

Heart Transplant

Surgery Guidebook



FHTransplant.com

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Welcome



On behalf of our entire care team, I would like to welcome you to Florida Hospital. For more than 100 years, we have dedicated ourselves to improving the lives of others by delivering advanced healthcare to the communities we serve. Our mission — to extend the healing ministry of Christ — has inspired us to build a unique health network dedicated to providing comfort, healing, and the discovery of new treatments and cures.

We're honored that you have entrusted us with your health. We look forward to caring for you during your time with us.

Sincerely,

A handwritten signature in black ink that reads "Daryl Tol". The signature is fluid and cursive.

Daryl Tol

President and CEO

Florida Hospital and Central Florida Region – Adventist Health System





Introduction

You can trust your heart care in our hands — from the referral and evaluation process to donor matching and surgery through recovery and ongoing care. As a national leader in cardiology and heart surgery, the Florida Hospital Transplant Institute heart transplant program team utilizes revolutionary technology to provide the most advanced procedures available — saving lives and providing new hope to you and your family every step of transplantation. In fact, we are the first hospital in Central Florida to offer this life-saving measure.

What is heart transplantation?

Heart transplant surgery is a life-saving measure performed when there is otherwise no hope of survival. It is most commonly performed when you have been diagnosed with congestive heart failure, the result of a heart muscle that is too weak to pump an adequate amount of blood through your body.

Overview of heart transplantation

During a heart transplant, your damaged or weakened heart is removed and the pumping of blood is rerouted through a bypass machine. A healthy heart from a deceased donor is transplanted into your chest and blood flow is again rerouted, this time into the transplanted heart.

Using this Guidebook

This guidebook will acquaint you with Florida Hospital's heart transplant program, the transplant evaluation process and the benefits and risks of heart transplant surgery. We will also introduce you to our highly experienced transplant team, along with your personal care logs and reference materials — all to ensure you have the information and resources to understand and accept the process of heart transplantation. Your transplant education begins long before the actual surgery date and continues as a lifelong journey of learning. We're here with you every step of the way.

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Pre-transplantation Process

Understanding Heart Failure

Heart failure is the result of conditions that cause the heart muscle to weaken and decrease its pumping ability. The most common reasons for advanced heart disease, leading to heart failure and transplantation, are severe coronary disease and cardiomyopathy. There are medical treatments or therapies that may help ease the symptoms; however, heart disease gradually worsens despite therapy, and the disease then becomes “end-stage.” **Many physicians recommend transplantation as an alternate treatment when they feel that the end-stage point is near.**

Normally, blood circulates through the heart by way of its four chambers. Two chambers are on the right side of the heart, and two chambers are on the left side. Each side of the heart has an atrium and a ventricle. The role of the four chambers is to pump blood by relaxing and contracting. When heart failure exists, the chambers cannot contract and relax properly.

The left ventricle is the main pumping chamber of the heart and responsible for pumping oxygen-rich blood to the rest of the body and vital organs. When



cardiomyopathy develops, there is a weakening of the heart (cardiac) muscle.

People with cardiomyopathy have poor pump performance, an enlarged heart and thinning of the muscle walls of the heart. In addition, fluid may build up in the lungs, resulting in shortness of breath with simple activities, such as bathing or walking.

Stages of Pre-transplantation

The pre-transplantation process can be divided into several stages. The simplest way to separate the stages that occur prior to transplantation is as follows:

- 1) Referral
- 2) Evaluation
- 3) Case Review
- 4) Acceptance
- 5) Waiting Period

Once approved for a heart transplant, the actual procedure and recovery while in the hospital can be viewed as another stage. After the heart transplant procedure, the return home and long-term ongoing care is considered the final, lifelong stage.



Referral

If you have been referred for transplantation, it is most likely that you have advanced heart disease, like congestive heart failure, or irreversible damage to your heart, meaning that the heart is no longer able to function properly.

The main reason your doctor has decided to refer you for a transplant evaluation is because your heart disease is no longer responsive to standard medical treatment or surgery. Transplantation offers the potential of living an independent, normal and active life again.

If the transplant team determines that you are a good candidate for transplantation, it is important to note that you will be responsible for your new heart. This means a lifetime management of a healthy diet, lifestyle, medications and medical follow-up.

Eligibility

As stated, many patients evaluated for heart transplant have heart failure. For most, this has been a long-standing diagnosis, but sometimes it can be made relatively quickly. During this time, symptoms can no longer be managed by medications and there are no other surgical options that would offer better long-term survival. The person is referred by his or her regular doctor to a transplant center.

Before you can be put on the heart transplant waiting list, you will need a careful evaluation. If you are an outpatient, you may want to make arrangements to stay within the medical-center area to make your testing more convenient. A list of resources in the area will be provided to you. If you need to be hospitalized, the team will make the necessary arrangements.

Criteria

- Candidates will be considered for transplant up until their 70th birthday.
- Very rare exceptions are made for people over 70.
- No significant disease may be present, which would diminish the chances of long-term survival.
- There can be no evidence of active cancer within the past five years. Exceptions may be made on an individual basis.
- Patients must be substance-free of alcohol, drugs and tobacco for at least six months, and must remain abstinent through all phases of transplant.
- There can be no evidence of extensive vascular disease that affects your circulation, brain or other major arteries.
- The patient must be psychologically committed to participate actively in the transplant process.
- There must be an intact support system to assist with the necessary tests and exams during the pre- and post-transplant phase.
- The patient must be able to follow instructions related to treatment, prescribed medications, appointments and education meetings.
- There should be adequate financial coverage for medications needed to prevent rejection.

Pre-evaluation

Before you can be placed on the waiting list for a heart transplant, a detailed evaluation is necessary. The purpose of this evaluation is to determine if a transplant is your best option or if you might benefit from other treatments. The decision about whether one is a good candidate for heart transplant is made on an individual basis and involves many factors. The testing is designed to give a clearer picture of your overall health.

The purpose of all these studies is to:

- Determine that no other medical or surgical option is possible for you, that heart transplantation is your only and best option for survival.
- Establish your baseline medical condition.
- Determine if you meet the criteria for transplant and if the timing is right for you to be officially listed as a candidate.

- Reveal any conditions that might need to be corrected before a transplant surgery. Sometimes the evaluation may uncover an issue where transplantation is determined to not be your best option.
- Educate you and your family about heart transplantation.
- Identify those individuals who would not benefit from heart transplant or pose too great a risk for successful transplant.

At this stage, you and your family will be provided with basic information about what a heart transplant involves. It will be necessary to identify the people who will be able to provide support to you at the time of transplant and for at least the first few months after the transplant.

During this time, it is important to be fully committed to taking an active role in your own healthcare. The transplant team will be concerned if you show a lack of interest or cooperation or are not really committed to the transplant process. Remaining positive can be a critical contribution toward your recovery and general well-being.

Evaluation

Initial Contact and Consults

Your doctor has contacted Florida Hospital's Heart Transplant Program to have you evaluated for transplantation or other therapies for heart failure. Once your records and results are obtained, a transplant coordinator will call you to further discuss your clinical history. A thorough review of your medical history is done to determine if there are reasons an evaluation for heart transplantation would be a good choice for you. Your coordinator will make arrangements for you to meet the various members of the heart transplant team and for preliminary testing as needed. The evaluation will take place either in our transplant clinic or at the hospital.

The purpose of the pre-transplant evaluation is to determine the severity of your heart disease and which form of therapy is best suited to your condition. We do not recommend a heart transplant unless it is necessary and likely to be associated with long-term success. Oftentimes, alternative therapies are possible, such as LVADs.

The evaluation work-up is comprised of the tests listed below. Some of these may have been performed recently and will not need to be repeated. The decision on candidacy for transplantation is made on an individual basis. Your commitment and cooperation during this period will certainly help the process.

Medical Evaluation and Testing

Abdominal Ultrasound/Abdominal CT

An ultrasound probe is used to identify the kidneys, liver, pancreas, gallbladder and stomach.

Blood Tests

Routine blood work, such as a complete blood count, pro-time INR and others, is performed initially. Your blood type, tissue type, blood chemistries and immune system will also be checked. This includes previous exposure to hepatitis, HIV and other infectious agents.

Chest X-ray/ Chest Computed Tomography (CT)

These tests help to determine the size of your heart, as well as the status of the lungs and bony structures.

Dental Consultation

Due to an increased risk of infection, you will need to complete major dental work before your transplant.

Echocardiogram (Echo)

This test records the motion of the heart walls and valves using sound waves passed through the chest. It helps us to determine the size and function of your heart.

Electrocardiogram (EKG)

This test records the electrical activity of your heart.

Metabolic Stress Test

This exercise test monitors how effectively your heart sends oxygen to your body and how well carbon dioxide is removed from your tissues during physical exertion; it can help determine your functional capacity, which might give the medical team an idea of the timing of transplant listing.

Ophthalmology Consultation

This examination will determine any vision or eye-related illness such as retinopathy, which is common

in patients with long-term diabetes, or glaucoma which can get worse after transplant if not identified.

Pulmonary Function Tests

These tests are used to determine whether your lungs function properly and can help to diagnose lung disease.

Right Heart Catheterization

This test measures blood circulation and the pressure within the heart and lungs. This procedure is performed in the catheterization lab (cath lab) or ICU.

Some patients may require individualized additional testing, such as mammography, colonoscopy, ultrasound of the carotid arteries and blood flow of the legs. In addition, other consultations may be performed as needed (i.e., infectious disease, gastroenterology).

Psychosocial Evaluation

Thoughtful consideration of psychological issues is important to any successful transplant surgery. Emotional stability and a supportive social network are essential for success. In order to better understand these elements of your life, a transplant team social worker will assess you and your family to determine the stresses you face, your social support, any financial concerns, transportation, housing and the ability to deal with your condition.

You may be required to undergo further evaluation by a psychologist or psychiatrist to help assess your mental and emotional well-being and determine how you would deal with the stress of the transplant process.

This information enables us to identify your strengths and coping resources. We will discuss any areas of concern regarding your ability to tolerate the transplant process. The concerns may be great enough to reconsider recommendation for transplant.

The social worker's role is a supportive one, using his/her counseling skills plus a knowledge of community resources available to those undergoing the transplant process. The goal of supportive counseling is to help you and your family maintain optimal function during the transplant process. In summary, the social worker learns of your psychosocial needs and is available to address them appropriately throughout the transplant process.

The social worker has a responsibility to all transplant team members as well as to you and your family. At times, grief and bereavement counseling is needed, as well as crisis intervention. Support groups can help you and your family members cope with the stress of transplant. **Listed below are some areas that will be covered:**

Compliance Pattern

Compliance with past medical regimes and physician recommendations are predictors of future compliance.

Education/Employment

Information related to your education level can be useful in evaluating your ability to understand medical directions. Limitations can be addressed on an individual basis. Current or previous employment history will also help to assist in job retraining if needed after transplant.

