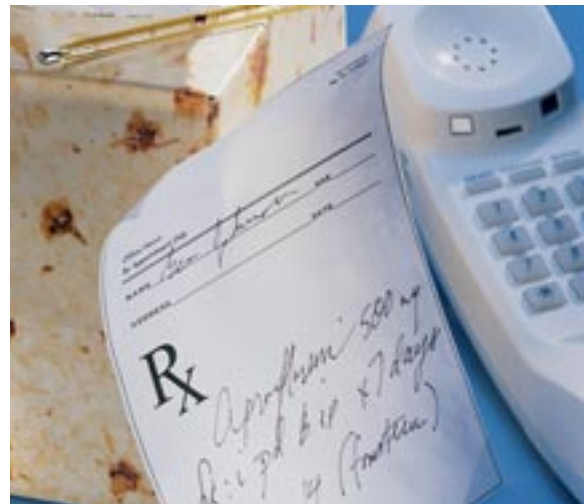
Prednisone is a steroid. It works with tacrolimus or cyclosporine in helping suppress the body's immune system to prevent rejection. Small amounts of Prednisone may be prescribed daily. This dose of prednisone may be decreased gradually and eventually stopped depending on your child's condition. Prednisone may also be prescribed in high doses that rapidly decrease (called a prednisone taper) to treat a rejection episode.

Prednisone is available in liquid and pill form. If necessary, the pill may be crushed or dissolved in ginger ale to make it easier to swallow. It is important to give Prednisone

with food or milk so that it is less irritating to your child's stomach. If your child is prescribed Prednisone only once a day, it should be given in the morning.

Side Effects associated with Prednisone

- Round face (extra fat deposits in the cheeks)
- Weight gain
- Mood swings (spells of being happy or sad)
- Easy bruising under the skin
- Stomach discomfort
- Fluid retention
- Blood or tar colored stools
- Sensitivity to the sun
- Increase in blood pressure
- "Coffee ground" vomit
- Increased blood sugar



Other Immunosuppressant Medications

Azathioprine (Imuran®, Roxane®)

Imuran is another immunosuppressive medication that your child may need to take to control a rejection episode. Your child may be on this medication if the physician



feels that additional help is needed to control rejection. Not all children who have had a transplant are prescribed this medicine.

Imuran is available in liquid or pill form. The pill may be swallowed, crushed or mixed with food or liquid. Liquid Imuran is good for only one month. If needed have it refilled by the pharmacy once a month.

Some side effects of Imuran® are:

- Stomach discomfort
- Bruising
- Low white blood cell count

Your child will need to have frequent lab work drawn if Imuran is decreasing your child's white blood cell count. Having the white blood cell count too low may make your child more likely to develop an infection.

Mycophenolate Mofetil (CellCept® , MMF)

CellCept® is also used in combination with Prograf® or Neoral® to help control rejection. Not all children who have had a transplant are prescribed CellCept®.

Your child will only be on this medication if the physician feels that additional help is needed in preventing and controlling rejection.

CellCept® is available in liquid and pill form. The liquid form is not routinely made in local pharmacies. If you are prescribed this medicine special mixing instruction will be given to your local pharmacy to help you get this medication. DO NOT attempt to crush the pill to prepare liquid CellCept® yourself. The liquid CellCept® is only good for a limited time.

Be careful not to use the liquid past the expiration date. Please note the date on your bottle or box carton.

Some side effects of CellCept® are:

- Nausea/ vomiting
- Diarrhea
- Abdominal cramps
- Low white blood cell count

If your child is started on CellCept® the dose will be gradually increased. This dosing helps to prevent the abdominal side effects from occurring. Giving the medicine to your child with food also helps to prevent these side effects.

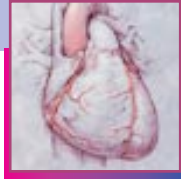
Certain medications interact with CellCept®. Again, if your child is prescribed medication not from the transplant team, please call the transplant office and confirm you are allowed to do so before giving your child this medication.

Side Effects of Immunosuppression

When children are taking immunosuppressive medications, other conditions may occur more frequently. These potential complications may occur:

Allergies

After transplantation, your child may develop allergies more easily to foods or other things in the environment (pollen, dust or animal hair). Common allergy symptoms include skin rashes or chronic runny nose. If your child develops any of these symptoms, please notify the transplant team if they seem to continue for a long time. The transplant team may refer your child to an allergy specialist.



