Emory Transplant Center
MAKING A DIFFERENCE IN THE LIVES OF OUR PATIENTS AND OUR COMMUNITY

Your Heart Transplant
AT EMORY UNIVERSITY HOSPITAL
A Journey for Life
# Table of Contents

2 THE MOST IMPORTANT INFORMATION YOU MAY EVER READ

3 WHY YOU MAY NEED A HEART TRANSPLANT
3 The Healthy Heart
4 The Failing Heart
4 Type of Heart Transplant
5 History of Heart Transplantation

6 YOUR TRANSPLANT EVALUATION
6 Tests
6 Meeting the Team
9 Financial Considerations

12 WAITING FOR YOUR TRANSPLANT
12 The Waiting List
12 Your Status on the List
13 Finding a Donor
13 Your Beeper
13 Air Transportation
13 Anxiety Is Normal
14 Dealing with Stress

15 GOING TO THE HOSPITAL
15 The Phone Call
15 Leaving for the Hospital
15 Arriving at the Hospital
16 The Heart Transplant Surgery
17 What Happens After Surgery
17 Deep Breathing and Coughing

18 POSSIBLE COMPLICATIONS AFTER TRANSPLANT
18 Rejection
19 Infection
19 Hypertension/High Blood Pressure
19 Post-transplant Diabetes
19 Cytomegalovirus
20 Graft Coronary Disease

21 MEDICATIONS
21 Learning About Your Medications
21 Where to Get Your Medications
22 Tips for Taking Medications
22 Frequently Used Medications

25 GOING HOME FROM THE HOSPITAL
25 Vital Signs
25 Daily Weight
26 Medic Alert Identification
26 Discharge from the Hospital
26 When to Call the Transplant Coordinator

27 GOING FOR CHECK-UPS
27 Routine Blood Tests
28 Heart Biopsy
30 Annual Exams
30 Cardiac Catheterization

32 STAYING HEALTHY
32 Your Daily Routine
32 Bathing
32 Driving
33 Exercise
34 Sexual Activity
34 Pregnancy
34 Smoking
34 Protecting Yourself from Infection
35 Returning to Work
35 Travel Tips
36 Routine Medical Care
36 Immunizations
36 Dental Exams
37 Vision Screening
37 Cancer Prevention and Early Detection
37 Dermatology
38 Colorectal Screening
38 For Women Only:
38 Pap Smears
38 Breast Self Examination
39 Mammography
39 For Men Only:
39 Testicular Exams
39 Prostate Exams
40 Nutrition and Diet

45 GLOSSARY

53 OTHER HELPFUL INFORMATION
53 Mason Guest House
53 The Mentor Program
53 JobLink
55 Helpful Resources and Web Sites for the Heart Transplant Patient

56 NOTES
The most important information you may ever read

Now that you are considering a heart transplant, your success as a transplant recipient may depend on your understanding of what to expect before, during and after your transplant. The purpose of this book is to provide you and your family with that information. Please read each section carefully. Feel free to jot down notes in the margins and ask questions about anything you do not understand or concerns you might have.

Heart transplantation is considered when conventional medication or surgery cannot improve the function of your failing heart. Transplantation offers many people the chance to survive and return to a normal, productive lifestyle.

The Emory heart transplant team seeks to thoroughly educate every candidate about transplantation. Post-transplant management can be difficult and demanding. You and your family must completely understand the benefits, risks, and limitations of transplantation before you can make an informed decision concerning this procedure.

It is important to understand that a heart transplant does not “cure” your heart disease. You can, however, look forward to a marked improvement in your energy level and the symptoms associated with your congestive heart failure. You will need daily medication and rigorous follow-up by the transplant team for the rest of your life.

The Emory heart transplant team is committed to helping you if you are committed to meet the demands and requirements of transplantation. Your attitude about surgery and recovery and your participation in your care will play a vital role in the ultimate success of your heart transplant.
Why You May Need a Heart Transplant

THE HEALTHY HEART

The heart is a very strong muscle that forcefully pumps oxygen-rich blood to all parts of the body. Located in the middle left of the chest, the adult heart is about the size of a man’s fist and has four chambers. The two upper chambers are the right and left atria. The two lower chambers are the right and the left ventricles. A muscular wall called the septum separates the heart into two sides: the right atrium and right ventricle, and the left atrium and left ventricle. Four one-way valves control the flow of blood in and out of the heart.