Family History and Significant Others

Family origins and cultural factors provide information regarding a patient's living situation. Positive support from family members, loved ones and friends is essential during all phases of transplant. This may be a stressful time for your family. Due to your illness, roles may need to change to handle family responsibility. It is very important for each family member, including your children, to understand and discuss their feelings.

Hobbies and Social Activities

These interests may be useful in helping you cope with the waiting period and to set realistic goals after transplant.

Social History

A history of smoking, alcohol or other drug abuse raises concerns about successful follow-up. Our

program requires a minimum of a six-month smoking and drug-free period before an evaluation is considered. Past and present psychiatric history is also explored. If you have a substance-abuse problem, you may be asked to participate in a treatment program or individualized counseling before consideration for transplant.

Support Groups

Support groups provide opportunities to connect with others who have experienced what you and your family are facing and help you realize you are not alone. In groups, people learn to help themselves and each other. Emotional support and specific information about diet, medications and financial assistance is provided. Our program conducts monthly support groups for pre- and post-transplant outpatients. (For our inpatients, we also have education and support during the hospital stay.)

Support Network

This includes family, friends, the community and church. The quality of these relationships is pertinent to your successful recovery. All significant members of your support network should be available during your meeting with the social worker.



Financial Assessment

There are a variety of costs associated with heart transplantation. A financial assessment helps the finance office establish financial eligibility and insurance benefits. Your insurance policy should be reviewed yearly and evaluated.

There are charitable organizations that offer transplant information and provide limited financial assistance. Advocacy organizations advise transplant patients on financial matters. Generally, all charitable and advocacy organizations work hard to be responsive to patient needs. Patients and families often use public fundraising to cover expenses not paid by medical insurance. The following are some transplant financial resources: COTA, Angel Flight, National Transplant Assistance Fund, National Organ Transplant Foundation, Organ Transplant Fund, Inc. and The Transplant Foundation, Inc.

We will help you confirm the following about your insurance policy:

- Is heart transplantation a covered procedure?
- Are there minimums, maximums or exclusions regarding transplant, rehabilitation (in- and outpatient) and home health?
- Is there a lifetime maximum on the policy?
- Is cardiac rehabilitation covered?
- Are post-transplant tests covered?
- Are immunosuppressant drugs covered?
- Are there caps on generic versus brand names, and what will the associated costs be?

Information regarding housing needs, transportation and post-transplant financial planning should be discussed during your initial consultation with the social worker.

During your evaluation, you are responsible for providing resources for living expenses, including transportation to and from the transplant clinic during the pre-transplant period and the post-transplant follow-up period. If you do not live within driving distance, you must make arrangements to stay in the Orlando area during the evaluation.

Case Review

Once the evaluation is completed and all test results are in, our entire team meets to formally review your case and make a decision regarding your candidacy for transplantation.

Making the Decision

Consideration is given to some of the following:

- Are you currently sick enough to need a heart transplant?
- Can your current medications be adjusted, or are other options available to you (i.e., heart failure study, angioplasty, revascularization, valve replacement)?
- Are there issues that need to be resolved prior to consideration for transplant? Circumstances such as emotional support, finances and available transportation need to be resolved before consideration.

Notifying You

The coordinator will notify you and your physician of the decision on candidacy and provide you with a written copy of the decision. If you are not a candidate for transplantation, we will research other therapy options for you, and you will return to the care of your referring physician.

Acceptance

If you are accepted as a candidate for heart transplantation, final authorization will be requested from your insurance company. Once it is received, you will be notified and placed on the heart transplant waiting list. This begins the waiting period.



Multiple Listings

You have the right to be evaluated by different transplant institutes. If you have previously been evaluated by another institute, be sure to let us know, as we may not have to duplicate some of your testing. If you would like to have your information forwarded to another institute for consideration, we will be happy to assist you. Remember that each institute must evaluate and accept you to be on their transplant list based on their criteria. Just because you are listed at one institute does not guarantee you will be accepted by another.

Listing Status

Listing status depends on the severity of illness.
There are currently three active statuses and one inactive status:

Status 1A	This is the top-priority status. These patients are critically ill. Patients in this group generally require intensive care monitoring, intravenous medications and special heart monitoring lines, and may need assist devices, such as an intra-aortic balloon pump or mechanical circulatory support device. Any available donor organ would first be offered to Status 1A patients on the UNOS list.
Status 1B	These patients require continuous infusion of special medication to help support heart function. These medications are called inotropes (i.e., milrinone, dobutamine). Under current UNOS guidelines, patients listed as Status 1B may wait at home or in the hospital. This is dependent upon their individual medical condition..
Status 2	All other candidates for transplant
Status 7	Temporarily inactive

Waiting Period

Once you are accepted as a candidate for transplantation, you will be expected to see your transplant physician for appointments at minimum every four to six weeks while you are waiting. You may also be asked to repeat certain tests (i.e., right heart catheterization, echocardiogram, labs) while you are on the wait list. This is to keep you as healthy as possible during the waiting period and to look for any changes that could affect transplantation and your overall health.

Please keep the Transplant Institute informed if your symptoms worsen, if you go to the Emergency department or if you get any blood transfusions. This will allow the team to monitor you closely and possibly change your status on the wait list.

You will be placed on the national organ donor computerized waiting list. The donor list is nationwide, and broken down into regions and states. This list is managed by the United Network for Organ Sharing (UNOS), a non-profit organization operated under the federal government whose mission is to distribute organs in an equitable, fair manner.

UNOS has many guidelines and policies to help them do this. This computer match allows for accurate matching of the donor heart and the recipient who most needs the organ. Actual recipients are matched according to a complex set of criteria that commonly includes blood type, organ and body size, medical priority and length of time on the waiting list.

Frequently Asked Questions

How long is the waiting period for a heart transplant?

There is no way to determine how long this period will last. The usual waiting time for a heart may take several weeks to several months or even up to a year. While on the waiting list, the transplant coordinators must be able to reach you 24 hours a day. During this time, most of our patients are discharged from the hospital. You are urged to have a cell phone if you are able to afford one; this gives us 24-hour access to you and gives you freedom from feeling restricted to your home.



What can I do to prepare for my transplant?

To make the wait for your new heart more bearable, we suggest that you focus on the following goals:

- Understand WHY and HOW long you may have to wait. Empower yourself with knowledge during this time.
- Learn how to deal with potentially stressful situations in a positive manner. Waiting for a matching heart to become available, especially during those especially bad days when you do not feel well, can be very stressful. Fear of the unknown is normal and it is okay to be scared. Contact a transplant team member if you need to talk to someone.
- Remember support groups are vitally important during this time. Use this time to get answers to your questions, which will in turn reduce your fear of the unknown. Your transplant coordinator or social worker can put you in touch with the transplant support groups or individual transplant recipients so that you can share your feelings and ask personal questions. It also is helpful for you and your support person to consider counseling to deal with the many changes, uncertainties and stresses that occur during this time. By channeling your energies and simply talking with others, you can decrease your stress and

frustration. Stress-reduction tapes, exercises and books are also helpful.

- Improve your overall health by following the recommended nutritional and exercise program.
- It is important to keep as “well” as you can. The better you are before your surgery, the stronger you will be afterward. Proper nutrition and moderate exercise will help you feel good. Walking may be an excellent way to spend time IF YOUR DOCTOR HAS APPROVED IT. Don’t push yourself too much. Use caution; if you experience discomfort or chest pain, stop and rest. See the Diet and Exercise section for more information.
- If you are unable to walk, you can try leg and arm exercises to maintain some muscle tone. Talk it over with the team to make the best exercise and activity plan for you. The better shape you are in when you go into surgery, the easier your recovery will be afterward.
- Be ready to go to the hospital as soon as you are called. Arrange contact persons, transportation and last-minute plans AHEAD OF TIME.
- Have an established plan for when your call comes. You want to ensure that you have a designated driver, established transportation and have available phone numbers to put this plan in operation. Have money set aside in case you need to take a taxi if your designated driver is not available.
- Keep on living your life while you wait!

Can I become too sick for a transplant?

Heart transplant candidates may become too sick for a heart transplant. It is important for you to continue seeing your local physician while you are waiting for your transplant, in addition to seeing a cardiologist from our heart failure team at a minimum of every four to six weeks. All attempts will be made to keep you out of the hospital by making adjustments to your oral medications; however, you may require intermittent or continuous infusions of a drug to strengthen the heart muscle. It is your responsibility to keep the transplant office up to date on your medical condition or changes made by your doctors during your waiting period.

If you are thought to be too sick for transplant, you may be placed on hold. This is usually a temporary status until your condition can be re-evaluated. You will not lose any time on the UNOS waiting list during this period.

If you get sick at home while you are waiting and think you need to go to the hospital, go to the nearest facility. While you are being seen, make sure to identify yourself as a heart transplant candidate and ask the nurse or doctor to call us. If you are sick and have a fever or flu-like symptoms, please notify the transplant office.

What if I have advanced heart failure?

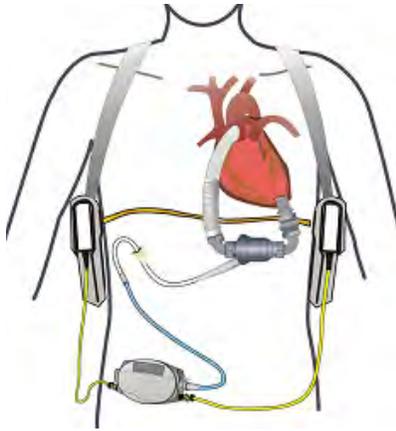
Patients with advanced heart failure waiting for a heart transplant may benefit from a ventricular assist device (VAD), which is the use of mechanical circulatory support that allows for more time and works until a donor heart becomes available. This is known as a “bridge to transplant”.

A VAD is a mechanical blood pump that is implanted inside your chest and is attached to your heart and aorta to assist your heart in pumping blood. The VAD doesn’t replace the heart — it just helps it do its job. The power source for the VAD is located outside the body and is connected to the VAD by a driveline that is placed through a small hole in your upper abdomen.

The controller contains the electronics that control the pump. It also gives warnings, or alarms, if the power is low or if it senses that the device isn’t working correctly. The controller is powered by either a unit that plugs into the wall or by batteries; the batteries last about 10 hours and allow you to be mobile.

Some VADs pump blood like the heart does, with a pumping action. Other VADs keep up a continuous flow of blood. With a continuous-flow VAD, you might not have a normal pulse that can be felt, but your body is getting the blood it needs.

If your transplant team feels that you may benefit from a VAD, you will be given this option after your physicians have discussed all the risks and benefits of getting this device and you are accepted as a transplantation candidate.



The HeartMate II implanted blood pump with the system controller, powered by two batteries

From where does the donor heart come?

Organ donors are typically ordinary individuals who have sustained severe brain damage that results in brain death. This usually results from an injury or other terminal process that has not damaged the chest and from which they will not recover. Brain death, by law, is death, although the heart and other organs can be kept alive by machines for a short period of time. It is up to that person's family to choose to donate his or her organs. This is a very precious gift that you will receive.