Warts

Some transplant recipients develop skin warts. They usually occur on the hands or feet. Your child may need to be referred to a dermatologist for treatment of this problem.

Sinus Infections

Sinusitis (sinus infection) is a problem seen more frequently in transplant recipients than in other children. Symptoms include runny nose with green or yellow mucus, post-nasal drip (drainage from the nose that runs down the back of the throat), persistent headache, or fever. If any of these symptoms occur please notify the transplant team.

Post Transplant Lymphoproliferative Disorder (PTLD)

This disease is caused by infection with the Epstein-Barr Virus (EBV), the same virus that causes "mono" or mononucleosis. Because of the immunosuppressive medicines, your child may not be able to fight off this infection. The infection causes special cells in the immune system to grow like a tumor. Sometimes your doctor first notices this on a physical exam when your child complains of tiredness, fever, and painful lumps under the arms or in the groin (lymph nodes). However, other infections may also cause these symptoms.

Unlike with many tumors, decreasing the child's daily dose of immunosuppressive medicine can often control PTLD by your doctor. Usually the tumors disappear completely after the dose has been lowered. Fortunately, PTLD occurs in only a small number of transplant recipients.

To help prevent PTLD the doctor will check your child's blood regularly for the presence of the Epstein-Barr Virus. However, if you notice any different or unusual lumps in your child's body, especially in his neck, groin, or armpit, please notify the transplant team immediately.

Skin Cancer

Because your child is taking immunosuppressive medications, he/she may be at risk for developing skin cancers. For this reason, your child must use sunscreen 30 SPF or higher at all times when exposed to the sun. Please keep in mind that not all children develop skin cancer. Prevention is the best cure. Please apply sunscreen to your child when exposed to bright sun.

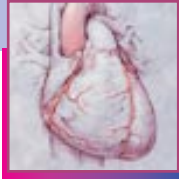
Methods to Treat Rejection

Mild to severe episodes of rejection may occur following heart transplant. Performing an endomyocardial biopsy (biopsy) does diagnosis of rejection. Simply increasing the daily dosages of immunosuppressive medications your child takes may treat mild rejection episodes. The following treatments or medicines may also be used to treat rejection if it occurs.

Prednisone Taper

In addition to being given daily, prednisone may be prescribed in a "taper" to treat a mild rejection episode.

A prednisone taper involves giving higher doses of prednisone for several days then rapidly decreasing the dose. Steroids like prednisone and Solu-Medrol (see below) work to control rejection by causing a



decrease in the number and effectiveness of special cells in the immune system.

NOTE: When high doses of prednisone are given in a taper to treat rejection, the medicine may cause high blood sugar.

Signs of a high blood sugar are:

- Excessive thirst
- Frequent urination
- Increased tiredness
- Irritability

If your child develops any of these symptoms while receiving a high dose of prednisone, please notify your transplant team at once.

Solu-Medrol

Solu-Medrol is used to treat moderate to severe rejection. It is the IV (intravenous) form of Prednisone. Solu-Medrol is usually once per day for three days. This medication is usually given when the child is an inpatient in the hospital. There, the child can be monitored closely for signs of high blood sugar.

Side effects of Solu-Medrol may include:

- Increased blood sugar
- Increased sugar in the urine
- Mood swings
- Increased appetite
- Irritability
- Difficulty sleeping

Anti-lymphocyte Agents

Antithymocyte globulin (Atgam® thymoglobulin, ATG®)

ATG® is used to treat moderate to severe rejection. It is given intravenously (IV) dose 10-14 days. Children must be

hospitalized while they are receiving this medication, and a special IV catheter to the central blood system must be inserted for its safe use. The child will be placed on a monitor and vital signs are taken frequently during the first dose of the medication.

Side effects of ATG® include:

- Low blood pressure
- Rash
- Difficulty breathing
- Fast heart Rate
- Generalized allergic reaction

If the child develops an allergic reaction to ATG® then the medicine must be discontinued.

