# HEART TRANSPLANT PATIENT MANUAL

SECTION 1: BEFORE YOUR HEART TRANSPLANT		PA	GE
1. Introduction		 	. 1
2. What Is Heart Failure?		 	. 2
3. Evaluation Process		 	. 2
4. Heart Transplant Team Members		 	. 3
5. Heart Transplant Screening Tests			
6. Selection Committee			
7. The Donor Heart		 	. 7
8. Potential Donors			
9. Waiting for a Transplant			
10. Being Prepared			
11. When a Donor Becomes Available			
12. Surgery			
13. Risks of the Procedure			
14. How Successful are Heart Transplants?			
'			
SECTION 2: AFTER YOUR HEART TRANSPLANT		PA	GE
15. Post-Operative Care			15
16. What to Expect During your Hospitalization			
17. Potential Complications			
18. Heart Biopsy			
19. Infections			
20. Other Transplant-Related Complications			23
21. Going Home			
22. Keeping Your New Heart Healthy			
23. Outpatient Clinic Visits			
24. Health Maintenance after Discharge			
25. Nutrition			
26. Exercise			
27. Loss of Nerve Supply			
28. Resuming Regular Activities			
29. Routine Health Care			
30. Medications			
31. Your Commitment to a Healthy Life			
ACKNOWLEDGEMENTS			<b>∆</b> C
NOTES			
	-		

## SECTION 1: BEFORE YOUR HEART TRANSPLANT

## 1. Introduction

Welcome to Stanford Hospital's Heart Transplant Program. Stanford is the birthplace of heart transplant surgery in the United States. Dr. Norman Shumway and his colleagues at Stanford developed the experimental basis for heart transplants in the 1960s. He also performed the first successful adult heart transplant in the United States at Stanford in January, 1968.

Since then, the Stanford team has developed many innovations that are now standard practice. Today, the team advances new surgery techniques, develops better anti-rejection medications and provides the absolute best care for heart transplant patients.

Stanford innovations include:

- The heart transplantation surgical technique
- Percutaneous, transvenous heart biopsy to detect rejection
- New drugs, including cyclosporine, to treat rejection
- The first successful heart-lung transplant
- The first successful mechanical bridge device to heart transplantation

Stanford Hospital performs approximately 50 to 60 heart transplants each year. Patients range in age from newborns to adults. They have almost every type of end-stage heart disease. More than 1,450 heart transplants have been performed at Stanford.

Many patients have now survived more than 25 years. We remain in touch with patients throughout their lives. We continue to offer support and education as well as medical assistance related to the transplant. Never hesitate to ask your transplant team questions at any time.

This manual is a resource about the transplant process. Education begins during your initial evaluation and continues long after your heart transplant is complete. **Please keep this manual.** It will be referred to throughout the transplant process.

You play an active role in the transplant process. Please feel free to ask any questions of any member of your transplant team. Your concerns are important to us. Our goal is to provide you and your family with all of the information and support you need.

SECTION 1: BEFORE YOUR HEART TRANSPLANT

## 2. What Is Heart Failure?

Approximately 5 million Americans currently live with heart failure. Although heart failure risk increases as we age, it affects all ages.

Heart failure occurs when the heart muscle becomes impaired. The weakened heart can't keep up with the body's need to pump out blood. That allows fluid to collect in the lungs and other parts of the body.

Heart failure may start slowly and progresses over time or may happen suddenly. The outlook for improvement in heart function depends on the cause and severity, as well as how strictly the patient follows prescribed treatment. Lifestyle changes, diet, medication and following doctor's orders can help improve your symptoms and quality of life.

## 3. Evaluation Process

### Why has my Doctor sent me for this evaluation?

You may be a candidate for a transplant to replace a failing heart that has not responded to other treatment. Your doctor is having you examined at Stanford to determine the best treatment for your condition. While a heart transplant may be the best option for you, often other treatment strategies are first explored.

Some causes of congestive heart failure (CHF), or weakening of the heart muscle, include:

- heart attack (also called myocardial infarction, or MI)
- high blood pressure (hypertension)
- leakage or blockage of the heart valves
- congenital (present at birth) heart conditions
- cardiac arrhythmias (irregular heartbeats)
- pulmonary hypertension (elevated blood pressure within the lungs' blood vessels)
- alcoholism or drug abuse
- viral infection
- pregnancy related
- · diabetes related

We realize you have many questions about the evaluation process. You will have a chance to discuss them during your clinic appointments.

# 4. Heart Transplant Team Members are:

- The **Pre-Heart Transplant Cardiologist** specializes in managing weakened heart muscles (cardiomyopathy). This doctor has extensive experience in deciding which patients will benefit from a heart transplant. He or she will make a recommendation to the Stanford Heart Transplant Selection Committee. If you are accepted as a candidate, this doctor cares for you while you wait for a donor.
- The **Pre-Heart Transplant Coordinator** coordinates tests and appointments during your evaluation.
- The **Heart Failure Nurse Coordinator** works with the cardiologist. This nurse helps you understand your illness, sodium restrictions, medications, testing and initial transplant education.
- The **Heart Transplant Clinical Social Worker** has specialized training to help you and your family. The clinical social worker will conduct a formal psychosocial evaluation as part of your evaluation for transplant candidacy. The clinical social worker helps with counseling, education and teaching, relocation and adjustment issues before and after transplant. They also provide ongoing assessment, intervention and counseling after transplant. Patients and caregivers are encouraged to attend a variety of Stanford Hospital support groups designed to help patients achieve the best possible transplant outcome.
- The **Heart Transplant Financial Counselor** works with your insurance company to determine coverage for your visits and tests here. The financial counselor makes sure your insurance company authorizes your treatment. If a transplant is recommended, the counselor also will find out what coverage you have for the operation, medications and post-transplant care. Please contact us to discuss any financial hardship with your current coverage
- The **In-Patient Transplant Nurse Practitioner** works with you from the time of your transplant through your discharge from the hospital. This nurse works closely with the Surgeons, Cardiologist and social worker to make sure your hospitalization and recovery go as smoothly as possible. You and your family will receive extensive education from this nurse to prepare you for discharge and life after transplant.
- The **Post-Transplant Nurse Coordinator** works with you in the outpatient setting after you have been discharged from the hospital. You will see this nurse during your clinic visits and communicate with her frequently over the telephone. He or she will continue to support you as you recover from your transplant and will work with you after your surgery. This nurse provides extensive education as well as continued care in the outpatient clinic.
- The **Post-Transplant Cardiologist** cares for you after you leave the hospital. This doctor specializes in managing anti-rejection medications and treating the special needs of post-transplant patients.
- The **Transplant Surgeon** performs your surgery, assisted by other doctors and nurses who specialize in anesthesia and transplant surgery. The surgeon evaluates your medical history and your condition to determine if you are a good candidate for transplant surgery. The surgical team cares for you while you recover from surgery.
- The **Physical Therapist** (PT) helps restore your strength and stamina after surgery. The PT also teaches safe and effective ways to increase your level of activity after discharge from the hospital.
- The **Dietitian** educates you about proper nutrition and maintaining a heart-healthy diet.

# 5. Heart Transplant Screening Tests

### You may have some or all of the following tests

- You may have had an **echocardiogram** test in the past but we may need to repeat it during your evaluation. During the test, a special probe that looks like a microphone is passed over your chest. Sound waves bounce back from the heart and generate a picture of your pulsing heart muscle. It also shows how the heart valves are functioning and if your heart is enlarged.
- An exercise (VO2) test shows the maximum amount of oxygen your heart and lungs can provide to your muscles during sustained activity. It is performed on a treadmill or bicycle using special equipment to collect expired air. This test is very useful in determining which patients will benefit most from a heart transplant.
- A right heart catheterization (RHC) checks the pressures in the right side of your heart. After numbing the area, a narrow flexible tube called a catheter is inserted into a vein in your neck or groin. Pressure will be measured in the heart chambers and main blood vessels.
- A **coronary angiogram** (LHC) checks for blockages in your heart's arteries. A catheter is inserted into the blood vessel (artery) in the groin or arm and advanced to the arteries which supply blood to the heart. Dye will be injected to look at the arteries and the pumping function of the heart.
- Laboratory tests determine your blood type and whether you have been exposed to certain viruses.
- A **chest X-ray** is an image of your lungs and heart. It may show abnormalities in the lungs as well as the size of the heart.
- A pulmonary function test shows your lung function and oxygen-carrying abilities.
- Carotid and peripheral doppler studies look for blockages in the carotid and leg arteries. This non-invasive test uses an ultrasound probe.
- A **colonoscopy** is often performed to rule out colorectal cancer. This is done at Stanford or by your own gastroenterologist.
- A **mammogram** may be performed for breast cancer screening.
- A **dental exam** evaluates your oral health.
- An eye exam looks at the blood vessels behind the eye as well as the overall eye health.
- An **electrocardiogram** (EKG) traces electrical voltages in the heart.
- Psychosocial Evaluation

Heart transplant is a complex therapy and is not recommended for every patient. Psychological and social risk factors can often lead to poor outcomes. Pre-transplant, the clinical social worker provides transplant counseling, education and teaching. The clinical social worker helps monitor how you and your caregiver manage the daily challenges related to your situation, and helps you develop a strong coping plan and offers psychological support.

Practical assistance and resource education also is available. The clinical social worker will conduct a psychological evaluation with you and your support system to determine your readiness for heart transplant. The psychological evaluation includes:

- availability of appropriate caregivers before and after transplant
- understanding illness and transplant process
- attitude about and acceptance of transplant
- mental status and mental health evaluation
- substance use history
- treatment self-management/compliance
- religious and/or cultural issues
- financial and insurance management
- post-transplant work planning
- transplant goals, quality of life definition
- transplant expectations, goals and desire
- confidence and commitment to post-transplant care
- healthcare beliefs, values and wishes
- healthcare planning: Will/Living Trust, Durable Power of Attorney, Advance Directive/Living Will
- post-transplant relocation planning
- coping and stress management barriers or challenges

### **Additional Testing**

Depending on your age and other medical conditions, you may need tests for cancer, vascular disease, pulmonary disease etc. Each person is different and if you need additional tests, your pre-transplant cardiologist will discuss them with you.