While you have met the criteria for transplant, organ donors must meet a certain set of criteria as well. As soon as the transplant team is notified of a matching organ donor, the donor undergoes special tests to determine if he/she is suitable for transplant. The evaluation of potential organ donors includes their medical history, blood tests and studies looking at the functionality of the specific organs.

When a heart donor becomes available, UNOS checks the waiting list to see which patient is at the top of the list. If the tissue type, the blood type and size match, the organ procurement agency contacts the transplant program to see if they would accept that organ. If not, the next institute is contacted on the list. This process continues until all the available organs are accepted by one or more transplant institutes. Currently, there is an agreement with all institutes within the state of Florida to offer the organs statewide first, then regionally and then nationally.

What happens when a donor heart becomes available?

When a suitable donor has been accepted, you will be contacted. Keep in mind, this call may come in the middle of the night. There are times testing delays result in a longer wait. Transplant surgery is scheduled as soon as EVERYTHING is ready.

It is vitally important that the transplant team be able to reach you at all times. As you are planning for transplant, plan ahead. Establish a plan that you can quickly put into action and come to the hospital. Identify how you will get there, who will bring you and a back-up plan for transportation if that individual is not available. Discuss arrangements for children who may need babysitting.

If you need to travel somewhere that is out of cell phone range, please provide the transplant office with information on how you can be reached and establish an approximate traveling time to the hospital.

What information can I know about my donor?

Curiosity about the donor is very natural. Some recipients worry that they may take on the emotional, physical or psychological characteristics of their donor, but this will not happen. Some patients and family members wish to know who the donor is, and some do not. It is natural to feel grateful to the donor and the donor family; however, because of

confidentiality laws, we cannot provide information on the identity of the donor.

If you wish, you can write an anonymous letter to the donor family and give it to your transplant coordinator or social worker. He/she will forward the letter to the Organ Procurement Agency for delivery to the donor family. Donor families are extremely appreciative of letters that come from individuals who have received their loved one's organs.



HOW AND WHEN DO I GET CONTACTED?

If a heart is available for you, the coordinator will call you first at your primary number. If you do not answer, he/she will contact you by an alternate phone number. Make sure cell phones and answering machines are set at night so that they can be heard. Should your cell phone ring, please respond as soon as possible. Keep your cell phone with you at all times, charged and turned on 24 hours a day.

You will be given instructions about when and where to go. Generally, you will need to immediately travel to the hospital. After you are contacted, you will be given specific instructions on the next steps, including whether or not to take your medications.

ONCE WE NOTIFY YOU:

You need to get to the hospital as quickly, but as safely, as possible.

- Plan to leave for the hospital within 30 minutes of being notified. If you experience delays, let us know, as timing is critical to the entire process.
- **DO NOT EAT OR DRINK ANYTHING.**
- Notify the coordinator if you are on a blood thinner (i.e., Coumadin), or if you are sick (i.e., cold, viral illness, infection) or have recently been sick.
- Bring your insurance cards, identification and medication list with you to the hospital.
- You will not need any clothing from home for several days; however, you may want to bring a small bag of toiletries. Personal items should be left with family members or in the car until several days after your transplant.



Your transplant coordinator will tell you where to go upon arrival to the hospital.

During the day, you can come to the main hospital entrance and will be directed to the Admitting Office. The front lobby in Florida Hospital's Ginsberg Tower is attended 24 hours a day.

This is a time when you will probably feel both excited and fearful. Most of the time, you are rushing to get to the hospital and rushing to get prepared for surgery, so there is often little time for last-minute preparation.

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Heart Transplantation Surgery and Recovery

At the Hospital Before Your Surgery

It is important for you and your family to realize that plans for the transplant may change if there is any indication of donor complication. Although disappointing, this evaluation is done for the best possible transplant outcome. If you are admitted with an unexpected health problem, the surgery may have to be cancelled. Careful screening of both the donor, as well as the recipient, continues until the actual time of surgery.

Before your surgery, the hospital staff will help you get ready and answer any last-minute questions. After you arrive at the hospital, one of the transplant team members will review your medical history and do a complete physical examination. Anesthesiologists and surgeons will come to obtain your written permission (consent) for the transplant surgery.

Preparing you for transplant surgery usually includes:

- Waiting in a temporary room until your surgery (your family can stay with you until you are taken to the operating room)
- Not having anything to eat or drink after you are notified that a donor has been found, to ensure your safety during the operation
- Surgical consent (if you have any questions regarding the surgery, please be sure to discuss them with your doctor or your transplant coordinator)
- Blood tests and chest X-rays
- Start of an intravenous (IV) line for fluid and antibiotics
- Washing your skin with a special soap to reduce the risk of infection
- Shaving of the area from the chest to the knee
- Medications to help you relax as needed

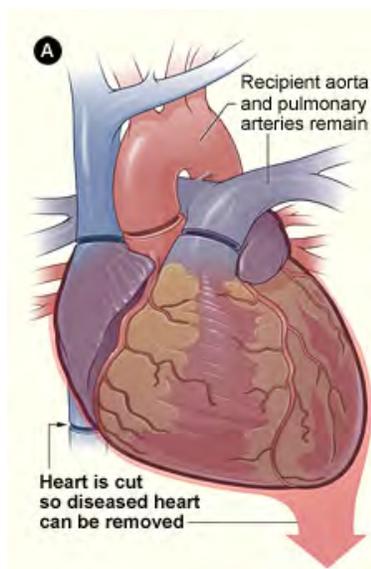
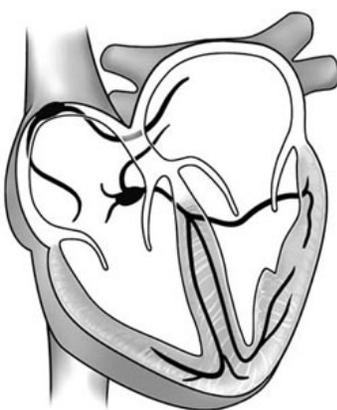
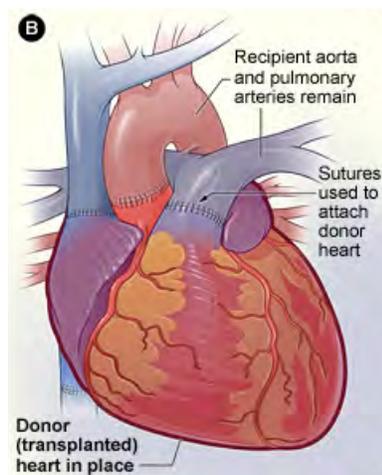


Figure A shows where the diseased heart is cut for removal.

Figure B shows where the transplanted donor heart is sutured to the recipient's arteries and veins.



The denervated heart, where the nerves have been disconnected.

When the operating room calls for you, you will be placed on a stretcher and transported to the operating room waiting area. Your family can accompany you to this point.

Then, they will take you directly into the operating room. It might seem a bit cold in there, but you will be wrapped in warm blankets once you are settled. In the operating room suite, there will be many people wearing masks. They will introduce themselves as the operating room staff. There will also be a lot of equipment that will be used to monitor you during your surgery.

While you are being prepared for the surgery, our procurement team will travel to the donor hospital. While in the operating room at the donor hospital, further testing and visual inspection of the donor heart is done. Remember that the transplant could still be cancelled after you are admitted and have had your pre-operative workup. This can happen if there are any problems with the donor organ. If the donor heart is thought to be unsuitable, the procurement team will relay this information back to the transplant surgeon for a final decision. We know that this is very disappointing, but it is important to ensure the best possible heart for transplant.

The Transplant Surgery

- In the operating room, you will have special IV lines and an oxygen mask. The anesthesiologist will give you medicine to make you fall asleep. Once you are asleep, the transplant team starts to work.
- The surgeon will make an incision in your chest, and you will be attached to the heart-lung (bypass) machine that will take over the function of your heart and lungs during the surgery.
- Once the donor heart arrives, the surgeon will remove your diseased heart and replace it with the healthy donor heart. The entire surgical process usually takes about six to eight hours, but it varies from case to case and may take longer if there are delays with the donor.
- Once surgery is complete, you will be taken to the Intensive Care Unit (ICU), where your family can see you once you are settled.

The Donor Heart

The donor heart comes with its own pacemaker and its own coronary artery supply. However, when the donor heart is removed from the body, the nervous system is disconnected. The heart continues to beat adequately, but without the external nerve supply. This is referred to as a denervated heart. In a small amount of cases, a pacemaker is needed after surgery to help the heart rate.

The resting rate of a denervated 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 the capability to sustain vigorous physical activity.

Recovery and Independence

The Surgical Floor

It is during this time you will become more independent in your care. Your goals now will be to continue to gain strength, TO LEARN ABOUT YOUR MEDICATIONS and to get accustomed to new and necessary routines. This may include learning how to check your blood sugar, inject insulin and/or take your blood pressure. The nurses will instruct you on your medications as you begin to administer them.

As your condition improves, you will be transferred to a private room on the thoracic surgery floor. There is an adjustment period going from the ICU, where your nurse is always in your room, to the floor, where your nurse has other patients to care for as well as you.

The length of your hospital stay can never be predicted, because it varies from individual to individual. The average stay is around seven to 10 days after your surgery.

If you live more than 50 miles from the medical center, you should plan to temporarily relocate closer to the hospital for at least six to eight weeks. This will allow for close care and observation, which can only be met through frequent visits.

There is also an adjustment period going from the hospital to your own home. While most people look forward to leaving the hospital, the actual discharge may be met with mixed emotions. You may feel overwhelmed by the medication schedules, blood pressure monitoring, etc. However, remember that you will be in close contact with the transplant team.

You will be seen at the clinic weekly at minimum, and you can call your transplant coordinator at any time if questions or problems arise. You can also write down questions and bring them to your visits to go over with your coordinator. He/she will spend as much time with you as necessary to go over any and all concerns.

Each person recovers from surgery at a different pace. It is normal to have good days, as well as some that are not so good. Your body is going through many adjustments as you recover from the surgery. For some patients, they may have forgotten how to be healthy, and this re-adjustment may be difficult.