Orthoclone

OKT3® is an anti-rejection medicine that is used to treat moderate to severe rejection. This medicine is usually used only after other medicines have been tried but have been unsuccessful in treating the rejection. It is given IV (intravenously) once daily for 10-14 days. The child will need to be hospitalized while receiving this medication. An allergic reaction to this medicine may occur. Therefore, certain medications are given to reduce the chance of an allergic reaction to OKT3®. In addition, the child will be placed on a monitor and vital signs will be taken frequently during the first 3 doses of the medication.

Side effects of OKT3® may include:

- Fever
- Chills
- Nausea
- Diarrhea
- Difficulty breathing
- Tiredness
- Irritability



Total Lymphoid Irradiation (TLI)

TLI is used to treat rejection when other medicines or treatments have been unsuccessful. It involves daily radiation treatments to the body for six weeks. The radiation is directed toward the lymph node tissue in the child's neck, armpit, chest, abdomen, and groin. The goal of TLI is to reduce the amount of a specific cell in the immune system that is causing the rejection to continue.

The TLI treatments can be done as an outpatient in clinic. A more detailed description of this procedure will be given to you if it is needed for your child.

NOTE: This procedure is rarely used to treat rejection.

Some side effects of TLI include:

- Tiredness
- Loss of appetite
- Nausea/Vomiting
- Diarrhea
- Weakness
- Low white blood cell count

NOTE: Any of the above treatments for rejection also will lower your child's ability to fight off infection. If one of the above is prescribed for your child it will be especially important to observe them for signs and symptoms of infection and report them to the transplant center immediately.

Other Medications

As mentioned earlier, all children with heart transplants must take either Prograf® or cyclosporine. Other medications that may also be prescribed for your child are listed below with a brief description of how they work.

Antifungal Medications

(Mycostatin®, Mycelex® troche, Mycostatin® nasal spray)

Antifungal medications are prescribed to prevent and treat thrush (mouth infection). Thrush is a fungal infection that causes a white film to cover the tongue and or inside of the mouth. Because your child's immune system is suppressed, he or she is more likely to get this infection if not properly treated. This medication should be taken after meals and at bedtime. Early post transplant it will be prescribed as a liquid that your child will be asked to swish and swallow. Later on it is available as a tablet your child can suck on after meals. It needs to coat the entire mouth to be effective. Do not let your child eat or drink anything immediately after taking this medicine.

Remember good mouth care is important in preventing infections of the teeth and gums.

Sometimes stronger antifungal medications such as Fluconazole (Diflucan®) or Ketaconazole (Nizoral®) or Itraconazole (Sporanox®) are needed to treat fungal infections. These medicines affect the FK 506 (Prograf®) and cyclosporine blood levels and should only be given with careful medication supervision.

**Antacids**

(Mylanta®, Maalox®, Alternagel®)

Sometimes antacids are prescribed to lessen stomach discomfort caused by Prednisone and the many other medications your child will be asked to take. Antacids coat the stomach and should be given one to two hours after immunosuppression medicines so that the absorption of these medicines is not affected. Some children may develop either constipation or diarrhea with the use of these medicines. If this occurs, your doctor may want you to change the brand of antacid you give your child.

Antibiotics

Heart transplant recipients take the antibiotic Bactrim® (Septra) three days a week to prevent a specific lung infection called Pneumocystis Carinii. If your child is allergic to SULFA medications, a substitute to Bactrim® will be prescribed.

In addition, antibiotics will be ordered before certain surgical, dental and medical procedures. Antibiotics will be ordered if your child also develops an infection. Before starting antibiotics, the physician may obtain blood urine or throat cultures. Never begin an antibiotic without first calling the transplant office.

Blood Pressure Medications**Antihypertensives**

Antihypertensive medications are used to lower blood pressure. After transplantation, some children experience high blood pressure. This is more likely to occur with the use of cyclosporine. Your child may be prescribed one or more of the following blood pressure medications:

Capoten® (Captopril)
Cardizem® CD (Diltiazem)
Procardia® (Nifedipine)
Vasotec® (Enalapril)
Atenolol® (Tenormin)

While your child is taking blood pressure medications it is important for your child to record their blood pressure twice a day. You will be given vital sign sheets and a digital blood pressure cuff before you are discharged from the hospital. The physician gradually may stop these medicines if your child's blood pressure returns to normal.