## 6. Selection Committee

After all of your tests have been completed, your pre-transplant cardiologist will present your case to the heart transplant selection committee. This team meets weekly and is comprised of surgeons, cardiologists, nurses and clinical social workers. Your pre-transplant cardiologist will review your case and the group will discuss recommendations for the best treatment for you.

In some instances, a patient may not require listing at that time and may continue on medications. In other cases, a patient may benefit from an additional surgery or therapies before a heart transplant. Others may need to be listed for transplant immediately.

In some cases, a patient may not be a good candidate for a heart transplant. Some reasons to be declined for transplantation include, but are not limited to:

- current or recurring infection that cannot be treated effectively
- · active cancer
- inability to tolerate the surgery
- serious conditions other than heart disease that would not improve after transplantation
- noncompliance with treatment
- substance abuse
- lack of adequate support system

Other risks depend on your specific medical condition. Be sure to discuss any concerns with your doctor before the procedure.

The committee's recommendation will be relayed to you and your referring doctor.

## 7. The Donor Heart

Once you are accepted as a transplant candidate and your insurance company clears you, we will list you on the United Network for Organ Sharing (UNOS) national computer system. Patients are listed by blood type, height, weight and urgency.

The categories of urgency are

- 1A Patients are very sick and are in the hospital with intravenous monitoring equipment or mechanical devices helping to temporarily sustain heart function.
- 1B Patients may be in or out of the hospital and have IV medications or a mechanical device stabilizing heart function.
- Status 2 Most patients are out of the hospital and stable.
- Status 7 Patients temporarily inactive on the transplant list.

Your pre-heart transplant cardiologist will discuss your status with you. Your status may change as your condition improves or deteriorates.

## 8. Potential Donors

Organ donors are individuals who are declared "brain dead" due to a severe brain injury. To remove the heart, two or more doctors must declare the donor brain-dead. Family consent also is necessary before an organ is available for transplant. The donor information is then transmitted to the UNOS computer and a recipient "match list" is generated. It is important to remember that you are waiting for a family to make a decision to donate, rather than waiting for someone to die. Deaths happen regardless of your need for a transplant. The decision a family makes to donate is often the only way in which they can find comfort with their loss and at the same time give hope to another family.

SECTION 1: BEFORE YOUR HEART TRANSPLANT PAGE 7

# 9. Waiting for a Transplant

How long you wait for a donor will depend on your UNOS status, your blood type and size, and how long you have been waiting on the list. You may wait a few days or over a year. The donor's body must be close to your own height and weight. Your pre-transplant cardiologist will discuss the possible length of your wait.

You may wait at home or in the hospital, depending on whether you need IV medications and other devices to support your heart. The heart transplant team's goal is to maximize your treatment and enhance your quality of life during this period. Since hearts can be transplanted only within a short time of being taken from the donor, you may be asked to move temporarily near the hospital.

You will need a cell phone so you can be contacted immediately if a donor organ becomes available while you are away from home. Always tell the pre-heart transplant coordinator about any trips out of the area.

While waiting, keep yourself as healthy as possible. Continue to take your medications as prescribed. Follow the diet recommendations. Stay as active as possible by walking or with an exercise program approved by your cardiologist. It is also recommended for you to see your dentist and your primary care doctor when indicated.

#### Weigh yourself every morning after going to the bathroom and before eating breakfast.

Wear similar clothing each time. Keep a record of your weight. If you gain 2 pounds or more in one day, or 3 to 5 pounds in one week, notify your doctor. This may indicate fluid retention rather than a weight increase from fat.

#### **Avoid**

- Heavy cleaning such as vacuuming, sweeping, or mopping
- Isometric exercises or weight lifting
- Raking leaves or garden hoeing
- Playing golf, tennis, basketball, football, or soccer.
- Ask your doctor whether or not you should drive.

Consult with your individual cardiologist regarding drinking alcoholic beverages. In some individuals, alcohol can poison the heart muscle cells and further weaken your heart. Alcohol also makes the heart more vulnerable to irregular heart rhythms. Continue to maintain a smoke-free lifestyle.

Above all, continue to live your life by seeing family and friends and participating in activities you enjoy. You will be invited to join a support group led by our clinical social worker. The group consists of other patients waiting for transplant as well as patients who have received transplants and their families. This group can provide valuable information and may be a source of emotional support. A separate support group for care givers is also available.

# 10. Being Prepared

Once you are on the transplant list, our staff will need a way to contact you at any time of the day or night. You will need to be ready to come at a moment's notice. Thanks to cell phones, it should be easy to get in touch with you as soon as a potential donor is located. As for your preparation, here are a few tips.

#### Communication

- In addition to your cell phone, give the transplant team a list of telephone numbers for the homes of friends and relatives or other locations you visit often.
- Check your cell phone, answering machine or voicemail often. This is especially important if you are someplace where it is hard to reach you.

#### **Finances**

Check with both your insurance provider and Stanford's financial counselors to make sure your transplant is covered as much as possible.

### **Mental and Emotional Preparation**

It is important to stay positive and manage the very natural stress that occurs from having heart failure.

Learn everything you can about your condition, your transplant and what to expect can make the transplant process a little less frightening. If you can, talk with people who have had transplants. Be sure to ask members of your transplant team any questions you may have.

Support groups can be very helpful for you, your family and friends. Stanford hosts a monthly support group for both patients and caregivers. Patients waiting for a donor organ are especially encouraged to attend. Our clinical social workers also offer a number of resources to help you cope and manage stress in a positive way.

### Packing for the Hospital and Post-Hospital Care

Every patient is different so it is hard to know how long you will need to stay in the hospital and how long you will need to recover outside the hospital. However, most patients stay in the Intensive Care Unit for one to three days. They are then transferred to the Step-Down ICU, for another five to seven days before being discharged from the hospital.

You will be asked to stay in the area for 10 to 12 weeks after you leave the hospital. You may be ready to go home earlier, but it is always better to plan ahead. During the first month after your hospital stay, you need to have someone with you most of the time. This guideline depends on your progress. However, it is generally safe for your caregiver to leave you alone for brief periods.

While waiting for a donor, pack a small bag to carry you through the first few days in the hospital. A friend may bring additional articles later, or you may want to pack enough in advance for the full stay.

- Bring only personal items you will need during your stay, including a robe, reading material, one or two checks and \$10 or less in cash. Small electrical appliances such as shavers and hair dryers are acceptable, except in the intensive care unit.
- Clothes may include pajamas if you don't like hospital gowns. Tops should be button down or zip-front, so the nurses can reach the wound for dressing changes and monitor cords, etc. Short sleeves or baggy sleeves are preferable for IV access.
- Slippers or some kind of comfortable slip-on shoe for walking around the hospital. You may
  want to bring something roomier than usual because swollen feet and ankles are common after
  surgery.
- Tennis shoes for physical therapy when you are more mobile
- A list of current medications, dosages and allergies.
- A journal writing about your experience is a great exercise in processing and adjusting to the transplant experience. It may be helpful to consolidate thoughts, process, and put your emotions on paper.
- A copy of your Advance Health Care Directive If you have not already done so, please send a copy of this document before or when you are listed for transplant. For more information about an Advance Health Care Directive, please ask your social worker or transplant coordinator.
- If you're a reader, bring a good book although, you may not feel like, or have the concentration to read immediately after transplant, reading may be a good way to ease anxiety.
- A portable CD player, iPod, etc. the ICU and step-down units can be noisy. Music that you enjoy may calm you as you rest or fall asleep. Music may ease anxiety and restlessness.
- Be sure to pack comfortable clothes such as sweats or jeans for your recovery. Of course, if no one is returning home to gather your personal items BEFORE you are discharged, you may plan to pack a few days worth to tide you over.
- Contact lists or phone trees of persons you want notified or who you want to call. Initiating a phone-tree where one or two folks call others is a good way to alleviate the stress on your family of having to field calls from numerous people. Computers are available in the hospital for email.
- Bring enough medication to get you back home if it's a "dry run." Plan for unexpected delays such as trouble getting travel arrangements, etc.
- Camera some patients like to have photos taken in the hospital to make scrapbooks or to get pictures of the transplant team.
- Photos of family or inspiring family/friends to have around you for comfort or support.
- Toiletries and products you "can't live without" such as a favorite foot cream, lotions, shampoos, etc. to comfort and pamper yourself with.
- Spiritual or cultural items such as prayer books, rosaries, scripture, etc.
- Your cell phone and a pre-paid calling card you are not allowed to use your cell phone in MANY parts of the hospital. Long-distance calls from your hospital room are prohibited. You may want a few calling cards to use after discharge if you prefer to not use your cell for longdistance.

• Eye-glasses – many people find it difficult to use contact lenses initially after the transplant operation.

### For your support person

- Any essential medications, information to obtain refills at local pharmacies and medical insurance cards.
- Enough clothing for the hospital stay or to last until reinforcements arrive. Be sure to include a warm sweater or sweatshirt. The ICU waiting rooms are routinely CHILLY.
- Comfortable walking shoes. Many support persons walk to decompress and get fresh air as a coping mechanism.
- Bring contact information so you can check in with people supporting you emotionally and other helpers.
- A cell phone and phone calling cards since cell phone reception can be challenging in the hospital. Pay phones are available.
- Spiritual or cultural items such as prayer books, rosaries, scripture, etc.
- Phone trees, email addresses or contacts of people for support and information sharing.
- Checkbook and/or ATM cards and credit cards.
- Toothpaste/toothbrush, hairbrushes to refresh since you may be in the ICU waiting room overnight.
- Eyeglasses, reading glasses and/or back-up contact lenses and solution.

#### What to Leave at Home

Please leave valuables such as jewelry, large sums of cash, pagers or video equipment at home. The hospital cannot be responsible for the loss or damage of any personal property in your room. Electronic appliances with the exception of shavers and hair dryers are not allowed in patient rooms for safety reasons. Don't bring medications from home unless your doctor told you to.