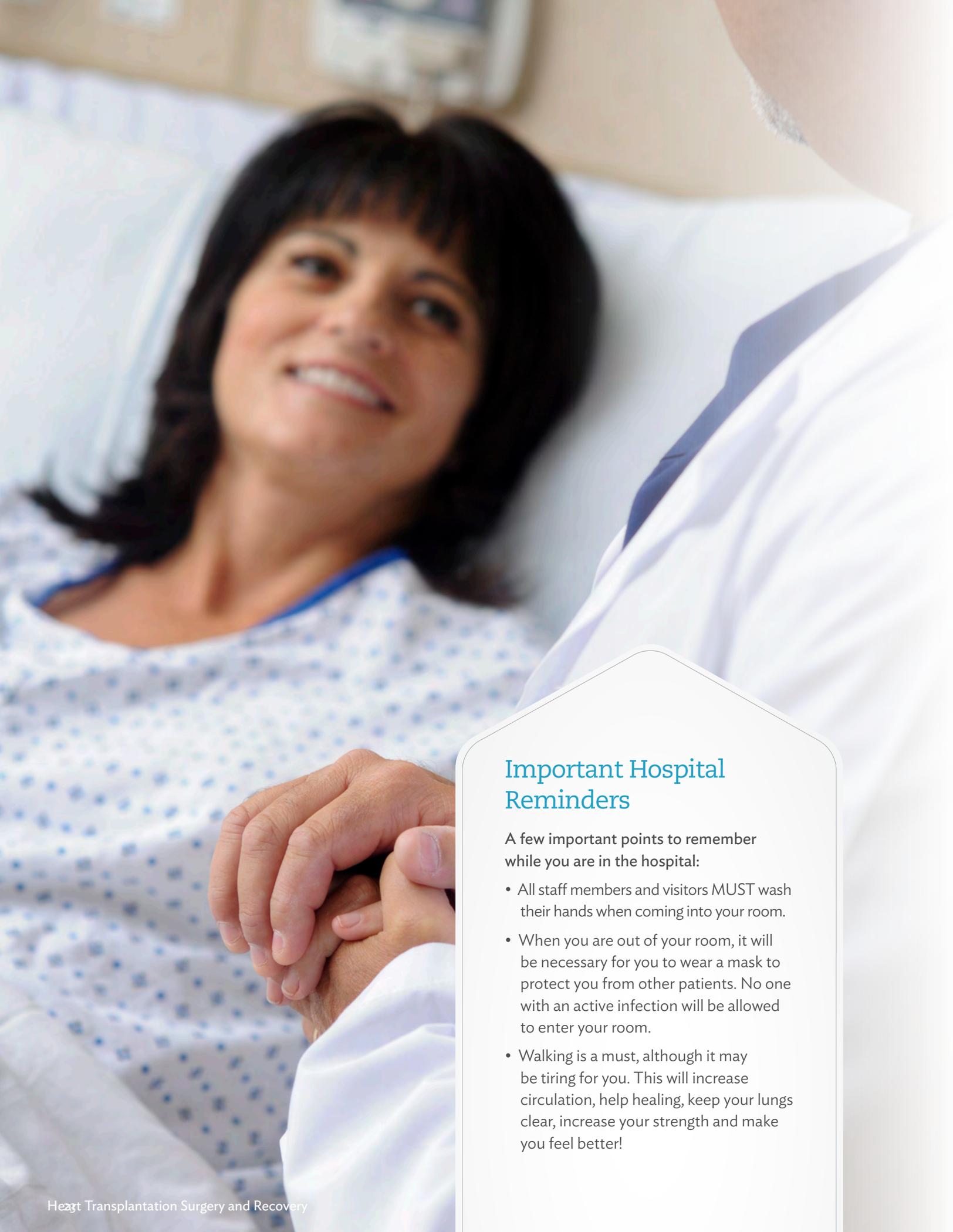


Post-transplant Clinic Follow-ups

All transplant recipients will need regular follow-up care; a schedule will be provided before discharge. It will include instructions needed for clinic visits, lab work, X-rays and biopsies.

Family members may feel very tired by the time you leave the hospital. It is important for your caregivers to take care of themselves, get plenty of sleep and eat healthy. Your family members may have their own fears about you leaving the hospital. It can be overwhelming to learn all the medications and routines. However, this is normal, and your transplant team is here to help you every step of the way.

At this time, you will be learning what life is like after transplant. It is a time of change and adjustment, which for some may take several months. As you did before your transplant, you may have roles shift within your family. You will find yourself doing things that you may have been too sick to do before your transplant. It is very important to keep an open line of communication with your family and friends and to talk about it. Discussing issues that arise with the transplant social worker or within your support group meetings may also be helpful.



Important Hospital Reminders

A few important points to remember while you are in the hospital:

- All staff members and visitors **MUST** wash their hands when coming into your room.
- When you are out of your room, it will be necessary for you to wear a mask to protect you from other patients. No one with an active infection will be allowed to enter your room.
- Walking is a must, although it may be tiring for you. This will increase circulation, help healing, keep your lungs clear, increase your strength and make you feel better!

Potential Complications

Possibility of Rejection or Infection

It is possible that you can undergo a transplant and not have any complications; however, it is more realistic that you will experience at least one. This is not a cause for panic, but it is important to understand the possible complications that you may encounter. The transplant team will be monitoring you closely during this time and looking for signs that might lead to these problems. It is best to identify and treat changes in your condition before they become serious complications that result in hospitalization. These complications and medications will be discussed in detail in the next section of this journal.

Rejection

Your body's immune system has the unique ability to differentiate between its own tissue and from tissue which is foreign to it. Under normal circumstances, this ability works to your advantage. For example, when you develop an infection from an organism such as bacteria or virus, your body's immune system recognizes the infectious organism as foreign and immediately goes to work to fight and destroy it.

When you undergo a heart transplant, your immune system sends special messenger cells to your new heart to try to identify them. These cells alert your immune system that your new heart is foreign, or "nonself." This process is called rejection. It is normal for your body to want to reject your new heart. If rejection is not treated, it could cause permanent damage to your new heart. Therefore, the rejection process must be stopped.

Anti-rejection Medication

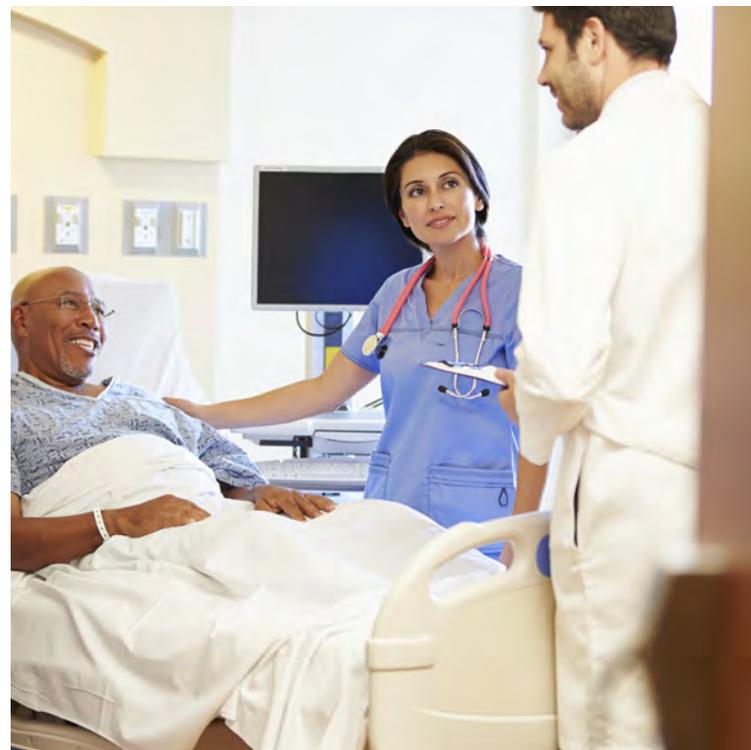
To prevent rejection from happening, your immune system must be controlled or suppressed. Anti-rejection medications work to do just that. You will be taking a minimum of three different immunosuppressive drugs; each has a distinct action on the body's immune system, and each work together to prevent rejection. These drugs are powerful, and they work well. Unfortunately, they also have several side effects.

These side effects include, but are not limited to:

- Diabetes
- Hypertension
- Infection
- Kidney dysfunction
- Osteoporosis (bone loss)
- Weight gain

These side effects can sometimes be more difficult to manage than the rejection itself. No matter what the side effects are, these anti-rejection drugs cannot be stopped without the supervision of the transplant team; this can lead to organ failure.

Despite these medications, rejection can still occur. In fact, it is normal to be treated for acute rejection several times during the first three to six months following the transplant surgery. You will be taught how to recognize early signs of rejection. Rejection can usually be controlled or suppressed with quick treatment. The most important way to monitor for rejection in its early stages is to do biopsies of your heart. After your heart transplant, you will have frequent biopsies, initially every week for the first four weeks. This schedule will be altered according to your progress and whenever rejection occurs.



Rejection can be classified as mild, moderate or severe. In order to prevent it from affecting the function of your heart, it is important to detect it early and to treat it immediately. This is done by making adjustments to your anti-rejection therapy. In the best of circumstances, the frequency of rejection should lessen over time as your body gradually adjusts to the transplanted organ. Unfortunately, some patients may have persistent problems with this, in which case the anti-rejection therapy may have to be altered.

Infection

Transplant recipients continually walk a fine line between rejection and infection. The rejection medications allow you to keep your new heart, but depress your immune system, thereby putting you at risk for developing infections. Because of this risk, you must be diligent in taking care of yourself after transplantation.

Early post-transplant, you should always wear a mask in crowded places to prevent the transmission of organisms. Some infections have very subtle symptoms, and a simple cold could quickly turn into a bacterial infection. You will be placed on selected antibiotics as protective therapy against certain types of infection. It is important to realize that almost all infections can be easily treated if recognized and caught early.

To help prevent and provide early treatment of these potential problems, you will have what our team calls “routine surveillance” tests or exams. Some of these can be invasive and may be inconvenient, but they are necessary to keep you in the best of health. This is a long-term process. Some of these exams include yearly dental and eye exams, a yearly echocardiogram, mammograms and gynecological exams for females, and a rectal exam with a prostate check for males.



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Going Home

Follow All Instructions

You must follow certain instructions once you are discharged from the hospital. You will be expected to weigh yourself daily, as well as check your blood pressure, pulse and temperature. You will be given a transplant teaching journal before you go home that features a log to easily record this information. This journal also has a detailed list of your medications, their use and side effects, as well as more in-depth information regarding transplant, laboratory tests, wound care and outpatient care follow-up.

To protect you from infection, you will be expected to wear a mask at all times when in our hospital for any reason. You should avoid crowded areas during the first six months and any person you suspect may be sick. Avoid construction sites or other areas where there is dust in the air. These areas harbor fungus and other types of bacteria that can colonize in your lungs and cause infection. You should also wear gloves and a mask when doing yard work, as soil also harbors fungus and bacteria.

Keep All Appointments

You must come to all of your appointments. Be aware that you may have other problems or issues that could increase the frequency of visits to our facility. Depending on your insurance, you may need authorizations for each and every visit to our hospital. Learn your insurance plan's restrictions and guidelines now, before transplantation. Our staff can assist with the medical-necessity explanations.

Remember, we are here to help you.

Please call us with any questions or concerns you may have related to your health and your newly transplanted heart.



Pet Ownership

Overall, pet ownership is not restricted; however, take the following special precautions:

- Keep pets clean and well-groomed.
- Keep pet living and eating areas clean.
- Consult your veterinarian regarding flea prevention.
- Whenever possible, avoid contact with your pet's vomit, stool, saliva or urine. In the event of an accident, wear gloves or have someone who is not at risk take care of it.
- Do not allow your pet to lick your face.
- Do not allow your pet to drink toilet water.
- Keep your pet healthy with current vaccinations and regular check-ups.
- Feed your pet only commercial pet food, not table scraps.
- Ideally, someone else should clean the litter box, bird cage and fish or reptile aquarium. Avoid contact with stray animals, animals with diarrhea, exotic animals, sick animals, wild animals or monkeys.