The primary function of your heart is to pump the oxygen-rich blood that your body needs for energy. Here’s how:

- The right side of the heart receives the blood that has been used by your body. This blood contains waste in the form of carbon dioxide as well as a small amount of oxygen. Blood comes to the right side of the heart through two large veins called the superior and inferior vena cava. The blood enters the right atrium and passes through the tricuspid valve to the right ventricle.
- The blood then passes through the pulmonary valve and pulmonary artery and enters the lungs. There, the carbon dioxide is removed from the blood, and the blood picks up oxygen that you breathe into your lungs.
- Blood that is now rich with oxygen leaves the lungs and returns to the left atrium through the pulmonary veins.
- Blood flows from the left atrium, through the mitral valve into the left ventricle. The left ventricle is a thick powerful muscle that pumps oxygen-rich blood to the body through the aorta. This delivers energy to all the cells of the body.

The heart repeats the cycle of receiving and delivering blood to the body many times a minute. This cycle is called your heart rate.

Just as your tissues need oxygen-rich blood for energy, your heart needs its own supply of blood for its energy. The coronary arteries are blood vessels that wrap around your heart and supply it with oxygenated blood.
The Failing Heart

People need heart transplants for different reasons. The two most common reasons are severe coronary artery disease and cardiomyopathy. Less common causes of heart failure include:

- valvular disease caused by abnormal valves at birth
- infection or rheumatic fever
- congenital (birth) heart defects
- viral infection
- severe high blood pressure
- diabetes
- alcohol or other drug abuse
- chemotherapy
- pregnancy (peripartum or postpartum cardiomyopathy)

Regardless of what has caused your heart function to deteriorate, the result is the same: your heart becomes weak and unable to pump enough oxygen-rich blood through the vessels of your body. Over time, fluid can build up in your lungs, abdomen or legs and feet. This is called congestive heart failure (CHF). CHF can cause you to feel weak, tired and short of breath. The increased stress on the heart muscle may cause your heart to eventually enlarge.

We try to manage CHF by correcting the cause of the heart failure, relieving the symptoms and decreasing hospitalizations. However, when medicine or surgery can no longer improve the function of your heart, you may need a heart transplant. In these situations, heart transplantation offers you the potential of living a normal, active life.

Type of Heart Transplant

Orthotopic heart transplantation is the most common type of procedure performed. In this surgery, the diseased heart is removed and replaced entirely with the new donor heart. The donor heart is sutured (stitched) to remnants of the top two chambers of the native heart that are left in place for that purpose.
HISTORY OF HEART TRANSPLANTATION

Dr. Christian Barnard performed the first successful human heart transplant in South Africa in 1967. Many transplant operations were performed over the next 10 years around the world, but unfortunately, few patients survived.

Survival rates improved in the early 1980s with the discovery of cyclosporine (a medicine developed to decrease the body’s ability to reject a new heart). Today, more than 100,000 people have had successful heart transplant surgeries to treat end-stage cardiac disease. Results continue to improve from year to year because of better medicines and treatment of infection and rejection. The main factor which limits the number of heart transplants performed each year is the small supply of donor organs.

Emory University Hospital is one of the leading heart centers in the world. Our heart transplant program began in 1985 and was the first heart transplant program in Georgia. Today, our patients’ survival rates are among the best in the country.
Your Transplant Evaluation

To decide if you will benefit from a heart transplant, both you and your family will go through an extensive evaluation. During this process you will meet many people on our staff, share your feelings and learn all about transplantation.

TESTS
The evaluation consists of meeting many different people who will perform several different tests. We will draw blood to determine your blood type and how well your organs are working. A urine test tells us if your kidneys are working well, and special breathing tests called pulmonary function tests may be done to check your lungs. We will do an echocardiogram to look at the structure of your heart and to see how well it is pumping. You may also undergo a cardiopulmonary exercise test (treadmill test) to determine how well your heart meets your body’s needs during exercise. Finally, we will perform a right heart catheterization to measure the pressures inside your heart.