Diuretics (Water Pills)

Diuretics are medications used to remove excess fluid your child has retained. Some examples of these medicines include:

Lasix® (Furosemide)
Bumex® (Bumetadine)
Aldactone® (Spironolactone)
Zaroxolyn® (Metolazone)

Diuretics will increase your child's urine output. Therefore, it would be helpful to give these medicines first thing in the morning and several hours prior to bedtime.



Antiviral Medications

Antiviral medications such as Acyclovir (Zovirax®) may be given to your child to treat or prevent a viral infection. Examples of such viruses are:

Chicken Pox (Varicella)
Cold Sores (Herpes)
CMV (Cytomegalovirus)
EBV (Epstein-Barr virus)

Specific doses of Acyclovir will be given to your child according to lab work that will be drawn before the transplant. If your child becomes ill with one of these viruses, they may be admitted to the hospital to get this medicine IV (intravenously).



Vitamin Supplements

Vitamins may be given to your child to supplement his or her nutrition and healing post-transplant or because lab work indicates that your child is low in one of the following essential chemistries in the blood. Some examples of these medications include:

Multivitamin
Vitamin C
Calcium Supplement
Potassium Supplement
Magnesium Supplement
Tums®
Oscal®

Infection



Because the medication given to prevent rejection also affects the body's ability to fight off infection, your child may be more susceptible to certain illnesses. Because early treatment of infection is extremely important, notify the transplant team immediately if your child develops any of the following symptoms.

- Persistent cough or cough producing sputum
- Any fever above 100.5°F orally or 101.5°F rectally
- A fever of 99°F (orally) or 100°F (rectally) for more than 24 hours
- Chills, shaking episodes or night sweats
- Cold or flu-like symptoms
- Redness, swelling or drainage around a cut or wound
- Nausea vomiting, diarrhea
- Increased tiredness or generalized weakness, irritability
- Loss of appetite
- Burning with urination
- Sore throat
- White patches in the mouth or throat
- Rash

If your child has any of these symptoms, the doctor will examine your child and order specific tests to find out what may be causing the symptoms. The tests may include a chest X-ray, blood tests and cultures of the blood, urine, stool or sputum. The physical exam and tests will help the doctor decide whether or not to prescribe antibiotics, order additional tests, or whether the condition is serious enough for your child to be admitted to the hospital.

Preventing Infections

Colds and Flu

When your child is discharged from the hospital he or she can participate in most activities without the risk of infection. There is no need to ISOLATE your child from others to protect him/ her from infection. In fact the transplant team encourages you to allow your child as much freedom as possible. However care should be given to avoid close contact with people who you know have a cold or flu or other respiratory infection. This precaution is particularly important for the first 6 months after transplant. If a member of your family develops a severe infection, contact the transplant office about special precautions you may need to take.

No matter how careful you are, eventually your child WILL EXPERIENCE the same common infections as other children. It is important to remember that your child can recover from most of these illnesses with the proper care and early diagnosis.

If your child is an infant, and sharing toys with others, please be sure you wash them before and after use. Remember that the frequent washing of hands is also the BEST prevention for infections.

Diarrhea

Diarrhea may be a symptom of an infection or the side effect of a medication. Therefore, if your child has diarrhea that does not improve within 24-48 hours, please notify the transplant office. In addition, if your child has any symptoms of



dehydration noted below, please contact the transplant office immediately.

- Dry mouth
- Sunken eyes
- No tears when crying
- Decreased urine output
- Not taking fluids/bottle
- Persistent vomiting

To help control frequent or loose stools, you may limit your child's diet. For example, give him/her clear liquids to drink for 24 hours (12 hours for children less than 1 year of age). Clear liquids include:

- Water
- Ginger-ale
- Kool-Aid®
- Popsicle®
- Jell-O®
- Apple Juice
- Pedialyte®

Limit foods to a bland diet or BRAT diet. Examples of these foods include any of the following:

- Noodles
- Potatoes
- Rice
- Crackers
- Bread
- Soup
- BRAT (bananas, rice, applesauce, toast)

When your child had diarrhea, avoid using over the counter anti-diarrheal medicines. For children older than 3 years of age, you may give him one or two doses of Pepto-Bismol®, but please contact the transplant office prior to doing so.