#### No Smoking

Stanford Hospital and Clinics does not allow smoking anywhere within its premises. This includes the hospital entrances, courtyards and most outdoor areas.

#### **Interpreter Services**

Interpreter Services can contact an interpreter 24 hours a day, seven days a week. The phone number is (650) 723-6940.

### **Spiritual Services**

The Spiritual Care staff helps patients obtain comfort and support within their own faith traditions. Staff and volunteers as well as community resources are available for all heart transplant patients.

## 11. When a Donor Becomes Available

You will be contacted by the surgeon once a potential donor becomes available. Keep all phone numbers current with the transplant coordinator to prevent delays in reaching you. The surgeon will ask if you have had a recent infection such as a cold or flu, or signs of infection such as fever, cough with sputum, flu-like symptoms, diarrhea etc. It is important to be completely honest. An existing infection could cause complications after transplant since the medicines you will receive prevent you from fighting infection as you would normally. If you have an infection at the time of transplant, you might not be able to fight any infections making it dangerous to proceed with surgery. If you have an infection making it unsafe to go through with surgery the heart will go to the next candidate on the list.

Once you are called, do not have anything more to drink or eat. You will be asked to report to the hospital immediately. The surgeon will tell you where to go once you arrive at Stanford. Once you have been admitted you will have an IV placed, blood drawn, and receive a chest x-ray. The surgeon and an anesthesiologist will see you and take your medical history. The surgeon will go over the procedure with you and review the risks of the operation with you and your family.

Once it is time for your operation, a team of anesthesiologists will take you to the operating room. Once there the anesthesiologists will place special IVs for your surgery, give you medications to help you relax, then place a breathing tube into your airway to help you breath during your operation. You will also have a urinary catheter placed to drain your bladder during the surgery.

While this is occurring another team of surgeons will travel to the donor's hospital. Once there, the team will examine the donor's heart to make absolutely certain that it is a suitable match. Sometimes they discover circumstances that make the donor heart unacceptable for you. If the donor isn't suitable, your transplant will be cancelled. Though it is rare, there is always a very small chance that the surgery may not take place. Sometimes the transplant can even be cancelled at the last minute after you have gone into the operating room and been put under anesthesia. This can be very difficult and disappointing for you and your family, but canceling your transplant is done only in instances when it would be unsafe to proceed.

#### **Questions About Your Donor**

Although personal information about your donor is kept confidential, you are welcome to write to the donor family. Expressing how the donor's gift will impact you and your family can help convey your thanks. We suggest that you avoid identifying information about your family.

You may send the completed letter to your transplant coordinator or social worker, who will forward it to the appropriate agency to send to the donor family. If the donor family chooses to write to you, the letter will be forwarded through the same anonymous procedure.

# 12. Surgery

During the heart transplant, an incision will be made in the midline of your chest. A heart-lung bypass machine will take over the work of the heart and lungs. Your diseased heart will be removed and replaced with a healthy donor organ.

The doctors will leave a small piece of the top (atria) and back of your heart, as well as the big blood vessels that bring blood to and from the heart.

The operation usually lasts between five and six hours, but can last longer if you have had previous open-heart surgery or have a left ventricular assist device in place.

## 13. Risks of the Procedure

Complications may occur with any surgery. Potential risks associated with heart transplantation include, but are not limited to:

- infection
- bleeding during or after the surgery
- blood clots that can cause heart attack, stroke or lung problems
- breathing problems
- kidney failure
- coronary arteriopathy (similar to coronary artery disease)

Your body may reject your new heart. Rejection is a normal reaction of the body to a foreign object or tissue. When a new heart is transplanted into a recipient's body, the immune system reacts to what it perceives as a threat and attacks the new organ.

To allow the transplanted organ to survive in your body, you must take medicines to trick the immune system into accepting it. However, the medicines that prevent or treat rejection have side effects. The exact side effects depend on the specific medicines. Although the dosages may be lowered, you will need to take these medicines for the rest of your life to avoid rejection.

## 14. How Successful Are Heart Transplants?

Survival following heart transplantation has steadily improved over the last 20 years. Each transplant patient faces specific risks depending on his or her particular condition. Your doctor will discuss these risks with you. In general, 85 percent to 90 percent of patients survive past one year and 80 percent survive three years.

Survival statistics for each transplant program in the United States are available online at, www.ustransplant.org. The survival statistics for every heart transplant program in the country are on this site. The information is updated in January and July.

As of July 2007, the survival rate for adult heart transplant patients at Stanford Hospital at one month is 96 percent, at one year is 87 percent, and at three years is 86 percent. Many patients at Stanford have survived more than 20 years. Two of the most important factors for long-term survival are taking medications properly and appropriate follow-up care.

# SECTION 2: AFTER YOUR HEART TRANSPLANT

# 15. Post-Operative Care

This section of the binder is about taking care of yourself after your transplant. It provides information to help you adapt to your new daily healthcare routine, learn your medicines, and monitor yourself for possible complications.

An enormous amount of team effort is necessary to ensure transplant success. The teamwork between you, your family/caregivers and the transplant team is vital. We will work closely with you from the time you are evaluated for your transplant, throughout your hospitalization, and as an outpatient. However, <u>YOU</u> are the most important member of the team! Your responsibilities include:

- Adopting a healthy lifestyle including a heart-healthy diet, regular exercise, and stress management.
- Taking all of your medicines correctly and on time.
- Monitoring for infection, rejection and/or other complications.
- Communicating regularly with the Transplant Team.
- Attending Transplant Clinic regularly and having your blood work done as instructed.

# 16. What to Expect During Your Hospitalization

#### **Intensive Care**

During your surgery, your family will wait in the North ICU waiting area. Once the operation is over, the surgeon meets with your family to update them about the surgery. You will be taken to the North ICU to recover. Doctors and nurses who have been trained to recognize any problems will watch you closely.

### While you are in the ICU, expect:

- Everyone who enters your room to wash their hands with soap and water or anti-bacterial hand gel. This protects you from potential infections due to the anti-rejection medication.
- To be on a breathing machine for the first 8 to 24 hours while the effects of the anesthesia wear off. You can communicate with your nurse and family by nodding your head and/or writing on a tablet.
- A special tube or catheter will be in one of the big veins of your neck to monitor the pressure in your new heart. Other catheters in your arms provide IV medications and fluids.
- A catheter in your bladder will drain your urine. It is very important to monitor your urine
  output to make sure your kidneys are functioning normally.
- Two or three tubes coming out of your chest drain fluids that may collect in your chest due to the operation. The tubes will be removed once the fluid decreases or stops. A bandage will cover your chest incision for the first 24 to 48 hours. The bandage will be removed if there is no drainage.
- Two temporary pacemaker wires may come through the skin below the chest incision. These wires can be attached to an external pacemaker if your new heart needs the help. The wires will be removed before your discharge from the hospital.
- You will get out of bed and sit in a chair the day after your surgery depending on how well you are doing. If you have pain, don't be afraid to ask for pain medication. Reducing your pain allows your body to move more easily and helps you recover faster. A physical and occupational therapist also will be available to work with you.
- Your blood will be drawn each day to adjust the dosages of the anti-rejection medications and to monitor kidney, liver and other bodily functions.
- You will learn to use a hand-held breathing exercise machine (incentive spirometer) to prevent pneumonia, once you are breathing on your own. It is important to use this machine and to cough and deep-breathe every hour. It may be uncomfortable the first few days, but practicing makes it easier.
- Your doctors will order chest X-rays every morning to check your lungs. It is common to be slightly short of breath after the surgery. Remember, you may have received substantial fluids, medications and blood products during the operation. As you begin to move, your body will naturally get rid of the extra fluid. Medications may be prescribed to help get rid of the fluid.

Most patients stay in the ICU for two to three days, although this varies depending on the pace of your recovery. Once you are stable, you will be transferred into a private room in the Step-Down ICU. Since you are in a private room, your family members can visit as much as they want and can even spend the night in the room with you. In fact, your family is highly encouraged to spend as much time as possible at your bedside in the Step-Down ICU. This is where you and your family will learn how to take care of your new heart, as well as your new medication regimen.

#### **Information for Visitors**

### • Visiting Hours

North Intensive Care Unit: 10 a.m. to 8 p.m. (First 30-minutes of every even hour i.e. 10-10:30a.m., 12-12:30 p.m., 2 -2:30 p.m., etc.)

General Care Units: 11 a.m. to 8 p.m.

- Visitors who have colds or flu or have been exposed to chicken pox, tuberculosis, mumps, measles or any other infectious disease within the past three weeks should not visit because it poses a risk to your health.
- Sending Cards or Mail to Patients

#### Please address mail to:

Stanford University Medical Center ATTN: Patient's name 300 Pasteur Drive Stanford, CA. 94305

Mail will be delivered to your room. After your discharge, mail will be forwarded to your home.