MEETING THE TEAM
It is important that you meet all the members of the heart transplant team. Each brings special knowledge that will help you during all phases of the transplant process. The cardiologist will see you in clinic and order the appropriate tests for you. You will meet the transplant coordinator who will explain the transplant process. The team social worker will discuss financial and social issues, while the psychiatrist/psychiatric clinical nurse specialist will talk to you about support systems and coping skills, such as how you deal with the stress of being ill. A nutritionist will also see you.

The team will review the results of your evaluation. If the team decides that you could benefit from a heart transplant, we will ask you and your family to consider this option.

Transplant Surgeon
The transplant surgeon will perform your heart transplant surgery and will be in charge of your care immediately following your surgery. The transplant surgeon will also follow your progress after you are discharged from the hospital and may perform routine heart biopsies after transplant.
Cardiologists
Transplant cardiologists will manage your medical care before and after the transplant. They will see you at regular intervals while you are on the transplant waiting list to adjust your medications and order tests as needed. After transplant, a transplant cardiologist will see you routinely to perform biopsies, adjust your medication and monitor your progress.

Transplant Coordinators
The transplant coordinator is a registered nurse who is specially trained to care for patients before and after heart transplantation. The coordinator will help arrange your evaluation, teach you and your family about transplantation, and follow your progress if you are listed for transplant. He or she will help answer your questions and provide support to you and your family. A coordinator and physician are available 24 hours a day for urgent problems that may arise after hours.

Social Worker
A social worker is available for supportive counseling for you and your family during this challenging and stressful time. If you need information about local housing, fund-raising and other transplant resources, the transplant social worker will assist you. He or she can answer general questions about insurance coverage and help you contact the appropriate personnel regarding these questions.

Psychiatrist
A psychiatrist will meet with you to obtain a general mental health history. He or she may recommend counseling to deal with emotional needs or issues, such as alcohol, drugs or tobacco that might affect the outcome of the transplant. A psychiatrist will be available for any developing needs.

Psychiatric Clinical Nurse Specialist
The psychiatric clinical nurse specialist works with you and your family on issues such as stress, anxiety, depression and addiction. The psychiatric clinical nurse specialist will see you and your family during your initial evaluation, while you are in the hospital and as needed after you have been discharged.
**Clinical Nutritionist**
Our clinical nutritionist will see you before and after your transplant to evaluate your diet and to help you maintain a healthy weight and a healthy heart. After your transplant, it is not uncommon to have difficulty maintaining your weight and blood cholesterol levels. Eating a balanced low-fat diet is very important, but can be challenging at times. The nutritionist will be available to see you regularly after transplant to discuss these issues.

**Pharmacist**
The transplant pharmacist will begin working with you the day you transfer to the surgery floor. It is important for you to clearly understand your medications and how each affects your body. The pharmacist will explain the actions, dosages and side effects of your medications. The pharmacist will be available during each hospitalization and by phone to answer questions about your medications.

**Physical Therapist**
A physical therapist is specially trained to help you regain your strength after surgery. He or she may refer you to a cardiac rehabilitation program or provide you with a home program you can follow after transplant depending on your needs. Exercise is important for your recovery. It can reduce complications after transplant surgery, improve your endurance and help you maintain a healthy lifestyle.

**Chaplain**
Transplantation often poses many spiritual issues. A chaplain, who is on call 24 hours a day, will visit with you while you are at Emory Hospital. The chaplain can help you and your family deal with conflicting emotions and difficult spiritual questions that are often associated with transplantation.

**Staff Nurses**
Staff nurses are responsible for monitoring your day-to-day progress while you are hospitalized as well as maximizing your environment for a smooth recovery. They will teach you how to monitor your vital signs, look for signs and symptoms of infection, and care for your incision once you go home following your transplant surgery.

**Financial Coordinator**
The financial coordinator will help you understand the cost of transplantation and your insurance benefits (see next section).
FINANCIAL CONSIDERATIONS

The following information regarding the financial costs of heart transplantation will help you begin financial planning, a task that the financial coordinator will be happy to help you with. You will need to know how much your insurance will pay for the heart transplant and for medications after transplant. It is unlikely that one single source will cover these costs. Often it is necessary to draw on savings accounts, investments, federal and private assistance options and fund-raising. The financial coordinator is available to answer questions about insurance coverage and to assist you in identifying financial resources available to you.