Dental Care

Another way to prevent infection is to make certain that your child had good dental health. Your child's teeth should be brushed at least twice a day with a soft toothbrush. The mouth should then be rinsed thoroughly after each brushing. If you or your child notices any cold sores, blisters or white film in the mouth notify the transplant office.



Regular dental check-ups should be scheduled with your dentist at least twice a year. These visits are very important, not only to prevent infection, but also to evaluate gum overgrowth which may be caused by cyclosporine.

After transplant surgery, an important precaution must be taken before appointments with the dentist. Antibiotics need to be given to your child before any procedure, including cleaning. This precaution is to prevent an infection called sub-acute bacterial endocarditis (SBE). Instructions for the dentist to use in prescribing these antibiotics are listed in the back of this educational booklet.

Other Operations

If your child needs to have another type of surgery (tonsillectomy, appendectomy, etc.) antibiotics may also need to be given for these procedures. All elective surgeries of



this type need to be reported to the transplant office. Please call and speak to the transplant coordinator if another doctor has told you that your child may need any type of surgical procedure.

Herpes Simplex

Because your child is immunosuppressed, he may be more likely to develop a herpes simplex (cold sore). This is a common viral infection. If anyone around your child has herpes simplex, special precautions should be taken to avoid any direct contact with the sores. Frequent hand washing is essential.

Before transplant, a blood test was done to determine whether your child has ever had herpes simplex. Many people have had this virus without getting a cold sore. If your child tests positive, he will be prescribed Acyclovir for 6 months post-transplant to prevent cold sores from recurring. After 6 months the need for continuing this medication will be decided by the doctor.

Childhood Immunizations: Exposure to Childhood Diseases

Immunizations

Because your child's immune system is suppressed, important attention must be given to childhood immunizations. Children who have had a heart transplant need to continue with immunizations listed below. Some vaccines used in immunizations contain viruses. The vaccines containing DEAD viruses are SAFE. Other vaccines contain LIVE viruses, which have been

treated so that they will not cause the disease in children with normal immune systems. However, your child is immunosuppressed and should NOT receive LIVE VIRUS VACCINES.

If transplantation occurs prior to your child's full set of immunizations being completed, your doctor can continue vaccinations 3 months after the transplant surgery. Also your child should not receive any vaccinations for 3 months after a rejection episode. Your transplant office will remind you of these important facts during visits to the clinic.

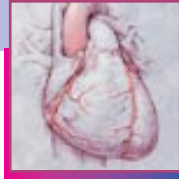
NOTE: All family members should receive the influenza vaccination every year in the fall.

At this time the MMR (Measles, Mumps and Rubella) vaccine contains LIVE virus and is not recommended for transplant patients. Other family members can receive the vaccine without risk to the patient.

Exposure to Childhood Diseases

Because your child is immunosuppressed, some common childhood illnesses could become a serious problem if your child does not already have immunity to them. Before transplantation, your child's blood will be tested for the presence of antibodies that fight common illnesses seen in the transplant patient (CMV, HSV, EBV, and VZV).

Alert teachers and babysitters and parents of your children's friends of the increased risk your child has to these diseases. Ask them to notify you immediately if their child or sibling is exposed to or develops



one of the following illnesses. Children being exposed to a disease usually means having close physical contact with and/or sharing toys with another child who has the disease or who becomes ill with the disease soon after being with your child.

As time passes, your child's immunity to childhood diseases may change. Your doctor will periodically order blood tests to check these immunities.

Chicken Pox (Varicella Virus)

If your child is immune to chickenpox, he/she will not need any special treatment or protection if he is exposed to chickenpox after transplant. If your child has NOT had chickenpox and is not immune to the disease, it is extremely important for he or she to



avoid contact with people with chickenpox. People are exposed to chickenpox through air or by close contact with the infected person. The person with chickenpox is contagious 2 days before the rash appears and until all lesions have formed scabs. If

your child is exposed he or she can develop the disease up to 21 days after being exposed.

Chickenpox usually occurs in children between 3 and 8 years of age. The first signs are fever, general discomfort and the appearance of a rash. The rash consists of small lesions surrounded by redness that eventually forms crusted over scabs. The rash usually starts somewhere on the head and then spreads down the body.

If your child has been exposed to chickenpox and is NOT immune to the illness, please call the transplant office immediately. He or she will need the VZIG (Varicella Zoster Immune Globulin) injection within 72 hours of being exposed.