Discuss your particular pet care concerns with your healthcare provider.

Nutrition and Activity

Before and after transplant, you should eat a well-balanced, low-fat, low-salt diet. Your ability to perform exercise and recover from transplantation is dependent upon your nutritional state. Our team will

monitor your weight to assure that you are taking in enough calories to support this regime.

Once you begin taking immunosuppressive medications (which include prednisone, a steroid), you will have a higher risk for diabetes and hypertension. Steroids increase your appetite, causing your body to retain fluid and fat. Salt increases your body's ability to retain water. This is why the low-salt / low-fat diet is so important.

Eventually, your recovery will reach a point where monitored rehabilitation is no longer necessary. At this point, you should be able to do most of the activities you were unable to do before the transplant surgery. Our team will expect you to continue regular exercise at home, in the rehabilitation maintenance program or a local gym. Activity may include walking, swimming, biking or lifting weights.

Medical Treatment

Cardiac Rehabilitation

Cardiac rehabilitation (rehab) is one of the most important parts of your recovery following transplantation and actually starts even before the surgery. Once you are accepted into the program, our team will expect you to attend cardiac rehabilitation two to three days per week.

If you do not live in our area, we will try to assist you in locating a cardiac rehab center near your home. Once you are transplanted, our team will want you to attend our rehab program for a minimum of two to four weeks, two to three days per week. Once we feel you are able, we will return you to your own program for long-term follow-up.

Simply put, cardiac rehab consists of monitored exercise that strengthens your heart and lungs as well as the rest of your body. You will be taught how to exercise safely after having heart transplant surgery. These movements will include aerobic exercises with warm-up and cool-down periods. Our rehab personnel will monitor your EKG, blood pressure and heart rate and also measure the length of time you perform the exercise. Cardiac rehab also includes lifestyle, risk-factor and medication education. This will give you the tools you need to live a healthy and active life after heart transplant.

Immunosuppressive Therapy

From the time of transplantation, and **for the rest of your life**, you will be taking some type of medicine to suppress your immune system and protect your new heart from rejection. Generally speaking, these medicines start at high doses at the beginning, but are then tapered down slowly over the first year to low maintenance doses. There are several important issues regarding these drugs of which you must be aware:

- Without the supervision of the transplant team, you cannot stop taking these medicines, or miss any doses, even if you have side effects.
- While on these drugs, you will have a higher risk of infections and certain cancers.
- These medicines are a very important part of your transplant care; you must know your doses, when they are due and the common side effects.

Our team cannot stress enough the importance of this therapy to all transplant recipients.

Management Medication

After transplantation, you will need to take medication to manage your heart health, again, **for the rest of your life**. The cost of transplant medication is very high.

Without medical insurance, the average cost can run between \$2,000 and \$3,000 per month. Most health plans will cover the cost of medicine for a certain amount of time. You should also be aware of out-of-pocket expenses with which you may be faced, including co-payments per drug, the number of medication refills allowed per month and payment for drugs that are not available in generic form. Therefore, established financial resources are very important.

You need to establish an idea of out-of-pocket expenses and make plans for a lifelong commitment to paying for these medications. Your transplant social worker and coordinator can further provide you with additional information and resources and answer any questions you may have.



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About Us

Florida Hospital Transplant Institute

Founded in 1973, the Florida Hospital Transplant Institute has performed more than 4,000 transplants, making us one of the busiest transplant centers in the nation. Our survival rates are among the highest in the country, making us one of the most highly sought, multi-organ transplant programs in the United States. We were the first hospital in Central Florida to successfully perform a heart transplant. Today we offer a wide range of transplant options including heart, kidney, liver, bone marrow and pancreas. We are also home to a comprehensive living donor program.



FLORIDA HOSPITAL IS RECOGNIZED BY U.S. NEWS & WORLD REPORT AS ONE OF AMERICA'S BEST HOSPITALS

A national leader in heart and vascular care, Florida Hospital is giving renewed hope with new, less invasive techniques and Central Florida's first heart transplant program.

You may already know that Florida Hospital is a community leader in cardiology and heart surgery, but you might not know that we are also:

#1

- ... IN CARDIOLOGY VOLUME IN THE NATION
- ... IN VASCULAR SURGERY VOLUME IN THE NATION
- ... IN WOMEN'S CARDIOLOGY VOLUME IN THE NATION
- ... IN HEART TRANSPLANT VOLUME IN THE STATE*

Based on 2013 Medpar data
*Based on 2016 SRTR data



FLORIDA HOSPITAL: THEN AND NOW

Established 1908:

1 DOCTOR

20 BEDS

**LESS
THAN 10**
EMPLOYEES

SERVING
**LOCAL
ORLANDO**
RESIDENTS

Today:

**MORE THAN
9,000**
PHYSICIANS
with privileges

**MORE THAN
4,800**
BEDS

**MORE THAN
36,000**
EMPLOYEES

SERVING PATIENTS
AROUND THE
WORLD

Florida Hospital is Recognized
by *U.S. News & World Report* as
one of America's best hospitals.



Transplant Team Members

The heart transplant team is a group of surgeons, cardiologists, nurses, social workers, pharmacists, dietitians and other personnel who are experts in the field of heart failure and heart transplantation. Florida Hospital's heart transplant team is dedicated to a coordinated and multidisciplinary approach for the care of patients.

Members of the transplant team will be involved in your care during the pre-transplant period, the listing or waiting period, the surgery and hospitalization, and for the management of your care after you are discharged.

Important Contact Information

Phone Numbers

Florida Hospital Transplant Institute Office
(407) 303-2474

Florida Hospital Transplant Institute FAX
(407) 303-0678

After-hours and Emergency Calls
(407) 303-2474

Florida Hospital Admitting
(407) 303-6996

Florida Hospital Cardiovascular Intensive Care Unit (CV ICU)
(407) 303-1543

Florida Hospital Emergency Department
(407) 303-1940

Circle of Friends
(407) 898-0034

Comfort Suites Downtown Orlando (on Orange Avenue, across from Florida Hospital)
(407) 228-4007

Office Hours

Monday through Friday, 8:00 am to 4:00 pm
Closed Weekends and Holidays

Florida Hospital Cardiovascular ICU Visiting Hours

Post transplant you will be in Cardiovascular Intensive Care Unit (CVICU). This unit has strict visiting hours.

Two visitors allowed at a time; immediate family only. Children under 12 years of age are not permitted in the Cardiovascular ICU.

Please wash your hands before entering and when leaving the patient's room. If you suspect possible illness, please see the nurse immediately.



Calling the Office

Non-urgent Calls

Call during the normal business hours of 8:30 am to 4:00 pm.

Call the clinic if

- You have questions about clinic schedules, appointments, medications, lab work or tests.
- Your primary care doctor starts you on a new medication, call prior to starting the medication to make sure it does not interfere with your anti-rejection medications.
- Your primary care doctor performs tests, ask him/her to FAX the results to the Transplant Office at (407) 303-0678.
- You need to change your clinic or test appointment.
- You are travelling and have questions.
- You need prescription refills or records.
- You are having dental work done.
- Your financial situation changes, your insurance changes or you have a problem obtaining your medications.



Prescription Refills

Call at least four to five days in advance so you do not run out of your medication. You may need to have a prior authorization for medications, which can take a few days. Medication refills should be called in on Tuesdays during office hours. Do not wait until late on Friday to request prescription refills.

Communication with the transplant team is key

- Remember, if prescribed antibiotics, take all that are given.
- Do not stop taking your medications without instructions from the transplant team.
- Do not take any new medication without clearance from your coordinator. There are many drug interactions which may alter your anti-rejection drugs' ability to work. This includes over-the-counter medicine as well.

Urgent or Sick Calls

All urgent and sick calls should be directed to Florida Hospital Transplant Institute at (407) 303-2474.

Examples of urgent or sick calls that should be directed to the Transplant Institute:

- Fever of more than 100.5 degrees Fahrenheit
- Shortness of breath
- Cough (persistent or productive with colored sputum)
- Changes in urination (frequency, burning, pain, blood)
- Nausea, vomiting or diarrhea lasting more than 24 hours
- New or persistent fatigue, or change in exercise ability
- If you are unable to take your anti-rejection medications due to nausea, vomiting or diarrhea



- Chills or “hot flashes”, swollen glands, sore throat, head colds with drainage or pain, headache, changes in vision
- Exposure to mumps, measles, chickenpox or shingles
- Redness, pain, swelling, odor, discharge from your surgical incision or drain site
- Skin rashes or lesions
- Bleeding or black stools
- Vaginal discharge or itching
- Irregular heartbeat; lightheadedness; dizziness; new or increased swelling in the hands, feet/legs or abdomen

After-hours and Emergency Calls

For after-hours calls, including weekends and holidays, contact the Florida Hospital Transplant Institute office at (407) 303-2474. The answering service will page the transplant physician or transplant coordinator on call.

All after-hours calls will be returned within one hour.

If it is an EMERGENCY, call 9-1-1 or go to your closest, local Emergency Room (ER).

- Tell the ED staff that you have had a heart transplant.
- IT is recommended that you bring all your medications with you.
- VAD patients are advised to bring all their equipment when coming to the hospital.
- Call the Transplant Institute for the transplant doctor or coordinator on call, and let them know you are at the ED.

Directions and Parking Instructions

Location

The Florida Hospital Transplant Institute is located at 2415 North Orange Avenue, Suite 700 | Orlando, FL 32804

Driving Directions

Just north of downtown Orlando in Florida Hospital Health Village, Florida Hospital Transplant Institute is housed in the new Medical Office Building at the intersection of Rollins Street and Orange Avenue. The closest parking is available in the McRae Avenue Parking Garage (as well as many surrounding garages). A crosswalk is located on the third floor of the McRae parking garage which leads directly to the Medical Office Building.

Parking

Self-parking and valet services are available to all patients and visitors of Florida Hospital Orlando.

Valet Services

Florida Medical Plaza (South and North Entrance) Valet Services are offered Monday through Friday from 7:00 am to 6:00 pm.