Before your Evaluation
Before you come to Emory for your evaluation, call your insurance company’s case manager to see if your insurance covers heart transplantation. (See sample questions to ask.) Get a copy of your benefits for heart transplantation including deductible and co-payment amounts.

If you are covered by Medicare, refer to the current Medicare handbook for deductibles and co-payment amounts.

Emory Hospital’s financial coordinator for transplantation will help you consider the financial arrangements you will need to make for transplantation. Call the financial coordinator at 404-712-4601 before your evaluation if:
• you have any questions regarding your insurance
• you do not have insurance
• you do not have benefits for transplantation, or
• you are denied coverage for a transplant.

Contact the social worker for heart transplantation at 404-712-5524 if:
• you need help applying for disability
• you would like to discuss other financial assistance options.

During Your Evaluation
Most insurance companies require a review of your evaluation results to see if you meet their criteria to pay for a heart transplant. You will be asked to sign a consent form authorizing Emory to release the medical information from your evaluation to your insurance company.

If you are a candidate for a heart transplant, the heart transplant program will work with you in obtaining insurance approval from your insurance company. If your insurance carrier denies authorization of benefits, the heart transplant program will be happy to write a formal appeal for you. However, please be advised that gaining insurance approval is ultimately your responsibility.

You will meet with the social worker and the financial coordinator for heart transplantation during your evaluation to discuss financial and social issues in detail.
**Heart Transplant Costs**
The cost of a transplant varies from patient to patient based on how sick the patient is before the transplant. Here are some of the charges you can expect:

- Hospital charges relating to the heart transplant admission (the day of admission to the day of discharge) range from $63,000 to $426,500. The range is large because some patients must wait in the intensive care unit until a donor organ becomes available. The average hospital charge for transplant admission is $166,000.
- Physician charges from the date of transplant, including 90 days of follow-up care, average $35,000.
- Annual outpatient immunosuppressant medications following transplantation cost between $10,000 – $15,000/year.

**Billing**
Authorization by your insurance company for medical services provided by Emory does not guarantee full payment of all charges. You will be responsible for the following:

- All deductibles, co-payments and noncovered services as outlined in your health plan.
- Any balance between charges and what your insurance carrier pays as “usual and customary charges”. Ask your insurer for a copy of its usual and customary charges and an explanation of how it derives them.

You will receive separate billing statements with separate billing account numbers for Emory Hospital (inpatient and outpatient hospital services) and The Emory Clinic (inpatient and outpatient doctors’ fees and medical services provided in The Emory Clinic buildings). All Emory Clinic charges will be billed on one account.

However, you will have several different accounts with Emory Hospital. The first nine numbers on every hospital account will always be the same; only the last four (4) numbers will change. Your accounts will include:

- Inpatient admissions (different accounts for each admission).
- Specimen accounts (a separate account for lab specimens drawn outside of Emory University Hospital including those specimens drawn at The Emory Clinic buildings).
- Recurring accounts (outpatient follow-up visits). This account is referred to either as an outpatient recurring or transplant recurring account.

Recurring accounts will remain open for three to six months. Any outpatient hospital charges during that period will be placed on that account. On recurring accounts, the hospital bills your insurance company once a month.
Sample questions to ask your insurance company:

1. Do I have benefits for heart transplantation?
2. What is my transplant maximum benefit?
3. What is my lifetime maximum benefit? How much have I used toward that maximum?
4. What is my annual maximum benefit? How much have I used toward this maximum?
5. Is organ acquisition covered? If yes, is there any limitation on how much my insurance will pay?
6. Does my insurance plan have “Centers of Excellence” for transplant services? If yes, is Emory University Hospital an approved transplant center? If so, is there a different billing address than listed on my insurance card that transplant claims must be sent to? (Note: If there is a different address to submit claims to, please be sure that each time you come to Emory for transplant services, you tell the insurance registration representative the correct address.)
7. What are my deductibles, co-payments and out-of-pocket expenses? How much have I paid this year toward my deductible and out-of-pocket expenses?
8. What are considered reasonable and customary charges? How much am I likely to pay?
9. Do I need to obtain authorization/precertification for outpatient office visits and medical services?
10. Are outpatient prescription drugs covered, specifically immunosuppressant medications? How much is my responsibility for paying for outpatient prescription drugs. Is there a mail-order pharmacy that I may use that provides a higher level of benefit?
11. Is there a specific nurse case manager that will coordinate my transplant care? If yes, what is his/her name and number?
12. Do I have any transportation or lodging benefits?
13. Are ambulance or air ambulance services covered should I be waiting at home at the time of transplantation?
14. Am I in a preexisting period of coverage so that treatment for my condition is not covered? If yes, what conditions need to be met to pass the preexisting period?