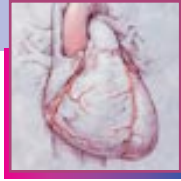
NOTE: This vaccine is not the same as the Varicella virus vaccine.

If your child needs to receive VZIG you can usually obtain the shot in your local pediatrician's office, American Red Cross or local Emergency Room.

If your child breaks out with chickenpox please contact the transplant office, your child may need to be admitted to the hospital for treatment.

Shingles (Herpes Zoster)

Shingles is a painful rash that occurs in a small area of the body. The same virus that causes chickenpox causes shingles. Shingles only occurs in someone who has already had chickenpox.

**Measles (Rubella)**

If your child is not immune to the measles and he or she is exposed to a child who breaks out with measles rash within 3-5 days after they have been together, call the transplant office. Your child will need a shot of immunoglobulin within 6 days of being exposed to the measles.

Tuberculin Skin Testing (TB test)

Tuberculin skin testing may be required periodically by your child's pediatrician or school district. Two forms of skin testing are available. Both forms of testing are safe for your child but the PPD (Purified Protein Derivative) is the only one currently recommended for use and is the one most commonly given. After transplantation neither test is reliable. If your child is exposed to someone who has TB, call the transplant office. We may need to arrange for the infectious disease doctors to examine your child. Further testing such, as a chest x-ray may need to be done.

Strep Throat

Your child may be exposed to other children who have had strep throat. Watch your child for signs of a sore throat, but no preventative injection will need to be given to your child to prevent him or her from getting a strep infection.

It is important to take the proper steps to prevent infections. Consult your pediatrician or transplant office with any concerns about vaccines and childhood diseases.

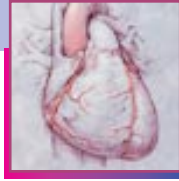
Nutrition

If your child was not eating well before transplant, it may take him or her a while to get their appetite back. After heart transplant, your child should still follow a good diet, avoiding foods high in cholesterol, fats, sugars and high sodium. The immunosuppressive medications that your child takes may affect the body's ability to store and use these foods. The doctor and dietician will determine if your child has any other special diet needs.

The heart transplant dietician is available to speak with you at any time regarding questions you may have about your child's diet or problems that come up during your child's recovery from transplant. The following are some general recommendations for food choices after you and your child leave the hospital.

Cholesterol and Saturated Fats

Cholesterol and saturated fats are substances commonly found in certain foods. A diet high in cholesterol and fats may lead to higher than normal blood cholesterol levels. High blood cholesterol may lead to damage of the coronary arteries of the new heart. For a healthy heart, all of us should avoid foods that are high in cholesterol and saturated fats. It is particularly important for a heart transplant recipient to follow a low fat diet to help protect the new heart.



Use the following recommendations for food choices:

- Use lean to medium fat meats and chicken whenever possible. Trim off extra fat and skin when cooking
- When frying, use a vegetable oil such as corn or safflower oil.
- Serve no more than 2 eggs per week. Egg substitutes can be used.
- Serve 1% or 2% milk, or try to serve skim milk if your child likes it.
- Select cheeses that are labeled "low fat" or "skim processed" whenever available.

Sodium (Salt)

Sodium is a mineral essential to life. Most people use more sodium than the body can use. Too much sodium in the body may cause swelling (fluid retention), high blood pressure and an increase in the workload of the heart. A "no added salt diet" helps in decreasing the amount of extra salt your child eats. This means that we encourage your child to not add salt to food that is prepared and that salt substitutes or other spices are used in the preparation of foods. Controlling the amount of sodium in your child's diet should help reduce swelling caused by the Prednisone and improve the effectiveness of the diuretics and blood pressure medications.

Use the following recommendations for food choices

- Avoid foods that are already highly salted, such as pizza, pretzels, potato chips, ham, lunchmeats, bacon, hot dogs and canned soups. Remember any foods that are processed (canned or prepackaged)

contain a higher than normal amount of sodium and should be avoided.

- Allow your child to have one "salty food" per week if needed.

NOTE: Check with your doctor before using a salt substitute. Most of these contain potassium. Extra potassium may be harmful to your child, especially if he/she is already taking a potassium supplement or a medication to lower an already too high potassium level in the blood.