- Balloons: Only Mylar balloons may be brought into the hospital because of the risk of latex allergies.
- Dining: Stanford Hospital & Clinics and Lucile Packard Children's Hospital offer patients and visitors a number of food and lodging options, including:
  - Market Square Cafeteria on the first floor of Stanford Hospital. Open 7 a.m. to 7 p.m.
  - Starbucks/Mrs. Fields located in the Market Square Cafeteria. Open 6 a.m. to 2:30 a.m.,
     Monday Friday and 7:30 p.m. to 2:30 a.m. Saturday, Sunday and holidays.
  - The Courtyard Cafe on the ground floor of Packard Hospital. Open 7 a.m. to 7 p.m.,
     Monday Friday and 7 a.m. to 3 p.m., Saturday, Sunday and holidays.
- **Banking:** Two ATM machines are located within the hospital. Both are located in the rear of the hospital near the cafeteria and emergency department.\*

#### Step-Down ICU

• Your nurse will teach you your new medication regimen. You will receive your own set of medications as well as a complete list of those medications to learn. Whenever it is time to take your medications, your nurse will bring your supply and ask you to pull out the correct

- medicine and dose based on your list. She also will teach you what the medications do and the correct way to take them.
- Physical and occupational therapists will work with you to build up your strength and stamina. They also will teach you and your family about the safest and most effective ways to increase your activity after your hospital discharge.
- You will continue to have regular blood draws and X-rays to monitor your response to the medications and track your recovery.
- A dietitian will teach you about proper nutrition and maintaining a heart-healthy diet.
- As you near discharge, the Transplant Coordinator will teach you about your transplant, potential complications and how to recognize them, and how the Transplant Team will monitor you for the potential complications.
- The clinical social worker works closely with you and your post-transplant team. Although most patients and families make an uneventful re-entry back to a healthy lifestyle, it is sometimes necessary to consult the clinical social worker. Help is available for patients, potentially life-long, after transplant. The first contact could occur during the patient's outpatient clinic appointments, via telephone, support groups, or any inpatient stays at Stanford. Areas of psychosocial and practical support may include:
  - post-transplant counseling, education and teaching
  - post-transplant relocation planning
  - coordinating resources to assist with post-transplant care, including resources in your home community
  - mental health maintenance, including adjustment-related issues, anxiety, depression and stress reduction
  - managing and retaining financial and/or medical insurance benefits
  - vocational issues; re-entry/transitions into work, school and/or home-based activities
  - substance use monitoring; smoking, alcohol and/or drug relapse prevention/intervention
  - relationship issues; communication, intimacy, sexual function
  - Heart Transplant and Caregiver Support group involvement
  - assistance with writing a letter to the donor family
  - end-of-life decision-making; grief, loss and bereavement
  - any other concerns that could compromise your transplant

Once you have recovered from surgery, have no outstanding medical issues, are knowledgeable about your medications, and have met with the Transplant Coordinator for education, you may be discharged from the hospital.

## 17. Potential Complications

Complications can occur after any surgery, but special complications are associated with transplantation. With your medical team's experience, we are aware of most things that can happen. We know how to prevent complications and how to treat them if they occur. However, your role in monitoring your health, following a healthy lifestyle and taking your medication, is critical.

### The Immune System and Rejection

In healthy immune system, white blood cells circulate through the body looking for foreign invaders like bacteria or virus. If a foreign invader enters your body, perhaps through a skin cut, your immune system automatically sees it as a threat and attacks it. Unfortunately, your new heart is also foreign and your immune system treats it the same as it would a bacteria or virus. Rejection is your body's attempt to protect you by attacking a foreign protein that has entered your body.

Preventing rejection requires taking medications called immunosuppressants. Immunosuppressant medications help prevent rejection and help your body to accept the new heart by weakening or suppressing the immune system.

Even with powerful immunosuppressants, rejection can still occur at any time. Up to half of all heart transplant patients have at least one rejection episode within the first year. The highest risk of rejection occurs during the first six months after your transplant. Over time, the risk decreases, however, you will always be at risk for rejection. You will need to take your immunosupressants for the rest of your life.

### **Recognizing Rejection**

Although most of the time, patients who experience a rejection will not have any symptoms, and the rejection is detected only by the heart biopsy. When symptoms of rejection do occur, they can be very subtle. Because rejection can be life-threatening if it not recognized and treated early, it is critical that you report any of the following symptoms to your transplant team immediately:

- Excessive fatigue or weakness
- Drop in blood pressure
- Sudden weight gain
- Shortness of breath
- Swelling in hands or feet
- Bloating, nausea, or vomiting
- Irregular or fast heartbeats
- Fever, 99.0 degrees or higher
- New onset of aches and pains

### **Treating Rejection**

Having an episode of rejection can be discouraging, but remember that they are common. Most rejection episodes can be reversed if detected and treated early. Treatment for rejection is determined by severity.

The treatment may include giving you high doses of intravenous steroids called SoluMedrol, changing the dosages of your anti-rejection medications, or adding new medications. Severe or persistent rejections may require treatment with powerful medications and/or plasmapheresis, a procedure in which antibodies are removed from your blood.

Early treatment is critical to successfully reversing rejection. Do not try to treat your symptoms yourself. Call your transplant team immediately if you have any concerns or any of the previously listed symptoms.

# 18. Heart Biopsy

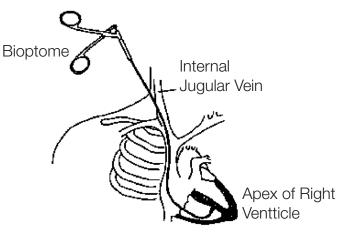
Currently, the only way to diagnose rejection is a heart biopsy. Routine biopsies begin approximately two weeks after your transplant and then as ordered by your transplant cardiologist. The biopsies will become less frequent as time goes on as long as you are not experiencing frequent episodes of rejection.

The procedure is performed in the Cath Lab and takes about 30 minutes. A doctor will give you a local anesthetic to numb an area around your neck. A long tube (catheter) called a bioptome is passed though a small puncture in your neck then down into your heart. Sometimes the biopsy catheter will be placed though a vein in your groin if the neck veins aren't accessible.

A type of X-ray called fluoroscopy helps the doctors guide the bioptome into your heart. Once the bioptome reaches your heart, the doctors remove five or six tiny samples of heart tissue to examine. They will look for white blood cells to determine if you are experiencing rejection. The biopsy results are usually available within 24 to 48 hours. The Transplant Coordinator will notify you of the results as soon as possible.

After the biopsy, gentle pressure will be applied to the puncture in your neck or groin. The doctors and nurses also will observe the area for bleeding. Notify the nurses or doctors if you experience either bleeding or swelling at the puncture.

Report shortness of breath or unusual chest pain after a biopsy immediately. They may indicate more serious complications. You will be encouraged to get up and walk soon after the procedure.



### Things to Remember for Your Biopsy

- If you have been prescribed a diuretic or "water pill," do not take the morning dose on biopsy days. Retaining a small amount of extra fluid makes your blood vessels slightly larger, which makes them easier to find and enter during the biopsy procedure.
- Unless told otherwise, treat yourself to a salty meal the night before your biopsy. The extra salt helps you retain extra fluid.
- Do not lift heavy objects for 24 hours after the procedure, as this may cause bleeding at the biopsy site.

### **Grading Rejection**

The presence and severity of rejection is graded by a scale based on the results of your biopsy.

Grade	Definition	Treatment	
Grade O	No Rejection	None	
Grade 1 R	Mild rejection	This type of rejection is so mild and harmless that it requires no treatment.	
Grade 2 R	Moderate Rejection	Intravenous steroids (similar to prednisone) will be given in the hospital or infusion clinic once a day for three days. Another biopsy will be done in about two weeks to make sure the treatment was successful.	
Grade 3 R	Severe Rejection	The treatment is similar to that given for a Grade 2 rejection; however, stronger intravenous medications may be used to destroy the white blood cells that are attacking your new heart. Hospitalization may be necessary if your heart function has been affected.	
Grade AMR	Antibody mediated Rejection	You will be connected to a machine that will remove the antibodies in your blood. This procedure is plasmapheresis. You may be given other IV medications to suppress the white blood cells that generate the antibodies in your blood. Hospitalization is frequently required to treat this form of rejection.	

## 19. Infections

The anti-rejection medications that keep your body from rejecting your new heart have the unfortunate side effect of compromising your immune system. You may no longer have the ability to fight off infections the way you used to. However, you can minimize infections by preventing exposure to infections, being aware of the symptoms and seeking treatment immediately. Now that you are a transplant recipient, view all infections as potentially serious.

Particularly in the first few months, we recommend that you avoid crowds where you could be exposed to infections. If you do leave home in the first few months, wear a mask. Recommendations you should follow indefinitely include:

- Washing your hands and using anti-bacterial soap or gel frequently, especially after using the bathroom, before meals, before and after changing dressings on wounds, and after coughing or sneezing. Other people around you also should follow these guidelines.
- Staying away from sick people. If you have to be around someone who is sick with a cold or flu, that person should follow normal precautions such as frequent hand washing and using separate drinking glasses.
- Taking antibiotics before ALL dental procedures.
- Getting annual flu shots.
- Avoiding outside animals that roam outside as well as cleaning fish tanks, cat boxes and bird
  cages. Let your transplant team know if you have any pets at home and they can advise you on
  how to avoid common pet-borne infections.
- Avoiding contact with plants and soil for the first few months after transplant to avoid infection from soil-borne organisms. Later, wear protective gloves if you garden or dig in the soil.
- Avoiding "live" vaccines such as those for polio, German measles, smallpox and mumps. Tell your doctor if you or anyone you live with needs a vaccination.
- Following food safety guidelines. Food contaminants can be especially problematic for transplant recipients. Avoid raw meats, including poultry; all meat, seafood and poultry should be cooked to medium. Pink meat is not acceptable. Use only pasteurized dairy products; either fully cook eggs or use pasteurized egg substitutes; wash fruits and vegetables with chlorinated water, even if they have a non-edible peel; and make sure countertops and cleaning products are clean to avoid cross-contamination.

Although you probably won't have any major complications from common cold and flu viruses, treat all symptoms of infection seriously. Call the transplant team right away if you have any of the following symptoms:

- Fever, 99.0 degrees or higher
- Abdominal pain
- Cough
- Diarrhea
- Difficult breathing
- Earache

- Headache
- Nausea
- Painful urination
- Runny nose
- Skin blisters or sores, especially in the mouth
- Sore throat
- Swelling, redness, tenderness or drainage from any incisions or cuts
- Vomiting

Some infections that can be especially problematic include:

- Pneumocystic carinii, a bacterial infection that causes a type of pneumonia in people who have compromised immune systems. Symptoms may include a mild cough and fever that don't get better.
- Cytomegalovirus (CMV), a viral infection that includes a number of flu-like symptoms including aching joints, headaches, nausea, vomiting, shortness of breath, diarrhea, fatigue, fever and nights sweats. Treatment may require hospitalization.
- Herpes-simplex virus type 1 and 2, a family of viruses that usually infects the skin, eyes, lungs or genital areas. Type 1 may cause blisters or cold sores around the mouth. Type 2 is associated with genital sores. Herpes can't be cured but there are effective treatments. Fluid-filled sores in the genital area or mouth accompanied by fatigue are the usual symptoms. Women also may have vaginal discharge.
- Herpes zoster, more commonly called shingles, appears as a rash or blisters, usually on the upper body.
- Varicella zoster or chicken pox, like herpes zoster, may appear as a rash or blisters. Even if you do not have symptoms, call the transplant team immediately if you are exposed to someone with chicken pox, if you have not previously had it.
- Candida, also called a yeast infection, can occur in the mouth or throat, at the surgical incision, in the respiratory or urinary tract, the eyes or even the blood stream. Candida can infect the vagina, as well as the esophagus. Thrush is a yeast infection in the mouth that causes white, patchy sores, a white film on the tongue and difficulty swallowing.