Please request a copy of your health insurance policy and bring it to your evaluation.
Waiting For Your Transplant

THE WAITING LIST

If you and the transplant team agree that you are a suitable transplant candidate, the team will place your name on a waiting list for a donor heart. The United Network for Organ Sharing (UNOS) is the national agency that regulates organ transplantation. UNOS, along with LifeLink of Georgia (our local organ procurement agency), puts your name on a national computerized transplant waiting list and helps locate donor organs.

Due to critical shortage of donor organs, adults may wait two years or more at home before a suitable donor heart is available.

YOUR STATUS ON THE LIST

You will be listed as a Status 1A, Status 1B or Status 2 patient on the heart transplant waiting list, based upon the urgency of your need:

• Status 1A patients are critically ill patients who need one or more special medications through the vein, in addition to other forms of life support/monitoring devices to assist the heart. An example of such a device is a pulmonary artery catheter in a vein in the neck to measure the pressures inside the chambers of the heart. As a Status 1A patient, you must stay in an intensive care unit (ICU) in the hospital.
• Status 1B patients are also critically ill patients who need special medications through the vein to support their heart function. However, they do not typically require any other forms of life support. As a Status 1B patient, you may wait in the ICU or on a special cardiology floor, depending on the severity of your condition. Under special circumstances determined by your physician, Status 1B patients may sometimes wait at home while on these medications through the vein.
• Status 2 patients stay at home or in the hospital but do not need special medications through the vein or other forms of life support.

When an organ becomes available, the computer first considers all Status 1A patients and tries to match the organ. The Status 1A patient with the greatest number of cumulative days spent as a Status 1A and with the proper blood group and body size will receive the donor heart. If no Status 1A patient is a match, then Status 1B patients are considered. Finally, if no Status 1B patient match is found, then Status 2 patients are considered.

The longer you are on the list, the more “points” (days on list) you accumulate. Moving closer to the top of the list makes it more likely that you will be transplanted if a donor heart becomes
available. Keep in mind that your priority or “position” on the list may change depending on the severity of your illness and on how much support you require while waiting.

FINDING A DONOR
Every effort will be made to find a donor quickly. The wait for a donor depends on your blood type, body size and critical nature of your disease. To find a donor match for you, we look at three things:
• You and the donor must have compatible blood types.
• You and the donor must be close to the same weight.
• You must not have antibodies that are incompatible with the donor.

Many families often ask questions about the age of the donor and how the donor died. The transplant team cannot give out any information to you about the donor nor do we give any information about you or your family to the donor family. The donor family has been promised that this information will be kept confidential.

We do encourage you to write a letter to the donor family at some point following your surgery. Please do not reveal your identity. If you choose to write a letter, a transplant coordinator will send it to LifeLink of Georgia who will then forward it to the donor family.

YOUR BEEPER
Once you are listed for transplant, you will need to purchase and carry a beeper so that we will be able to get in touch with you immediately when a donor becomes available. Be sure to notify the transplant office immediately with the number once you receive the beeper so that we will know how to reach you.

AIR TRANSPORTATION
Time is very crucial when a donor organ becomes available, and we need you to arrive at the hospital as quickly and safely as possible. If you live more than a four-hour drive from Atlanta, you may need to fly to Atlanta for your transplant. A coordinator will provide the names of local air ambulance companies. However, it will be your responsibility to set up air transportation with a special air ambulance service that is available 24 hours each day if you live outside the four-hour travel range.

ANXIETY IS NORMAL
Everyone has a different experience with transplantation. You may encounter personal, physical, psychological, spiritual and financial stresses during each phase of heart transplantation.
During transplant evaluation, waiting for the transplant and after the transplant, you may feel discouraged, afraid, anxious, sad or depressed. It is normal to worry that you might die before an organ becomes available. Members of your family may also experience emotional distress related to your illness and worry about the risk of death before transplantation.