Vitamins

If you are concerned about the amount to vitamins and minerals your child is receiving in his diet you may ask to speak with the dietician about special supplements. Your child will be prescribed a daily multivitamin as part of general discharge medications.



Monitoring Vital Signs



Some children with heart transplants experience high blood pressure. Medication is given to control your child's increased blood pressure. While you are at home, you will be required to monitor your child's blood pressure once in the morning and once in the evening (around 9AM and 9PM). The transplant coordinator will order you a digital blood pressure cuff from the hospital pharmacy to take these readings. This digital cuff will read out in numbers the blood pressure and also your child's pulse. You will be given a special set of papers to write down these readings. You must bring these vital sign sheets with you to each clinic visit to the transplant center.

An example of these sheets is included in the back of this booklet.

Medic Alert Necklace

Before you leave the hospital the transplant coordinator will get a medic alert necklace from hospital supply for your child. The transplant coordinator will fill out important information that must appear on the necklace. Some children may be too small for the necklace that the hospital provides. You may also order a medic alert necklace at most jewelry stores. Contact the transplant office for the information you should have engraved on the necklace.

After leaving the hospital

Having your child discharged from the hospital will be a big change for your entire family. You will be required to stay in the local area for approximately 3 months. Depending upon your child's age, they may also be required to perform physical therapy five times per week with the physical therapist during this time.

Most parents have said that one of the biggest adjustments that they needed to make after being discharged from the hospital was changing their daily routine. Before the transplant, much of their attention was focused on the sick child. It was difficult for the entire family to participate in activities because of their child's special needs. The improvement in your child's health after the transplant can make a difference in your lifestyle and that of your family. Your family will be able to have the chance to do things together again.

Although these changes will create a much more comfortable situation for you, you may also have some uneasy feelings. You will need some time to get used to being out of the hospital. Not having someone nearby if problems occur can be stressful. However as time passes you will gain more confidence and be comfortable away from the hospital.



Once you have moved home, as well as at the local residence right after the transplant, you will find that your child is able to do more things than ever before because he/she is feeling better. Often parents have said that this creates a difficult decision for them. On one hand, they want to protect their child, and on the other, they have a hard time saying no when their child is going through so many changes. As time passes, it is easier to be less protective. It is important to establish rules and to follow them. Most children feel safer when they have rules to guide them. In addition, consistent discipline will help your child get into a more normal routine.

As time goes on you will find that your child also gets into a routine of his own. If you notice that your child has difficulty in adjusting to his/her new heart and all the medicines, please contact the transplant office so that we may arrange for appropriate help.

Pets

There are only a few precautions that need to be taken with pets after your child's transplant. Cats have the ability to carry 2 diseases Toxoplasmosis and Cat Scratch Fever. To protect your child from these infections, he/she should avoid contact with the litter box. In addition, good hand washing is recommended if playing with kittens. Contact with cats or dogs that have fleas should be avoided.

All pets that are in the home should have regular veterinarian examinations. It is important to have all their shots up to date. If your pet has diarrhea or shows other

signs of being sick, your child should avoid contact with it.

Physical Activity

Most parents wonder how much they will have to limit their child's activity when they are home. Fortunately, children tend to pace themselves well and do only what they can do. They sit down when they are tired and play when they feel rested. Therefore, restrictions are not placed on children's activity routinely. In most cases, a child can gradually begin returning to normal activity for his or her age. If your child was receiving special therapy at the local residence that needs to be continued, arrangements will be made prior to you leaving for home.

Guidelines for physical activity

- Bicycling, walking and swimming are good examples of exercise.
- Very hot and humid or cold weather may make it more difficult to exercise. Exercise in these conditions should be limited if your child is uncomfortable, but is not prohibited.
- Make sure your child drinks enough fluid while outside playing in hot humid weather.
- Some medications, especially prednisone, can make your child's skin more sensitive to sunlight. Precautions should be taken when your child will be outside for extended periods of time. Sunscreen of SPF 30 or higher should be used on ALL exposed areas of skin and reapplied as directed.

Returning to school

After your child has been home for awhile, the doctors will tell you when he/she can



start back to school. This is another big change for you and your child. The transition is made somewhat easier if you do 2 things before your child returns to school.