# 20. Other Transplant-Related Complications

#### **Graft Coronary Artery Disease**

Graft coronary artery disease, which causes blockages in the heart, is the leading cause of death after the first year of heart transplantation. You can help prevent this condition by taking your medication and using conventional heart health practices. These include controlling blood pressure and weight, maintaining a low-cholesterol diet, and doing a reasonable amount of exercise. After the first 5 years after your heart transplant, you will have an annual examination

of your heart's blood vessels via a catheter inserted into the blood vessels. Blockages that can be reached by catheter may be removed or compacted with a balloon or a stent.

### **High Blood Pressure**

If you did not have high blood pressure before your transplant, you may have it afterward due to anti-rejection medication. Fortunately, a variety of medications are available to help you control this condition.

#### **Diabetes**

Diabetes can be a side effect of some of your anti-rejection medications. Warning signs may include thirst, increased urination, confusion and eye problems. Diabetes usually can be controlled through lifestyle changes, medication or insulin. African-American and Hispanic transplant recipients, overweight recipients and recipients with a family history of diabetes are more likely to develop post-transplant diabetes. Recipients who had diabetes before transplant may have a harder time controlling the condition after transplant.

In the Transplant process, everyone's blood sugars are different and sometimes unpredictable. Often the disease progression and/or medications used to treat the disease may cause blood sugars to run higher or lower than usual. Some people who did not have diabetes before their transplant may find that they now have high blood sugars. For those with diabetes before transplant, diabetes may be harder to manage. The medications that are taken to prevent rejection may cause blood sugars to go up. To prevent dehydration and reduce the risk of infection, it is very important to keep blood sugars within the goal that the transplant team and your primary doctor recommend. This will help with healing and recovery; and allow individuals in the transplant process to feel better!

Good blood sugar levels are important to decrease risk of infection, improve nutrition and promote heart health. Controlling diabetes is one of the most important things you can do to ensure the success of your transplant. The Transplant Diabetes Program at Stanford Hospital and Clinics has been developed specifically to accommodate the needs of both transplant candidates waiting for transplantation and for transplant recipients by providing individualized support and education for the best possible transplant outcomes.

We understand that diabetes affects each person differently. Because of this, we help create treatment programs for the special needs of each person. Individuals (pre- and post- transplant) and their families are welcome to contact the Transplant Diabetes Program and utilize the classes and programs provided. For more information about dates, times & location call: 650-498-4526 or 650-723-5094.

Or log on to our web site at: www.stanfordhospital.com/transplantdiabetes

#### **Anxiety and Depression**

A heart transplant is major surgery that may be life-changing. It is common to experience a number of intense emotions - including depression and anxiety. These emotions can also be a side effect of some of your medications. Your clinical social worker can evaluate your situation and discuss ways to manage these issues.

## 21. Going Home

### **Discharge Checklist**

The following is a checklist of things you <u>MUST</u> complete before you can be discharged from the hospital.

- Read your discharge teaching manual.
- Meet with the Transplant Coordinator for your discharge education.
- Know how to weigh yourself, take your blood pressure and temperature, and check your blood sugar if necessary.
- Know the signs of rejection.
- Know the signs of infection.
- Know <u>ALL</u> of your medicines including names, dosage, frequency and purpose.
- Be able to take your medicines <u>CORRECTLY</u> with little or no help from your nurse or caregiver.
- Know how to contact the Transplant Team with questions or concerns, or to report a problem or change in your condition.
- Identify where you will stay for the next 10 to 12 weeks.
- Discuss your temporary housing options with your clinical social worker.
- Receive a complete 30-day supply of all your medications before leaving the hospital. Your initial prescriptions will be filled at a pharmacy near the hospital based on what your insurance allows. Once you are ready to move home, your prescriptions can be sent to a pharmacy near your home.

# 22. Keeping Your New Heart Healthy

Your transplant team will do their best to make sure that you are educated about how to take care of yourself and your new heart. They will continue to be there for you and to help with any questions or problems you may have. However, your role in maintaining your health is absolutely critical and you must make every effort to be responsible for following your medical plan.

You will be asked to keep a chart of your temperature, pulse, blood pressure and weight. Make sure you know how to keep accurate records of these items before you go home. Bring your chart with you when you return for check-ups. You will receive a chart when you are discharged from the hospital.

• Blood Pressure – You will need to have a home blood pressure recording device, which can be purchased in most drugstores. Your transplant coordinator can check your digital cuff against a manual cuff to ensure accuracy. The top number, called the systolic number, is the first sound you hear and the bottom number or diastolic is the beat when the sound changes. You will need to learn what your normal blood pressure is so that you can respond to any abnormalities.

	Notify your doctor if your systolic blood pressure is more than or less than or less than or less than
•	Temperature – Record your temperature every morning, but also any time you feel sick or cold or experience other symptoms. Call your doctor immediately if your temper goes higher than 99.0 degrees. Don't use products such as aspirin, Tylenol or Advil unless your doctor prescribes them because they may interact with your other medication.
•	Pulse – If you're taking any medication that impacts your heart rate, your nurse will teach you how to check your pulse at home. Notify your doctor if your pulse if faster than or slower than
•	Weight – Weigh yourself every morning after going to the toilet. If you gain more than 2 pounds a day, you could be starting to retain fluid, so notify your doctor.

# 23. Outpatient 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. These visits help us to track your progress and find complications as early as possible.

Generally you will be seen in clinic twice a week on Mondays and Thursdays for the first three weeks after discharge. Afterward, your clinic visits will become less frequent as long as you are not experiencing problems or complications. The Transplant Team will determine how often you should be seen in clinic.

Bring your medication list and this handbook with you to follow-up visits. 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 you might need.

### **Lab Tests**

You will have some lab tests at each checkup. These can include blood and urine tests. Some of the things the tests look for are:

- Your white blood cell count, which can indicate an infection or side effects from medication.
- How well your blood clots, to avoid too much bleeding if you are injured.
- How well your kidneys and liver are working by measuring levels of creatinine and blood urea nitrogen, waste products your kidneys normally remove from the blood.
- How much immunosuppressive medication is staying in your bloodstream and for how long.
  High levels could lead to toxicity or over-immunosuppression and low levels may lead to
  rejection.
- How much sugar (glucose) is in your blood.
- 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 to 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. Echocardiograms are generally performed on the same day as biopsies or as needed.

#### • Right Heart Cath (RHC)

A right heart catheterization checks 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 for your 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.

#### • Bone Density Scan (DEXA Scan)

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

#### • Electrocardiogram (EKG)

This test involves placing 12 electrodes on your skin to measure the electrical voltages in your heart.

## 24. Health Maintenance after Discharge

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 with anti-bacterial soap or hand gel 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, 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 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.

### **Food Safety**

Food can carry bacteria, viruses, fungi and parasites. Foods that may be safe to eat for a 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. You will meet with the Transplant Nutritionist prior to your discharge 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 countertops and dishcloths.

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

## 25. Nutrition

### Part 1: Short term, following surgery

- Small frequent meals, small snacks, or optional supplements help to meet needs for wound healing, while avoiding feelings of fullness or bloating.
- Nutrient-dense fluids such as milk, juice, supplements/shakes and smoothies, in addition to plain water, help to meet fluid needs as well as calorie/protein needs. Drink ample amounts at least 8 to 12 cups (2-3 liters) each day.
- Stand and walk whenever possible to improve appetite, blood circulation and maintain muscle and bone strength.
- Goals during this period: wound healing while preserving muscle mass.

### Part 2: Long term

- With time, you may gain an average of 15 to 30 pounds, due to side effects from some medications. To prevent this:
  - Exercise 45 minutes to one hour daily.
  - Reduce animal fats and saturated fats (solid fats) in your diet.
  - Eat at least five servings of fresh fruits and fresh vegetables daily.
  - Control volume of food eaten through smaller portions at meals and limited between-meal snacking.
- High blood pressure due to steroids may be controlled with a no-added-salt diet and blood pressure medications. Limit salt or salt-based seasonings, and salt-processed foods such as fast foods whenever possible.
  - A diet that is high in fiber, fruits, vegetables and calcium-rich foods, and low in animal fats also may reduce your risk of heart disease, osteoporosis, cancer and diabetes. Eating the right foods can lower blood pressure significantly, see attached DASH diet (Dietary Approaches to Stop Hypertension).
- Transplant medications can cause high blood cholesterol. The American Heart Association recommends limiting food high in saturated fat.
  - Saturated fat raises your blood cholesterol level more than anything else that you eat
     Saturated fats are found in fatty cuts of meat, poultry skin, whole milk dairy products, lard, butter, shortening and coconut oil.
  - Choose lean cuts of meat, fish, poultry; nonfat dairy products; legumes and lentils; whole grains, and plenty of fresh vegetables and fruits.
- Transplant medications interfere with calcium absorption, making bones more fragile and easy to break from osteoporosis.
  - Adequate calcium and vitamin D from nonfat dairy products, calcium fortified juices, or supplements can help.
  - Weight-bearing activities such as walking also help keep bones strong.
- Transplant medications such as steroids may cause blood sugar or glucose to go up. Untreated high blood glucose (diabetes) can delay wound healing, increase risk of infection, and damage blood vessels to vital organs.
  - Keep weight in control through daily exercise.