Post-transplant life can be a challenge, too, even if you are highly motivated and well adjusted. Minor complications are likely for most recipients and may require treatment and hospital stays that interfere with your daily life. As a transplant recipient, you will also be recovering from surgery and taking new medications that may cause extremes in your emotions. These feelings should go away in six to eight weeks after the transplant. If they do not, please let your transplant coordinator know.

DEALING WITH STRESS

Many transplant candidates report that keeping a positive attitude about the situation helps. Other helpful coping strategies during the waiting period include getting involved in activities and seeking support from others.

Simply talking with someone may help put your feelings into perspective and relieve stress and anxiety. Check with your social worker for the time and place of support group meetings in your area. Another organization that may be able to help is The Mentor Project. You can find out more information about it later in this book.

While you can expect these brief periods of discouragement, they should not affect your usual daily activities. If these feelings occur frequently (for longer than a week or two) or begin to interfere with your daily activities, let your doctor or coordinator know.

Our goal, as the transplant team, is to help you openly explore and discuss your feelings at any time during the transplant process. Please do not hesitate to call us.
Going to the Hospital

THE PHONE CALL

When a donor heart becomes available, a transplant coordinator will phone you in your hospital room or at home first. If we cannot get in touch with you at home, then we will page you. Please call us back within five to ten minutes.

We will tell you that we have a potential donor and then ask how you have been feeling. If you have a fever, vomiting or diarrhea, we may not be able to do the transplant. The most important thing you can do while waiting for a transplant is to seek treatment quickly if you become ill, so that you will be ready at any time should a donor heart become available.

The first call you get does not always mean the transplant will occur. We will tell you that we have a potential donor. The surgeon examines each donor organ and may find that the organ is not strong and healthy. If the donor organ is not functioning well, we will not do the transplant. This does not happen often, but it is a possibility.

LEAVING FOR THE HOSPITAL

You need to leave your house within 15-30 minutes of our call so that you can arrive at Emory as soon as possible. If you have difficulty driving to the hospital, please call the coordinator and we will try to help you get here safely. We would not want you to lose a chance for a new heart.

If you have arranged to fly here, you will need to contact the air ambulance service immediately for departure and arrival times and then tell your coordinator. We can then anticipate when you will arrive at Emory.

ARRIVING AT THE HOSPITAL

When you arrive at Emory Hospital, please drive to the valet entrance on Clifton Road, and then go directly to Admissions located on the second floor of the hospital. They will direct you to your room where you will be quickly prepared for surgery. This time will be very hectic. Your surgery preparation will include getting weighed, having vital signs and blood taken, as well as a surgical scrub and chest X ray (CXR). You will also receive some medication by mouth and through a vein before going to the operating room.

If all goes as planned, you will probably go to the operating room within a few hours after arriving at the hospital. The entire surgery will last approximately four to six hours. If you have had previous open-heart surgeries, the surgery may take longer.
Your family can wait in a special waiting room of the hospital while the surgery is taking place. This is also the place where an operating room nurse will talk with your family during surgery, most likely calling them by phone to tell them how things are going during the transplant. The surgeon will also look for your family in this waiting room after the surgery.

**THE HEART TRANSPLANT SURGERY**

After arriving in the operating room, you will receive general anesthesia and be put to sleep. You will have a breathing tube (endotracheal tube) in your throat. This tube is connected to a machine called a ventilator, which will breathe for you during and after the operation. You will also be placed on a heart-lung bypass machine that will handle the functions of your heart and lungs while the surgeon is working on both your old and new hearts.

The surgeon will make an incision through your breastbone, called the sternum. When the new heart arrives, the surgeon will remove your heart, leaving only portions of the right atrium. The aorta, pulmonary artery and right and left atria from the new heart will be connected to the remaining portions of your old heart.

A temporary pacemaker will be needed to help your heart beat after surgery. Small pacemaker wires are attached to the heart, brought through the skin near your chest incision and attached to a temporary pacemaker box outside your body. This temporary pacemaker will help keep your heart at a normal rate until it regains its own rhythm. This may take a few hours or a few days after the surgery.