Valet Fees

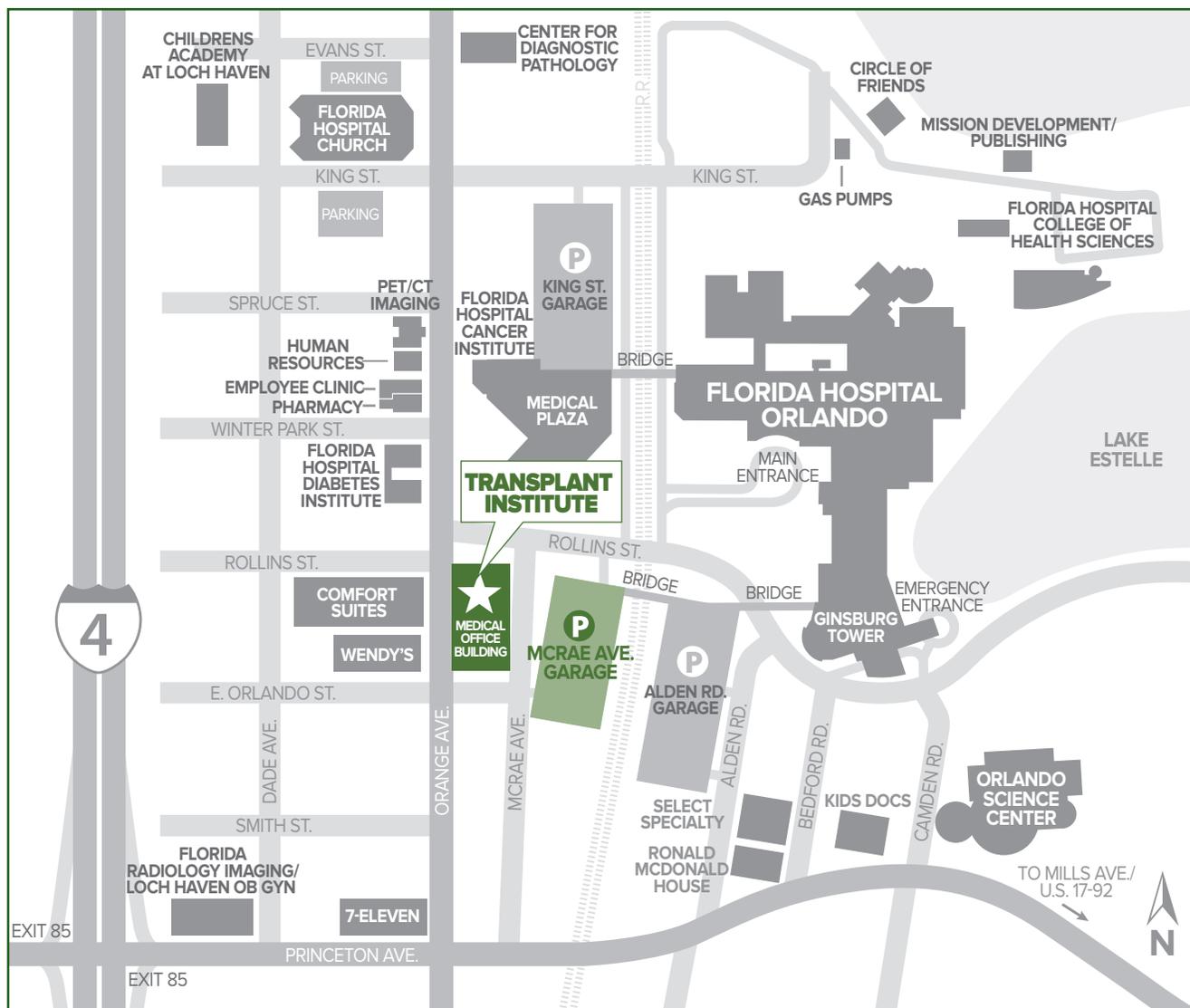
The charge for Valet Services is \$5 per day. Those who would like leave the hospital and return on the same day may do so for a re-park fee of \$1, providing they save their valet ticket. Handicap visitors with state-issued handicapped tab may valet park for \$2 per day. Emergency patients may use Valet Services free of charge at the Emergency entrance.

Self Parking

King Street Parking Garage

Open seven days a week, 24 hours a day

The King Street Garage is located next to the Medical Plaza. (Take Rollins Street toward Orange Avenue. Across the railroad tracks, turn right onto Sanitarium Road, then left onto King Street and the entrance will be on your left.) Once parked, take the elevators to the third floor and go across the walkway toward the Medical Office Building.



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44 Online Resources

44 Suggested Reading



Helpful Resources

In addition to this guidebook, there are several helpful resources for patients and family members preparing for or recovering from heart transplantation surgery. From your local book or grocery store to the internet, the assistance is both accessible and invaluable.

Support Organizations

United Network for Organ Sharing (UNOS)
(888) 894-6361

UNOS provides a toll-free patient services line to help transplant candidates, recipients and family members understand organ allocation practices and transplantation data. They are also available to discuss a problem you might experience with

your transplant institute that appears to have no resolution. Call the toll-free number or visit UNOS.org.

National Transplant Assistance Fund (NTAF)
(800) 642-8399

The NTAF works with families and volunteers throughout the United States to establish successful grassroots fundraising campaigns in honor of individuals facing transplantation. As a transplant patient, NTAF can help you raise funds in your community to pay for uninsured medical expenses related to your care. Call the toll-free number or visit NTAFund.org.

Online Resources

Looking for more information related to transplant or chat rooms to link up with others like you who are waiting for or have undergone transplant? **Check out the following websites:**

American Society of Transplantation
MyAST.org

Center for Disease Control
CDC.gov

Coalition on Donation
ShareYourLife.org

Medicare
Medicare.gov

National Council on Aging - Medicare Benefits
BenefitsCheckup.org

National Transplant Assistance Fund (NTAF)
NTAFund.org

**Pharmaceutical Research and
Manufacturers of America**
Phrma.org

**Transplant Buddies (English and Spanish
Links)**
TransplantBuddies.com

Transplant Foundation, Inc.
TransplantFoundation.org

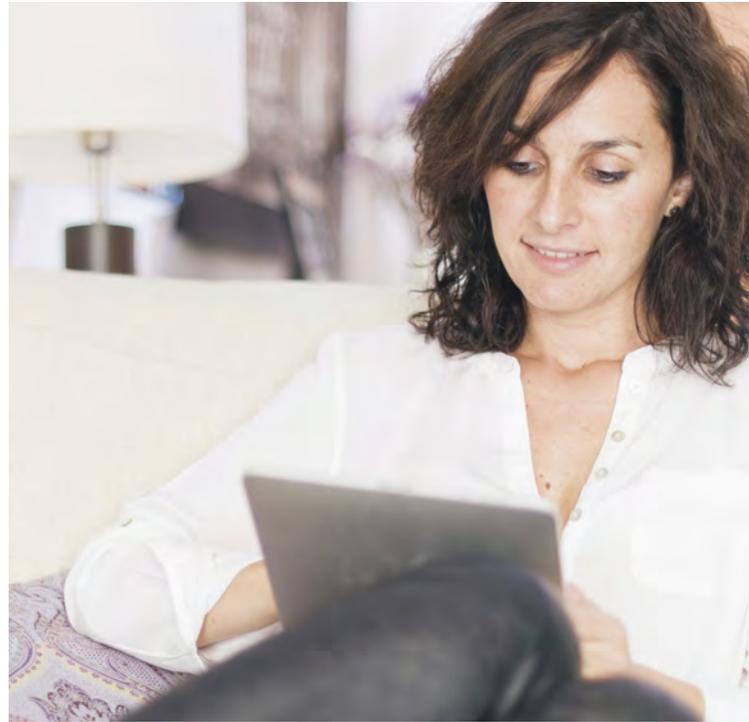
**Transplant Recipients International
Organization (TRIO)**
TRIOWeb.org

Transweb - Charity Benefits
Transweb.com

United Network for Organ Sharing
UNOS.org

United States House of Representatives
House.gov

United States Senate
Senate.gov



Suggested Readings

***How we Choose to be Happy
The 9 Choices of Extremely Happy People,
Their Secrets, Their Stories***

1999; by Rick Foster and Greg Hicks;
G.P. Putnam's Sons
ChooseToBeHappy.com

What Every Patient Needs to Know
A UNOS Publication

***Heart Family Handbook
A Complete Guide for the Entire Family of
Anyone with Any Heart Condition
to Make it the Speediest, Most Complete
Recovery Possible***

1990; by Jane Schoenberg and JoAnn Stichman;
Hanley & Belfus, Inc.

***Taking Heart
The Inspiring Medical and Personal History of a
Heart Transplant Operation***

1990; by A.C. Greene; Simon & Schuster

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Post-transplant Patient Care Reference Materials

A Compass for Keeping Track of Your Care

Use this journal as a quick reference guide for the post-transplant journey.

Throughout the transplantation process, you will receive a lot of information and instruction from a variety of team members. Though it can be overwhelming at times, we have provided resources to help you better track and navigate your journey.

As an active participant in your own care, it is vital to fully understand what is required and expected. This journal serves as your personal guide and health diary toward the best recovery possible. Within the pages of this section, you will find invaluable references and resources.

Your Care Providers

Doctor and Pharmacy Information

Pharmacy

Name: _____

Address: _____

Phone Number: _____ FAX Number: _____

Primary Cardiologist

Name: _____

Address: _____

Phone Number: _____ FAX Number: _____

Email: _____

Primary Care Physician

Name: _____

Address: _____

Phone Number: _____ FAX Number: _____

Your Doctor Appointments

Clinic Appointments and Instructions

The following journal pages are for you to enter your important transplant information, including post-transplant clinic appointments. You may need to be seen more often in the clinic if you are having problems or issues, such as rejection or an infection episode. This schedule will help you plan other activities around your clinic visits and tests.

Recording Your Vital Signs

- Measure your blood pressure and pulse each morning.
- Notify your transplant coordinator if your blood pressure is:
 - Systolic (top number) is more than **145** or less than **90**
 - Diastolic (bottom number) is more than **95** or less than **70**
 - Pulse is more than **120** or less than **80**
- Record your weight each morning at the same time. Watch for signs of fluid retention: swelling hands, feet or ankles and/or shortness of breath.



- Record your temperature each day. Call the transplant coordinator if your temperature is more than 100.5 degrees Fahrenheit.
- Record your exercise activities and amount of time spent exercising in your journal. Remember to properly warm up and cool down after exercising.

Instructions for Clinic Days

Do not take your medications the morning you have your labs drawn; bring them with you to take with breakfast after your lab work is completed.

- The clinic is located in the Health Village Medical Office Building, 2415 North Orange Avenue, Suite 700, on the seventh floor.
- Arrive at the lab between 7:00 and 8:00 am on the days you will have your labs drawn.
- If you are scheduled for lab tests the same day as your clinic appointment, bring your medications with you so you can take them with food after your blood is drawn.
- Biopsies after transplant will be scheduled for you and be done at Florida Hospital's main campus.
- Do not eat or drink anything after midnight the night before your scheduled biopsy. You may take only your blood pressure medications with a sip of water.
- Write any questions you have on your notes page.
- Bring this journal with you to all of your clinic appointments for your doctor to review.
- If you need to change an upcoming appointment, contact the Transplant Office by calling (407) 303-2474.

Always keep your current medication listing updated!

Blood Sugar Monitoring and Log

Transplant recipients are at increased risk of developing diabetes.

Facts

- Normal fasting blood sugar is less than 100 mg/dL.
- Impaired fasting blood sugar is 100 to 125 mg/dL or low blood sugar below 70.
- Diabetes may be diagnosed if a fasting sugar is 126 or greater or a random blood sugar reading of 200 or greater, or a Hemoglobin A1c greater than 6.5 percent.