- Control volume of food, especially high-calorie items as rich desserts, fried foods and chips.
- Transplant medications interfere with absorption of magnesium.
  - Whole grains, nuts, dark green vegetables and shellfish are good sources of magnesium, in addition to magnesium supplements.
  - See attached magnesium list.
- Occasionally, high blood potassium due to medications or rejection may mean a temporary low potassium diet.
  - Avoid salt substitutes, which contain potassium chloride (KCl).
- Unless otherwise specified, water is the best liquid to use to take medications.
  - Avoid grapefruit juice to take medications, as it will change the absorption of some transplant immunosuppressive medications.
- Please discuss whether you may drink alcohol with your transplant cardiologist.
- A common sense word about food safety:
  - Always wash your hands before handling food
  - Wash produce well before eating
  - Wash utensils, bowls or cutting boards that come in contact with raw meat, fish, or eggs to minimize risks of Salmonella contamination
  - Avoid eating any raw meat or raw fish items such as sashimi/sushi or oysters-on-the-half-shell.
  - Never leave perishable foods out for more than two hours

The DASH dietary guidelines on the next page are easy to follow. Just cut the fat, double fruits and vegetables, and use nonfat or low fat dairy products. Combine it with regular exercise and ample water as a part of your daily healthy lifestyle! Ask your dietitian to help you develop an eating plan that will work for you.

#### **DASH: Dietary Habits to Stop Hypertension**

The DASH eating plan is designed to control, or even prevent, high blood pressure (hypertension). It adds healthy foods to your diet, such as low-fat dairy, fruits and vegetables, rather than taking foods away. This is a heart-healthy style of eating that the whole family can enjoy.

High blood pressure is one of the leading causes of stroke, heart disease, kidney failure and premature death in this country. About one in four American adults has high blood pressure. Millions more have prehypertension, which means their blood pressure falls at the high end of the range formerly considered normal. The DASH diet, along with a sodium restriction (1500-2000 mg/day), helped improve blood pressures even more. Current guidelines recommend limiting sodium to no more than 2400 mg/day.

Here are the number of servings you should consume daily from each food group. Serving amounts are based on a 2000-calorie diet plan.

Food Group: Daily Servings	Serving Examples	Important Nutrients Provided
Grains & Grain Products: 7-8 servings daily	1 slice whole grain bread, 1/2 cup dry (amount may vary) or cooked whole grain cereal, 1/2 cup cooked rice or pasta 1/2 English muffin or bagel	Carbohydrates, Energy, Fiber, Thiamin, Folate, Iron, B Vitamins
Fruits & Vegetables: 4-5 fruit servings daily 4-5 vegetable servings daily	6 oz fruit or veggie juice, 1 medium apple, orange, banana, etc; 12 grapes, 1/4 cup raisins, 1/2 cup frozen or canned fruit, 1 cup raw leafy or 1/2 cup cooked vegetables, 1 medium potato Apricots, melons, strawberries, tomatoes, peas, carrots, broccoli, squash, leafy greens	Potassium, Magnesium, Fiber, Folate, Vitamins A and C
Dairy Foods (low-fat or nonfat): 2-3 servings daily	8 oz low-fat or nonfat milk, 1 cup low-fat or nonfat yogurt, 1 1/2 oz nonfat or reduced fat cheese 1 cup low-fat or nonfat cottage cheese	Calcium, Protein, Phopshorus, Zinc, Magnesium, Vitamins A and D
Meats, Poultry & Fish: 2 or fewer servings daily	3 oz cooked lean meat, poultry, or fish (trim visible fat, remove skin from poultry; broil, roast or boil)	Protein, Magnesium, Iron, Zinc, B Vitamins, Thiamin, Niacin
Nuts, Seeds & Legumes: 3-4 servings per week	1/3 cup nuts (choose a variety) 2 Tbsp seeds (sunflower, sesame, etc) 1/2 cup cooked legumes (lentils, variety of beans)	Magnesium, Potassium, Protein, Iron, Fiber, Vitamin E, Thiamin, Niacin

Adapted from: National Institutes of Health, MayoClinic, and The American Dietitic Association

### **High Magnesium Foods**

The Recommended Dietary Allowance (RDA) of magnesium for men ages19 to30 years is 400 mg; for men 31 years and older, it is 420 mg. For women aged 19 to 30 years, it is 310 mg; for women 31 years and older, it is 320 mg of magnesium per day. Suggested foods are listed below.

GRAINS & CEREALS		NUTS, SEEDS & PROTEIN FOODS		
100% Bran Cereal (1/2 c.)	135 mg	Tofu, raw, firm (1/2 c.)	125 mg	
Brown Rice (1 c. cooked)	85 mg	Sunflower Seeds (1/4 c.)	125 mg	
Soybean Flour (1/4 c.)	60 mg	Almonds (1 oz.)	85 mg	
Bran Flakes (3/4 c.)	60 mg	Walnuts (1 oz.)	60 mg	
Oatmeal (1 c. cooked)	56 mg	Peanut Butter (2 Tbsp.)	50 mg	
Wheat Germ (1/4 c.)	45 mg	Peanuts (1 oz.)	49 mg	
Instant Oatmeal (3/4 c. cooked)	39 mg	Beef, Poultry, Fish (3 oz.)	24 mg	
Whole Wheat Bread (1 slice)	26 mg			
		VEGETABLES		
BEANS & LEGUMES		Spinach (1/2 c. boiled)	80 mg	
Black Beans (1 c. cooked)	120 mg	Swiss Chard (1/2 c.)	76 mg	
Navy Beans (1 c. cooked)	105 mg	Avocado (1 medium)	70 mg	
Refried Beans (1 c. cooked)	100 mg	Baked Potato w/skin	55 mg	
Pinto Beans (1 c. cooked)	95 mg	Beet Greens (1/2 c.)	49 mg	
Lima Beans (1 c.)	85 mg	Broccoli (1/2 c. cooked)	47 mg	
Kidney Beans (1 c. cooked)	80 mg	Okra (1/2 c. cooked)	46 mg	
Lentils (1 c. cooked)	70 mg	Baked Potato, no skin	39 mg	
FRUITS		Source: Bowes & Church's Food Value	es of	
Figs, (1/2 c. dried)	60 mg	Portions Commonly Used, 17th edition, 1998.		
Pineapple (1 c. canned)	36 mg	•		
Banana (1 medium)	35 mg			
Raisins (2/3 c.)	35 mg			

## 26. Exercise

Exercise is important to both your physical and emotional health after a transplant. But remember that your sternum is wired and needs at least 12 weeks to heal. During this time:

- Do not lift more than 5 pounds.
- Minimize use of your arms. No lifting, pushing, pulling, twisting or raising your arms above your head, and avoid sleeping on your side.
- If you experience fatigue not related to lack of sleep, shortness of breath, dizziness during exercise, irregular heart rate or pain in your chest, neck or jaw, stop exercising until after you consult your doctor.

# 27. Loss of Nerve Supply

The incision cuts the nerves that ordinarily regulate your heart rate. This lack of nerve connections is called denervation. Denervation causes your new heart to beat faster than your previous heart at rest.

The "resting rate" of a transplanted heart usually ranges between 90 and 110 beats per minute. While this rate is faster than "normal," it is associated with perfectly normal function and capacity for vigorous activity.

Any change in your transplanted heart's rate depends on circulating adrenaline and related hormones. These affect your heart rate through the circulatory system rather than by direct nerve action on the heart.

The response is slower. A response to stimulation causing increased adrenaline, such as exercise, may take up to 10 minutes until the heart picks up the message through blood circulation rather than direct electrical brain impulse. The circulating hormones also may take up to an hour to decline and allow the heart rate to return to normal after exercise.

Another effect of denervation is that you may not sense chest pain or angina if blockages develop in the arteries of your new heart. Discomfort may be due to healing chest wall muscles or strain due to exercise, rather than lack of blood supply to the heart.

# 28. Resuming Regular Activities

You transplant team will probably wait at least 12 weeks after surgery before giving you permission to drive. A car accident could seriously harm the incision in your chest. Your surgery, your previous heart condition and your time away from driving may slow your reflexes and your stamina for driving. You may need to ease back into driving, working up to longer drives.

The team also will work with you to decide when you are ready to return to your normal activities. How soon will depend on what type of work you do, how your healing is progressing and a number of other factors.

### **Sex and Pregnancy**

How soon you return to sexual activity depends on when you and your doctor feel you are ready. Your surgery and some of the medications may impact your desire for sex and your sexual abilities.

Check with your transplant team about any concerns you have about medications, or your chances of infection from sexual activity. If you do not have a regular sexual partner, you will need to use condoms to reduce your chance of getting a sexually-transmitted disease.

Women will need to use contraception to avoid an unplanned pregnancy. If you want to get pregnant, discuss the potential risk to you and the baby with the transplant team. Although male transplant patients have fathered children, there are some potential risks due to the medications heart recipients must take.

#### **Skin and Hair**

Transplant patients generally don't need special skin-care, unless they develop an unusual skin condition or rash. Showering and bathing with regular soap is generally okay, but use mild soap and lotion after bathing if your skin is dry. To avoid shaving cuts, use an electric razor. If you have a nick or small cut, clean it every day. Larger cuts may require a visit to your doctor.

Since transplant patients are more likely to develop skin cancers, it is critical that you protect your skin from ultraviolet rays by:

- avoiding the sun between 10 a.m. and 3 p.m. when ultraviolet rays are the strongest
- wearing protective clothing, including a hat, when outdoors
- applying sunscreen and lip balm daily to uncovered areas of your body, even when it is cloudy or rainy. Remember to re-apply sunscreen because it wears and washes off.
- using skin products with a skin protective factor (SPF) rating of at least 30.

You may have to wait until your prednisone dosage is lowered to have a permanent or to dye your hair. This medication is likely to change the texture of your hair and adding harsh chemicals may result in brittleness and breakage. Your hairdresser will probably suggest a good conditioner to help with this.

Your medication also may cause more facial hair. Carefully follow the instructions for using a hair-removal cream to avoid skin irritation. You also may try bleaching, waxing or electrolysis. Your transplant team can offer other suggestions.

### Alcohol

Many of the medications you are taking can harm your liver when combined with alcohol. Avoid wine, beer and other alcoholic beverages. Discuss this with your transplant team if you have any questions.