- Take time to meet your child's teacher, school nurse and principal. Explain what has happened while your child has been away from the classroom.
- Arrange if necessary for the transplant coordinator to call and speak with the school nurse about any special precautions related to your child's return to school.

Such discussions between your family, the transplant team and the school will help clearly define what your child is able to do and what he/she cannot do. These steps can help the teachers understand what to expect from your child and ease any apprehension they may have about working with a child who has had a transplant.

Remember the school nurse should be given a copy of your child's medication card as well as have on hand the transplant centers number in case of an emergency or questions.

In most cases, your child can participate in all gym activities as long as he is able to rest when he or she feels tired.

Some parents have reported that it is difficult for their child to fit into "groups" at school. This probably occurs for many reasons. He or she has been away from school and other children for awhile. In addition he or she has also had an operation and takes medicines that make him/her different from the other children. All of these reasons may make your child stand

out and make it more difficult for him/her to be accepted as part of a group. Your child will need your support and love during these hard times. Allowing them to talk about their feelings will help. You can also suggest that they try to make one friend in class rather than being part of a large group. As time passes, your child may be more accepted and he or she will find ways to cope with the situation. If you notice that your child becomes more withdrawn and does not talk please let the transplant coordinator know. Your child may be exhibiting signs of depression, which can become serious if not treated or recognized in a younger child or adolescent.

Siblings

When your child has had a transplant and returns home, your other children also will have adjustments to make. If they have been close to you during the hospitalization for transplantation, the adjustment may be easier. However, often the transplant experience often means that one or both of the parents are separated for extended periods of time.

When you return home, your other children may want more of your attention. Often children try to get that attention in different ways. Some may be demanding or clinging. Some may break the rules. They need your love and support. Patience during this awkward adjustment will help them readjust to the transplant experience. Set aside some time alone to be with your other children. It may be helpful to plan a few activities that the whole family can enjoy. This will promote the feeling of the family being together once again.



Returning to the Hospital

After transplantation, your child will need to return to the hospital for both inpatient and outpatient visits.

Outpatient Appointments

Endomyocardial Biopsy

After discharge, the doctor will schedule appointments to see your child according to a set schedule for biopsies and protocol for the heart transplant program. The routine outpatient visit includes the doctor's physical exam, an interview by the transplant coordinator, an electrocardiogram (if needed), an echocardiogram (if needed), lab work, chest X-rays (if needed), and an endomyocardial biopsy.

Blood testing will be done at every visit. One of the tests done, is a measure of the Cyclosporine or Tacrolimus Level.

Therefore, on the day of the outpatient visit do not give your child the tacrolimus (Prograf®, FK 506) or cyclosporine (Neoral®) until after the labs have been drawn. The other blood tests done routinely include kidney and liver tests, blood counts and testing for exposure to common viruses such as the Epstein-Barr (EBV) and Cytomegalovirus (CMV).

You will be asked to keep your child from eating or drinking past midnight of the previous day for biopsy. Special instructions will be given if your child's biopsy will not be able to be performed until later in the day.

Clinic Visits

If your child is still living in the local area, and becomes ill, you may be asked to come to see the doctor. Lab work and any special tests related to your child's complaints will be ordered. You will be given instructions as to where to go when you arrange to bring your child to the hospital by the transplant coordinator.

Lab Work

The body varies in its ability to absorb the immunosuppressive medications. Therefore the doctor always closely monitors the amount of tacrolimus (Prograf®) or cyclosporine (Neoral®) in the blood. These tests will allow changes to be made in your child's dose of medication. The test results will allow changes in dose to be made so that high levels do not cause toxicity and low levels do not allow rejection of the heart.

Some times we will want to check blood tests on your child between visits to the hospital. In these instances we will send you a lab slip to be taken to the outpatient lab of the Children's Hospital while you are living locally, or to take to your local pediatrician's office or hospital once you have moved home. Some blood results can be done locally and faxed to the transplant office. For other tests like the tacrolimus (Prograf®, FK-506) or cyclosporine (Neoral®) level, the tube of blood, will need to be mailed to our lab so that the test can be performed here and appropriate levels recorded. These blood tubes must be overnight mailed or next day mailed to the hospital to make sure they arrive and are accurate.