Risk Factors

- Older than 45
- Have a family history of diabetes
- Overweight
- On anti-rejection medications
- Are being treated for rejection with increased doses of oral or IV steroids
- Are sick or have infections

Tips

- Monitor your blood sugars if you have diabetes or high blood sugar.
- Monitor more frequently if you are being treated for infection or rejection.
- Monitor at least twice a day (or as instructed) at different times to get a 24-hour “picture” of your readings. This will help the doctor manage your medication doses.
- Call your transplant coordinator if your blood sugars are more than 150 mg/dL.

Know the Signs of Low Blood Sugar

- Shaky, weak, sweaty, slow to answer, hungry, confused

Treatment for Low Blood Sugar

- Four ounces (half a cup) of juice or regular soda
- Two tablespoons of raisins, four or five saltine crackers, four teaspoons of sugar
- One tablespoon of honey or corn syrup
- Recheck to make sure your blood sugar level improves

Blood Sugar Monitoring

Date	Before Breakfast	Two Hours After Breakfast	Before Lunch	Two Hours After Lunch	Before Dinner	Two Hours After Dinner	Before Bedtime Snack	Comments
1								
2								
3								
4								
5								
6								
7								
8								
9								
10								
11								
12								
13								
14								
15								
16								
17								
18								
19								
20								
21								
22								
23								
24								
25								
26								
27								
28								
29								
30								
31								

Post Transplant Follow up

	1W	2W	3W	4W	5W	6W	7W	8W	9W	10W	11W	3M	14W	4M	18W	5M	22W	6M	7M	8M	9M	10M	11M	1YR				
DATE																												
Clinic Visit		X	X	X		X		X		X		X		X		X		X		X		X		X				
Labs	X	X	X	X		X		X		X		X		X		X		X		X		X		X				
Lipid Panel		X		X								X									X			X				
BIOPSY	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X				
ALLOMAP									X		X		X		X		X		X		X		X					
Echo	Lim	Lim	Lim	Com		Lim	Lim	Lim				Lim	Lim	Lim	X	Lim		Com		Lim	Com	Lim		Com				
Decrease Pred									17.5MG			15.0MG		12.5MG				7.5MG		5.0MG		2.5MG		OFF				
PHS Labs				X								X												X				
DSA				X								X						X										
Cardiac Rehab					X																			X				
CXR																								X				
Dexa Scan																								X				
Angiogram/ RHC																								X				
Dermatology																								X				
Ophthalmologist																								X				
Dentist																		X						X				
Mammogram																								X				
Pap Smear																								X				
PSA																								X				
Colonoscopy																												
Patient Name:																							DOB:			DOI:		

Post Transplant-2nd year

	13M	14M	15M	16M	17M	18M	19M	20M	21M	22M	23M	24M
DATE												
Clinic Visit			X			X			X			X
Labs			X			X			X			X
Lipid Panel						X						X
BIOPSY			X			X			X			X
ALLOMAP		X		X				X		X		
Echo												
Angiogram/RHC												X
CXR												
Dexa Scan												
Colonoscopy												
Dermatology												
Ophthalmologist												
Mammogram												
Dentist												X
Pap Smear												
PSA												
Mammogram												
Pap Smear												
PSA												
Colonoscopy												

Patient Name: _____ DOB: _____ DOI: _____



Medications

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Cyclosporine (Sandimmune, Neoral, Gengraf)

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

Dapsone and Atovaquone (Mepron)

Ganciclovir (Cytovene) and Valganciclovir (Valcyte)

Acyclovir (Zovirax), Valacyclovir (Valtrex)

Antifungal Medications

Gastrointestinal (GI) Agents, Antacids and Acid Inhibitors

Over-the-Counter (OTC) Medications

Medication Information

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

The brand name and generic name of all my medications.

Medications usually have two names. The brand name is the name given to the medication by the pharmaceutical company that produces it. The generic name is the common name of that medication.

The purpose or reason for taking my medications.

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

What each medication looks like.

You must be able to recognize each tablet or capsule by color, shape, and size. Many medications have a similar appearance with only slight differences. Look closely at your medications to be sure that you are taking the correct tablet or capsule.

When to take each medication.

It is important to know what time you need to take each medication. Your anti-rejection medications must be taken on time every day. This is because a certain level of that medication must be maintained in your bloodstream to help prevent rejection.

How to take each medication.

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

How long each medication will be taken.

Some medications can be discontinued after a complication or side effect has resolved. Be sure to know how long you are to take each of your medications. Others, like your anti-rejection medications, must be taken for your lifetime.

The most common side effects of each medication.

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

Any special instructions for taking the medications.

Some medications must be taken with food or on an empty stomach. Others must be taken a certain number of hours apart from other medications. Discuss any special instructions for your medications with your transplant team.

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

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

Medication Guidelines

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

Call your transplant coordinator if you are unable to take your medicines because you:

- are nauseated, feeling sick, or vomiting
- have diarrhea and are worried that your medication is not being absorbed
- have forgotten to take your medications or missed any doses
- notice that the directions on the label of the medication container are different from what you were told to take
- feel you are having an unusual reaction or side effect to a medication
- would like to take an over-the-counter cold remedy, cough suppressant, acetaminophen (Tylenol), diet aid, herbal medicine, or medication that you have not previously discussed with your doctor. This includes any new medications or changes made by another doctor including your family physician.

Organize a medication schedule that fits well with your daily routine.

- Work with your transplant coordinator, nurse, or pharmacist to arrange a schedule that fits into your daily routine. A convenient schedule will improve your success for taking all your medications at the right time every day.
- Some people find it helpful to follow a written schedule or a check-off list.
- Pill reminder containers and medication alarms may also be helpful. Pill containers can be stocked with a week's supply of medications. Medication alarms can be set to remind you to take your medications on time.
- Always keep a copy of your medication schedule with you. If you are being seen in the transplant clinic, your doctor's office, or in an emergency room, it will help to have a current list of your medications.

Storing your medications:

- Keep medications in the original container with the caps closed. If you use a pill reminder container, keep the container sealed. It is important that you can recognize different medications when they are together in a pill container in case a dose has changed.
- If you have trouble removing child-resistant caps, ask your pharmacist to use regular medication container caps.
- Store your medications in a cool, dry place away from direct sunlight. Do not store medications in the kitchen or bathroom because moisture and heat may interfere with the effectiveness of some medications.
- Do not allow liquid medications to freeze.
- Do not store medications in a refrigerator unless instructed to do so by your pharmacist.
- Keep all medications in a safe place, out of reach of children and pets.
- It may be helpful to keep a few doses of your medications in another place, aside from your household. Sometimes transplant recipients will store extra doses of anti-rejection medications at a family member's house, in their office, or with the school nurse in case of an emergency.
- It is helpful to bring your medications, filled medication container and/or medication list with you for clinic visits or if you are admitted to the hospital. This will insure that you will not miss any doses.

Medications to Treat or Prevent Rejection

Tacrolimus (Prograf)

Purpose:

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

Dosage:

Tacrolimus is available in 0.5 mg, 1 mg, and 5 mg capsules. Patients are usually asked to take a dose in the morning and in the evening, about 12 hours apart. You can take your doses at 8 AM and 8 PM, for example. It is important to take tacrolimus at the same time every day to maintain a steady level of immunosuppression so that the heart is protected from rejection. Most transplant centers advise that patients not be more than one hour early or one hour late in taking their doses of tacrolimus.

Side effects:

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

- Headaches
- Numbness or tingling in hands, feet, or lips
- Nausea & Vomiting
- Insomnia
- Itchy Skin
- High Blood Sugar

Additional information:

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

- On days when you are having blood work, be sure to have your labs drawn before taking tacrolimus so that an accurate trough level is obtained. Bring a dose with you to take after your labs have been drawn so you will not be late taking your dose.
- Your dose of tacrolimus may be increased if you are experiencing rejection. The dose may be decreased if you have an infection or if you have complaints or complications due to side effects of the medication.
- Take your tacrolimus dose in the same way and at the same time every day to maintain a stable level.
- You should not eat grapefruit or drink grapefruit juice while taking tacrolimus. A chemical in grapefruit can interfere with the enzymes that break down tacrolimus. Grapefruit, grapefruit juice, or the herbal products of grapefruit will increase tacrolimus levels.
- Some medications should not be taken at the same time as tacrolimus:
 - o Two hours after taking tacrolimus you may take: sucralfate (Carafate®), Mylanta®, Tums®, magnesium oxide, magnesium gluconate (Magonate®)
 - o Two to four hours after taking tacrolimus you may take: sodium bicarbonate (Bicitra®, Polycitra®)
- Tacrolimus interacts with some medications; causing higher or lower levels. Always check with your transplant coordinator before starting any new medication to be sure that it does not interfere with tacrolimus.
- If you miss a dose of tacrolimus, take it as soon as you remember. If it is near the time for the next dose, skip the missed dose and resume your regular schedule. Call your transplant coordinator if you have missed a dose because your levels may need to be monitored more frequently.
- Store tacrolimus capsules at room temperature and away from the reach of children and pets.

Cyclosporine (Sandimmune, Neoral, Gengraf)

Purpose:

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

Dosage:

Cyclosporine is available in two products (formulations), but these products are not the same. They are cyclosporine (Sandimmune®) and cyclosporine-modified (Neoral® and Gengraf™). Be sure that your pharmacist always gives you the brand of cyclosporine that your doctor has prescribed. Both types of cyclosporine are available as capsules.

Cyclosporine is prescribed to be taken once a day or twice a day. It should be taken at the same time each day to insure a steady level of immunosuppression.

Side effects:

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

The most common side effects are:

- Hand Tremors
- Insomnia
- Numbness or tingling in hands, feet, or lips
- Nausea & Vomiting
- High Blood Pressure
- High Cholesterol
- Bleeding or tenderness of the gums

Additional information:

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

- On days when you are having blood work, be sure to have your labs drawn before taking cyclosporine so that the trough level is accurate. Bring a dose with you to take after your labs have been drawn so you will not be late taking that dose.
- Your dose of cyclosporine may be increased during an episode of rejection or to prevent rejection if your level is low.
- The dose may be decreased if you have an infection or if you have complications due to side effects of the medication.
- Take your cyclosporine in the same way and at the same time every day to maintain a steady level.
- You should not eat grapefruit or drink grapefruit juice while taking cyclosporine. A chemical in grapefruit can interfere with the enzymes that break down cyclosporine. Grapefruit, grapefruit juice, or the herbal product of grapefruit will increase cyclosporine levels.
- Some medications should not be taken at the same time as cyclosporine.
- Two hours from cyclosporine: sucralfate (Carafate®), Mylanta®, Tums®, magnesium oxide, magnesium gluconate (Magonate®)
- Two to four hours from cyclosporine: sodium bicarbonate (Bicitra®, Polycitra®)
- Cyclosporine interacts with some medications, causing higher or lower levels. Always check with your transplant coordinator before starting any new medication to be sure that it does not interfere with cyclosporine.
- If you miss a dose of cyclosporine, take it as soon as you remember. If it is near the time for the next dose, skip the missed dose and resume your regular dosing schedule. Call your transplant coordinator if you have missed a dose.
- Cyclosporine capsules should be stored at room temperature and away from direct sunlight.
- Cyclosporine capsules are packaged in individual blister packs. Do not open the blister pack until you are ready to take the medication because air and light will damage the medication

Prednisone (Deltasone) or Prednisolone (Orapred)

Purpose:

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

Dosage:

Prednisone is available in several strengths including 1 mg, 2.5 mg, 5 mg, 10 mg, and 20 mg tablets. Prednisone is usually prescribed once daily and should be taken in the morning.