#### **Smoking**

Smoking can be especially damaging for heart patients. Don't start smoking after your surgery or resume it if you smoked previously. Smoking can add to your already increased risk of cancer, additional heart disease and other complications. Please consult your transplant team if you require smoking cessation support.

#### **Travel**

Always keep your medications with you, along with a letter from the transplant team verifying that you are a transplant patient.

If you're planning to visit a foreign country, consult your transplant team about what to do if vaccinations are required that would harm you. This may make that particular country unsafe for you to visit.

Another issue for travelers who are heart recipients is time changes, which need to be taken into account when you take your medications. Remember to space your medication with the same timing and sequencing as you have at home. You also may have to consider diet and hygiene issues in foreign countries.

## 29. Routine Health Care

Although you will continue to have annual check-ups at the transplant center, your day-to-day care medical care, including routine screenings exams, will usually return to your regular primary care doctor. Make an appointment once you return home to bring your doctor up to date on your condition and to review your records. Give your transplant team this doctor's name and contact information.

## **Monitoring Your Health**

Because you are living with your transplant, you are the one most likely to notice any changes, side effects from medication or other complications. By the time you leave the hospital, you should have learned the risks that accompany a transplanted heart and the required medications. It also is your responsibility to make sure that your other health care providers, including your pharmacist, primary doctor and dentist, are aware of your transplant. Give them contact information for the transplant team in case they have questions or concerns about your condition or care.

#### **Dental Care**

Dental health is important for transplant recipients for several reasons. First, dental problems such as abscesses or mouth pain can become major problems because of your compromised immune system. Preventive care is more important than ever. Some transplant medications also cause gum problems. It is critical that you tell your dentist that you are a transplant recipient

before even the most routine tooth maintenance care. An antibiotic is usually prescribed to prevent any chance of infection from a dental procedure.

Heart infection (endocarditis) prevention measures are recommended for:

- Teeth cleaning or implants where bleeding may occur
- Dental extractions (tooth pulling)
- Periodontal procedures including surgery, scaling and root planing, probing and recall maintenance
- Endodontic (root canal) instrumentation or surgery only beyond the apex
- Subgingival placement of antibiotic fibers or strips
- Initial placement of orthodontic bands but not brackets

Please ask your nurse for a wallet card to give your dentist before any dental procedure.

### 30. Medications

#### Reminder

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

You will have an individualized regimen, adjusted to your body's needs and response. You may not receive, or be discharged on, all of these medications.

This chapter provides an overview of the usual dosages, and side effects, and is not intended to be totally inclusive. Please consult your doctors, pharmacists or nurses with any questions about your medications.

The post-transplant nurse coordinator will give you a detailed list and schedule of when to take your medications as part of your discharge education.

#### Important take-home points

- Learn BOTH the generic and brand names of each medication
- Maintain a written record of the name, dose and administration times for all medications. Please keep your medication schedule log updated at all times.
- Take all of your medications precisely as directed. Try not to miss any doses, and adhere to your prescribed schedule.
- If the current prescribed schedule doesn't work well for your lifestyle, consult your team pharmacist, nurse coordinator or doctor for advice.
- If you miss a dose, take it as soon as possible. If it is almost time for your next dose, do not take the missed dose or take a double dose.
- Do not take any NEW medications or supplements without your doctor's approval. This includes over-the-counter drugs for appetite control, asthma, colds, cough, allergy or dietary supplements.
- Store all your medications away from heat and direct sunlight. Remember your medications are comfortable where you are comfortable.
- Do not keep medications in the bathroom cabinet since heat and moisture may cause deterioration.
- Keep your medication in their original containers. The label on the container specifies the expiration date, the prescribing doctor and the original prescription date.
- Report dizziness or fainting immediately to your nurse or doctor along with the name of the blood pressure medication and other medications you take.
- Notify your doctor of severe or continuing nausea, vomiting, diarrhea or any possible side effects or new symptoms.
- Blood pressure monitoring is recommended after you are discharged.

The medications most commonly used by transplant patients are:

- Immunosuppressants
- Antihypertensives
- Anti-infectives
- Lipid-lowering agents
- Mineral and electrolyte replacements
- Acid-reduction agents

Your Transplant Coordinator will review your specific medicines with you once receive your transplant. However, the following is a brief overview of the most common medications and their side effects. Please take the time to review these medications and become familiar with them BEFORE your transplant.

#### Cyclosporine - Brand Name: Gengraf<sup>®</sup>, Neoral<sup>®</sup>, Sandimmune<sup>®</sup>

Pharmacologic Category: Immunosuppressant Agent

What is this medicine used for?

• This medicine is used to prevent rejection after organ transplant.

How does it work?

- Cyclosporine helps the body accept a transplanted organ.
- It decreases the body's harmful response to diseases affecting the immune system.
- It reduces irritation and inflammation.

How is it best taken?

- To gain the most benefit, do not miss doses.
- A pungent odor may be noticed when removing the capsules from their protective packet.
   This is only an alcohol based preservative and the odor will dissipate quickly. It has no effect on the medication.
- The capsules should NOT be opened until you are ready to take them or they can lose efficacy when left exposed to the air.
- Follow diet plan and exercise program as recommended by healthcare provider.

What are some possible side effects of this medicine?

- Worsening kidney function
- High blood pressure
- Risk of infection. Avoid people with infections, colds, or flu
- Headache
- Elevated cholesterol levels
- Belly pain
- Nausea or vomiting. Small frequent meals, frequent mouth care, sucking hard, sugar-free candy, or chewing sugar-free gum may help.

- Diarrhea
- Hair growth
- Eye irritation, visual changes or disturbances

Additional comments specific to Cyclosporine: Your blood pressure will be monitored closely while you are taking cyclosporine, since hypertension is one of the drug's most prevalent adverse effects. High blood pressure medications will be prescribed as indicated.

Routine laboratory testing to monitor blood concentration or levels of the drug will also be necessary for the duration of cyclosporine therapy to avoid or minimize kidney and liver toxicity.

A blood specimen for the serum level of cyclosporine needs to be drawn eleven to thirteen hours following a dose of cyclosporine.

Food Interactions (please consult with your doctor before starting any new herbal supplement or diet regimen)

- Do not take medications with grapefruit juice
- Avoid St. John's Wort, Cat's claw, Echinacea.

#### Mycophenolate - Brand Name: Cellcept®, Myfortic®

Pharmacologic Category Immunosuppressant Agent

What is this medicine used for?

• This medicine is used to prevent rejection after organ transplant.

How does it work?

- Mycophenolate helps the body accept a transplanted organ.
- It decreases the body's harmful response to diseases affecting the immune system.

How is it best taken?

- Take this medicine on an empty stomach. Take 1 hour before or 2 hours after meals.
- Swallow whole. Do not chew, break, or crush.
- A liquid (suspension) is available if you cannot swallow pills. Shake well before use.
- Those who have feeding tubes can also use the liquid. Flush the feeding tube before and after medicine is given. Tube feeding should be held a couple of hours before and after medicine are given.
- Follow diet plan and exercise program as recommended by healthcare provider.

What do I do if I miss a dose?

- Take a missed dose as soon as possible.
- If it is almost time for the next dose, skip the missed dose and return to your regular schedule.
- Do not take a double dose or extra doses.
- Do not change dose or stop medicine. Talk with healthcare provider.

What are the precautions when taking this medicine?

• Be careful about taking vaccinations while you are receiving this medicine.

- If you have PKU, talk with healthcare provider. Some products do contain phenylalanine.
- Check medicines with healthcare provider. This medicine may not mix well with other medicines.
- Do not take antacids, cholestyramine, colestipol, or iron within 2 hours of this medicine.
- The risk of cancer is higher after taking this medicine.
- You may bleed more easily. Be careful. Avoid injury. Use soft toothbrush, electric razor.
- There is a risk of skin cancer. Avoid sun, sunlamps, and tanning beds. Use sunscreen; wear protective clothing and eyewear.
- Use birth control that you can trust before treatment begins, during treatment, and for 6 weeks after treatment ends.

What are some possible side effects of this medicine?

- Risk of infection. Avoid people with infections, colds, or flu.
- · Headache.
- Nausea or vomiting. Small frequent meals, frequent mouth care, sucking hard, sugar-free candy, or chewing sugar-free gum may help.
- Diarrhea.

#### Prednisone - Brand Name: Sterapred®, Prednisone Intensol®

Pharmacologic Category: Corticosteroid (Immunosuppressant)

What is this medicine used for?

• This medicine is used to treat organ transplantation.

How does it work?

• Prednisone decreases the body's harmful response to diseases affecting the immune system (immunosuppressant).

How is it best taken?

- Take this medicine with food.
- Take this medicine in the morning if taking once daily.

What do I do if I miss a dose? Use a missed dose as soon as possible

- If it is almost time for the next dose, skip the missed dose and return to your regular schedule.
- Do not take a double dose or extra doses.
- Do not change dose or stop medicine.

What are the precautions when taking this medicine?

- Check medicines with healthcare provider. This medicine may not mix well with other medicines.
- Check with your transplant cardiologist before drinking any alcohol.
- Tell healthcare provider if you are pregnant or plan on getting pregnant.
- Tell healthcare provider if you are breast-feeding.

What are some possible side effects of this medicine?

- High blood sugar. Can cause diabetes mellitus while on medicine, usually reverses when stopped.
- Risk of infection. Avoid people with infections, cold, or flu. Consult with healthcare provider before receiving any vaccinations.
- Belly pain
- Nausea or vomiting. Small frequent meals, frequent mouth care, sucking hard, sugar-free candy, or chewing sugar-free gum may help.
- · Weight gain.
- Change in body fat distribution.
- Weakened bones. Take calcium and vitamin D as recommended by healthcare provider.
- Skin changes (acne, stretch marks, slow healing, hair growth)

#### Valganciclovir - Brand Name: Valcyte®

Pharmacologic Category: Antiviral agent

What is this medicine used for?

• This medicine is used to prevent or treat cytomegalovirus (CMV) infection.

How does it work?

• Valganciclovir works to injure the virus and fight the infection.

How is it best taken?

• Take this medicine with food.

What do I do if I miss a dose? Use a missed dose as soon as possible

- If it is almost time for the next dose, skip the missed dose and return to your regular schedule.
- Do not take a double dose or extra doses.
- Do not change dose or stop medicine.

What are the precautions when taking this medicine?

- Check medicines with healthcare provider. This medicine may not mix well with other medicines.
- Check with your transplant cardiologist before drinking any alcohol.
- Tell healthcare provider if you are pregnant or plan on getting pregnant.
- Tell healthcare provider if you are breast-feeding.

What are some possible side effects of this medicine?

- Anemia and low platelet count.
- Headache
- Nausea or vomiting. Small frequent meals, frequent mouth care, sucking hard, sugar-fee candy, or chewing sugar-free gum may help.

- Diarrhea
- Inability to sleep.
- Changes in vision.

#### Itraconazole - Brand Name: Sporanox®

Pharmacologic Category: Antifungal agent

What is this medicine used for?

• This medicine is used to treat a variety of yeast infections.

How does it work?

• Itraconazole works to injure the yeast and fight the infection.

How is it best taken?

- Take capsule with a full meal.
- Take liquid solution on an empty stomach. Take 1 hour before or 2 hours after meals.

What do I do if I miss a dose? Use a missed dose as soon as possible

- If it is almost time for the next dose, skip the missed dose and return to your regular schedule.
- Do not take a double dose or extra doses.
- Do not change dose or stop medicine.

What are the precautions when taking this medicine?

- Check medicines with healthcare provider. This medicine may not mix well with other medicines.
- Check with your transplant cardiologist before drinking any alcohol.
- Tell healthcare provider if you are pregnant or plan on getting pregnant.
- Tell healthcare provider if you are breast-feeding.

What are some possible side effects of this medicine?

- Headache
- Belly pain.
- Nausea or vomiting. Small frequent meals, frequent mouth care, sucking hard, sugar-fee candy, or chewing sugar-free gum may help.
- Diarrhea

#### Clotrimazole - Brand Name: Mycelex®

Pharmacologic Category: Antfungal agent

What is this medicine used for?

• This medicine is used to prevent or treat a variety of yeast infections.

How does it work?

• Clotrimazole works to injure the yeast and fight the infection.

How is it best taken?

• Suck on oral lozenge. Do not chew, break, or crush.

What do I do if I miss a dose? Use a missed dose as soon as possible

- If it is almost time for the next dose, skip the missed dose and return to your regular schedule.
- Do not take a double dose or extra doses.
- Do not change dose or stop medicine.

What are the precautions when taking this medicine?

- Check medicines with healthcare provider. This medicine may not mix well with other medicines.
- Check with your transplant cardiologist before drinking any alcohol.
- Tell healthcare provider if you are pregnant or plan on getting pregnant.
- Tell healthcare provider if you are breast-feeding.

What are some possible side effects of this medicine?

- Belly pain.
- Nausea or vomiting. Small frequent meals, frequent mouth care, sucking hard, sugar-fee candy, or chewing sugar-free gum may help.

#### Trimethoprim/Sulfamethoxazole (TMP/SMX) - Brand Name: Septra®, Bactrim®

Pharmacologic Category: Antibiotic agent

What is this medicine used for?

• This medicine is used to prevent of treat a variety of bacterial infections including Pneumocystis carinii pneumonitis (PCP).

How does it work?

• Sulfamethoxazole/trimethoprin works to injure the bacteria and fight the infection.

How is it best taken?

- Take this medicine with food.
- Take this medicine with a full glass of water.
- Suspension: Shake well before use.

What do I do if I miss a dose? Use a missed dose as soon as possible

- If it is almost time for the next dose, skip the missed dose and return to your regular schedule.
- Do not take a double dose or extra doses.
- Do not change dose or stop medicine.

What are the precautions when taking this medicine?

• Check medicines with healthcare provider. This medicine may not mix well with other medicines.

- You can get sunburned more easily. Avoid sun, sunlamps, and tanning beds. Use sunscreen; wear protective clothing and eyewear.
- Be careful if you have G6PD deficiency anemia may occur.
- Check with your transplant cardiologist before drinking any alcohol.
- Tell healthcare provider if you are pregnant or plan on getting pregnant.
- Tell healthcare provider if you are breast-feeding.

What are some possible side effects of this medicine?

- Nausea or vomiting. Small frequent meals, frequent mouth care, sucking hard, sugar-fee candy, or chewing sugar-free gum may help.
- Not hungry.
- Sunburn.
- Anemia (rare)

#### Pravastatin - Brand Name: Pravachol®

Pharmacologic Category: Antilipemic agent

What is this medicine used for?

• This medicine is used to lower cholesterol and other harmful types of cholesterol in the body. Good cholesterol (HDL) levels increase.

How does it work?

Pravastatin reduces cholesterol production.

How is it best taken?

• Take this medicine with or without food.

What do I do if I miss a dose? Use a missed dose as soon as possible

- If it is almost time for the next dose, skip the missed dose and return to your regular schedule.
- Do not take a double dose or extra doses.
- Do not change dose or stop medicine.

What are the precautions when taking this medicine?

- Check medicines with healthcare provider. This medicine may not mix well with other medicines.
- Check with your transplant cardiologist before drinking any alcohol.
- Tell healthcare provider if you are pregnant or plan on getting pregnant.
- Tell healthcare provider if you are breast-feeding.

What are some possible side effects of this medicine?

- Muscle weakness.
- Joint pain.

- Feeling dizzy.
- Flu-like symptoms. These include headache, weakness, fever, shakes, pains, aches, sweating.

#### **Aspirin**

Pharmacologic Category: Salicylate

What is this medicine used for?

- This medicine is used to relieve pain, fever, and inflammation
- This medicine is used to prevent strokes
- This medicine is used to prevent heart attacks.

How does it work?

- Aspirin blocks production and release of chemicals that cause pain and inflammation.
- It reduces fever by adjusting the body's thermostat in the brain.
- It prevents platelets from becoming sticky and clumping together.

How is it best taken?

• Take this medicine with food to avoid upset stomach.

What do I do if I miss a dose? Use a missed dose as soon as possible

- If it is almost time for the next dose, skip the missed dose and return to your regular schedule.
- Do not take a double dose or extra doses.
- Do not change dose or stop medicine.

What are the precautions when taking this medicine?

- Check medicines with healthcare provider. This medicine may not mix well with other medicines.
- Check with your transplant cardiologist before drinking any alcohol.
- Tell healthcare provider if you are pregnant or plan on getting pregnant.
- Tell healthcare provider if you are breast-feeding.

What are some possible side effects of this medicine?

- Belly pain.
- Heartburn.
- Nausea or vomiting. Small frequent meals, frequent mouthcare, sucking hard, sugar-free candy, or chewing sugar-free gum may help.

#### Magnesium-Protein Complex - Brand Name: Mag-Plus Protein®

Pharmacologic Category: Electrolyte Supplement

What is this medicine used for?

- This medicine is used to treat low magnesium levels.
- Short-term treatment of constipation

How does it work?

• Magnesium is a dietary supplement.

How is it best taken?

• Take this medicine with food.

What do I do if I miss a dose? Use a missed dose as soon as possible

- If it is almost time for the next dose, skip the missed dose and return to your regular schedule.
- Do not take a double dose or extra doses.
- Do not change dose or stop medicine.

What are the precautions when taking this medicine?

- Check medicines with healthcare provider. This medicine may not mix well with other medicines.
- Check with your transplant cardiologist before drinking any alcohol.
- Tell healthcare provider if you are pregnant or plan on getting pregnant.
- Tell healthcare provider if you are breast-feeding.

What are some possible side effects of this medicine?

Diarrhea

#### Famotidine - Brand Name: Pepcid® (OTC)

Pharmacologic Category: Histamine H2 Antagonist

What is this medicine used for?

- This medicine is used to prevent or treat gastrointestinal ulcers caused by infection.
- This medicine is used to treat gastroesophageal reflux disease.
- This medicine is used to treat heartburn, acid indigestion, and sour stomach.
- This medicine is used to treat syndromes caused by huge amounts of stomach acid.

How does it work?

• Famotidine prevents symptoms and damage to the gastrointestinal tract caused by stomach acid or infection.

How is it best taken?

- Take this medicine at bedtime if you are taking once a day.
- Take this medicine with or without food. Take with food if it causes an upset stomach.
- Chewable tablet: Chew or crush well. Mix crushed tablet with food. Do not swallow whole.
- A liquid (suspension) is available if you cannot swallow pills. Shake well before use.
- Those who have feeding tubes can also use the liquid. Flush the feeding tube before and after medicine is given.

What do I do if I miss a dose?

- Take a missed dose as soon as possible.
- If it is almost time for the next dose, skip the missed dose and return to your regular schedule.
- Do not take a double dose or extra doses.
- Many times this medicine is taken on an as needed basis. Do not take more often than every 12 hours, unless instructed by healthcare provider.

What are the precautions when taking this medicine?

- Check medicines with healthcare provider. This medicine may not mix well with other medicines.
- If you have PKU, talk with healthcare provider. Some products do contain phenylalanine.
- Talk with healthcare provider before using aspirin, aspirin-containing products, other pain medicines, blood thinners, garlic, ginseng, ginkgo, or vitamin E.
- Avoid alcohol (includes wine, beer, and liquor).
- Tell healthcare provider if you are pregnant or plan on getting pregnant.
- Tell healthcare provider if you are breast-feeding.

What are some possible side effects of this medicine?

· Headache.

## 31. Your Commitment to a Healthy Life

A heart transplant is a gift of life which requires a personal commitment to living a healthy lifestyle. Post-transplant care requires a great deal of responsibility to maintain your new heart. You will have to continue to take all of the drugs as prescribed, monitor vital signs and weight daily, as well as attend all your scheduled clinic visits. A regular exercise program and healthy eating is essential to maintaining a healthy new heart.

The Stanford Transplant team is committed to helping you through this process by providing information and support. Please do not hesitate to ask any of our team members for additional information.

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We hope this manual provides you and your family, friends and caregivers encouragement, information and support for the years to come.

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