Side effects:

Prednisone may cause many side effects, but these vary depending on the dose, frequency, and duration of your treatment. The most common side effects include:

- Higher risk for infection
- Swelling of the face, hands or ankles caused by fluid retention
- Weight gain due to increased appetite or fluid retention
- Cataracts (decrease vision clarity) and vision changes
- Skin changes (acne, skin rashes, easy bruising, stretch marks, increased sun sensitivity)
- Muscle weakness
- Mood swings
- Night sweats
- Thrush (white patches in the mouth)
- Steroid-induced diabetes
- Bone and joint changes

Additional information:

- Be sure that you know your correct dose of prednisone and that you have the correct strength of tablets.
- Do not change the dose of prednisone or take it more or less often than prescribed.
- If prescribed once a day, prednisone should be taken in the morning so you do not have trouble sleeping.

- Prednisone should be taken with food because this medication can cause stomach upset.
- If you miss a dose of prednisone, take it as soon as you remember. If it is near the time for the next dose, skip the missed dose and resume your regular dosing schedule. Call your transplant coordinator if you have missed a dose.
- If you are taking prednisone, examine your skin routinely for bruising. Be sure to tell your doctor or transplant coordinator if you have any wounds that are not healing well. Take good care of your skin. This is especially important if you also have diabetes.
- Because prednisone can irritate the stomach lining, patients who take prednisone are at risk of developing stomach ulcers. Stomach ulcers are irritations of the lining of the stomach that can cause an upset stomach or abdominal pain. Because of this risk, you will be prescribed an antacid to protect your stomach from these complications. Occasionally, ulcers can become more serious and cause bleeding. Bleeding in your stomach and GI tract can cause your stools to look black and tarry and can cause your vomit to look like coffee grounds. Call your transplant coordinator immediately if you have any of these signs of a bleeding ulcer.

Sirolimus (Rapamune)

Purpose:

Sirolimus is used to prevent rejection in organ transplant recipients. It prevents rejection by inhibiting the cells in the immune system that cause rejection.

Dosage:

Sirolimus is available in 1 mg and 2 mg tablets.

Side effects:

The side effects of sirolimus vary and are usually related to the level of the drug. The most common side effects are:

- Joint Pain
- Decrease in red blood cells
- Diarrhea
- Rash or acne
- High Blood Pressure
- High Cholesterol

Additional information:

- Do not change the dose of sirolimus or take it more or less often than prescribed for you by your transplant physician.
- On days when you are having blood work, be sure to have your labs drawn before taking sirolimus so that an accurate trough level can be obtained. Bring a dose with you to take after your labs have been drawn so you will not be late taking your dose.
- If you miss a dose of sirolimus, take it as soon as you remember. If it is near the time for the next dose, skip the missed dose and resume your regular dosing schedule. Call your transplant coordinator if you have missed a dose.
- Sirolimus tablets should be swallowed whole without crushing or breaking.

Azathioprine (Imuran®)

Purpose:

Azathioprine is used to help prevent or treat rejection in organ transplant recipients.

Dosage:

Azathioprine is usually prescribed once daily and should be given at about the same time each day.

Side effects:

- Decrease in white blood cell count
- Decrease in platelet count
- Nausea & Vomiting
- Rash
- Abnormal Liver Function

Additional information:

- Do not change the dose of azathioprine or give it more or less often than prescribed.
- If you miss a dose of azathioprine, take it as soon as you remember. If it is near the time for the next dose, skip the missed dose and resume your regular dosing schedule. Call your transplant coordinator if you have missed a dose.
- Azathioprine interacts with a medication called allopurinol, a drug used to treat gout. Call your transplant coordinator if you are diagnosed with gout

or if a doctor has prescribed this medication for you. Azathioprine and allopurinol cannot be taken together.

Mycophenolate mofetil (Cellcept) Mycophenolate sodium (Myfortic)

Purpose:

Mycophenolate (MMF) is used to help prevent or treat rejection in heart transplant recipients.

Dosage:

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

Side effects:

The most common side effects include:

- Diarrhea
- Decrease in white blood cell count
- Infection
- Abdominal Pain & Vomiting

Additional information:

- Do not change the dose of mycophenolate or take it more or less often than prescribed.
- Mycophenolate capsules should be swallowed whole and should not be opened. The powder inside the capsule may be harmful if inhaled. Mycophenolate tablets should not be broken or crushed.
- On days when you are having blood work, be sure to have your labs drawn before taking mycophenolate so that an accurate trough level can be obtained. Bring a dose with you to take after your labs have been drawn so you will not be late taking your dose.
- If you miss a dose of mycophenolate, take it as soon as you remember. If it is near the time for the next dose, skip the missed dose and resume your regular dosing schedule. Call your transplant coordinator if you have missed a dose.

Medications to Treat or Prevent Infection

The medications that you take to stop your body from rejecting your new heart affect your immune system. Your body's ability to fight bacterial, viral and fungal infections is decreased. As a result, you are at greater risk of getting infections. Your doctor will prescribe one or more drugs to protect you from infection or to control infection. The following section includes some of the most commonly prescribed medications to prevent or treat infection following heart transplant.

Trimethoprim/Sulfamethoxazole (TMP-SMX, Bactrim®, Septra)

Purpose:

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

Side effects:

The most common side effects include:

- Nausea & Vomiting
- Rash & itching
- Decrease in white blood cell count

Dapsone and Atovaquone (Mepron)

Purpose:

Used to prevent or treat a type of pneumonia called pneumocystis jirovecii pneumonia (PJP). Patients who have suppressed immune systems have an increased risk of getting this type of pneumonia.

Side effects:

The most common side effects include:

- Nausea & Vomiting
- Rash & itching
- Headache
- Insomnia
- Psychosis
- Peripheral neuropathy
- Hepatitis
- Cholestatic Jaundice

Ganciclovir (Cytovene) and Valganciclovir (Valcyte)

Purpose:

Ganciclovir and valganciclovir are medications used to prevent or treat certain viruses that commonly

occur in patients who have a suppressed immune system. Cytomegalovirus (CMV), herpes simplex infections (HSV), and Epstein Barr Virus (EBV) infections are usually treated with ganciclovir or valganciclovir.

Side effects:

The most common side effects include:

- Fever
- Headache
- Diarrhea
- Decreased white blood cell count
- Decreased platelet count

Acyclovir (Zovirax), Valacyclovir (Valtrex)

Purpose:

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

Side effects:

The most common side effects include:

- Headache
- Insomnia
- Nausea & Vomiting
- Muscle Aches
- Fever

Additional information:

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

ANTIFUNGAL MEDICATIONS

Nystatin (Mycostatin) and Clotrimazole (Mycelex)

Purpose:

When you are taking antirejection medications, particularly prednisone, you have a greater chance of getting a fungus infection. This infection usually develops in the mouth and throat (thrush), in the vaginal area, or on the skin.

Dosage:

An antifungal medication is prescribed to treat fungus at the site of the infection. Nystatin, a liquid antifungal medication, is used to prevent or treat a fungus infection (thrush) that appears in the mouth. The liquid should be swished in the mouth for at least 30 seconds, like mouthwash, then swallowed. There is also a lozenge form (Mycelex® troche) that should be dissolved slowly in the mouth. Vaginal creams, suppositories, and ointments are also available for fungal infections that develop in the vagina or on the skin.

Side effects:

Side effects are uncommon, but may include:

- Nausea & Vomiting
- Abnormal Liver Function

Additional information:

- Nystatin oral solution should be swished and held in the mouth for as long as possible (at least 30 seconds) before swallowing.
- The clotrimazole lozenge should be dissolved slowly in the mouth.
- Patients should not eat or drink for about 15 to 20 minutes after taking nystatin oral solution or the clotrimazole lozenge so that the medication can be absorbed into the tissue of the mouth and esophagus.

GASTROINTESTINAL (GI) AGENTS, ANTACIDS AND ACID INHIBITORS

Sucralfate (Carafate) Antacids: Mylanta, Tums, Maalox

H2-BLOCKERS:

Famotidine (Pepcid) Ranitidine (Zantac)

Proton-Pump Inhibitors (PPis)

Omeprazole (Prilosec), Lansoprazole (Prevacid), Pantoprazole (Protonix)

Purpose:

Following transplantation, patients are at risk for developing stomach irritation and ulcers. This can be caused by steroids and also stress which may increase the amount of acid in your stomach. You may be prescribed one or two GI agents and/or antacids after transplant. Sucralfate works by coating existing ulcers and the lining of the stomach. This coating protects the tissue from irritation by stomach acid. Acid blockers (H2 blockers and PPis) work by blocking the mechanism that produces acid so you have a decreased amount of acid in your stomach.

Dosage:

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

Side effects:

Most patients are able to take these medications without any problems.

Additional information:

- Antacids may increase or decrease the absorption of many medications. Antacids (Carafate, Mylanta, Tums, Maalox) should be taken two hours away from other medications, particularly tacrolimus, cyclosporine, and sirolimus.
- Antacids should be taken on an empty stomach so that the stomach is coated with the medication.

- Omeprazole (Prilosec) and lansoprazole (Prevacid) capsules should be swallowed whole and not chewed. The capsules contain time-released granules that are slowly released in the body over 12 to 24 hours.
- Esomeprazole (Nexium) capsules can be opened and the granules mixed with water before taking.
- Prevacid is also available as a tablet that dissolves in the mouth (Prevacid Solu-tab) and as granules that can be mixed with water.

OVER-THE-COUNTER (OTC) MEDICATIONS

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

Always contact your transplant center before starting any new medications.

OTCs for Headache and Muscle Aches

If you have a headache or muscle aches that do not occur with fever, take acetaminophen (Tylenol). Check with your doctor or transplant coordinator for the recommended dose of acetaminophen and the frequency of dosing.

Ibuprofen products (Motrin[®], Advil[®], Nuprin[®], Midol[®], Brufen[®], Nurofen[®]) and naproxen products

Naprosyn[®] or Aleve[®] are common OTC medications used to treat headaches, muscle aches, and joint pain. Ibuprofen and naproxen products are not recommended to be used, particularly in the first few months after transplant. These medications can affect the kidneys and the liver. They can also cause stomach ulcers and bleeding in the stomach and GI tract. Although ibuprofen or naproxen may be appropriate medications to take for pain, be sure to talk to your doctor before using these medications.

Herbal Products

Herbal products, herbal remedies, and some herbal teas should be avoided after transplant. Herbal remedies may interact with your transplant medications or affect your transplanted heart. Never take an herbal supplement without telling your physician or transplant coordinator.