Other tubes and equipment will be used to monitor how well your heart and body is recovering after surgery.

IVs (intravenous tubes) will help you receive fluids and medications. A special IV called a pulmonary artery catheter (Swan Ganz catheter) in your neck vein will measure the pressures in your heart and lungs and tell the surgeon how well your new heart is functioning.

A heart monitor will record your heart rate and rhythm at all times.

Tubes in your chest near the bottom of your incision and possibly on the sides of your chest will drain the blood and fluid that collect in your chest after the operation. They are usually removed one to two days after the surgery.

A small tube, called a Foley catheter, in your bladder will help us measure how well your kidneys are working. This tube will be taken out a couple of days after your surgery, and then you will urinate on your own.

As you begin to recuperate and feel stronger, the tubes and catheters will be removed.
WHAT HAPPENS AFTER SURGERY

After surgery, you will go to the cardiac surgery intensive care unit (ICU) where a doctor and nurses are always very close by if you need anything. Initially, you will be under the effects of anesthesia. You will have many IVs, special tubes and a breathing tube. Once you wake up and breathe on your own, the breathing tube will be removed.

When you begin to wake up, you may feel like you are not getting enough air. It is important to relax and let the ventilator breathe for you. You will not be able to talk while on the ventilator, but you can talk immediately after the ventilator is removed. The ventilator may be uncomfortable, but the team will work very hard to remove it as soon as your heart and lungs are ready. You will also hear many different noises. These are normal sounds made by the equipment around you and by people talking.

You will probably look different to your family: You will be pale, possibly swollen and will feel cool to their touch. This will improve after just a few hours in the intensive care unit. You will also still be sleepy and may not remember the first time your family visits.

A typical stay in the ICU is three to four days. You will then be transferred to the cardiac surgery floor where our nurses and physical therapists will help you regain your strength, teach you how to care for yourself when you go home, and prepare you for discharge from the hospital. If all goes well, you can expect to spend three to four days on the cardiac surgery floor before your discharge.

DEEP BREATHING AND COUGHING

Deep breathing and coughing will help expand your lungs and remove lung secretions that have settled during your surgery. A respiratory therapist will show you how to use an incentive spirometer, a device that will help you take deep breaths. It is a good idea to take the incentive spirometer home with you to use the first four to six weeks after surgery.

Coughing may be painful, since you will have a chest incision. The nurse will teach you how to splint (decrease the pain by holding a pillow or your hands over your incision). Ask the nurse for pain medicine so you can breathe deeply and cough more easily and effectively.
Possible Complications
After Transplant

Most people who receive a heart transplant will develop one or more complications after their surgery. Most of these complications are minor, treatable and no cause for alarm. Your transplant team will help you understand early warning signs, be available to discuss your care, and will recommend further treatment when necessary.

Donor organs are screened for various diseases in accordance with standards required by the United States Department of Health and Human Services – Centers for Disease Control (CDC) and the United Network for Organ Sharing (UNOS). However, transplant recipients may be at risk of contracting certain diseases from the organ donor, such as various types of infectious diseases and cancers, which are not detected during the organ screening process.

Some of the most common complications seen after heart transplant are: rejection, infection, high blood pressure and graft coronary disease.

REJECTION

Rejection is a natural response of your body’s immune system. The immune system is the body’s defense against foreign invaders such as viruses, bacteria and even some types of cancers. This natural defense system will also treat a transplanted organ as foreign and try to reject or attack the new heart.

To prevent your body from rejecting your new heart, you will take medications called immunosuppressants that will lower your immunity or defense against foreign agents. These medications, when taken on time and as prescribed, reduce the risk of severe rejection that can damage the heart muscle. You will take these medications for the rest of your life.

You will have a cardiac biopsy at regular intervals so the doctor can check samples of your heart tissue to determine if your body is rejecting the heart. This biopsy is very important to diagnose rejection and evaluate the effectiveness of your medicines.

You may feel good and have no symptoms, yet still be experiencing rejection. That is why we follow your progress so closely after transplant.

If you have any of the symptoms of possible rejection listed here, call your transplant coordinator.

<table>
<thead>
<tr>
<th>REJECTION WARNING SIGNS</th>
</tr>
</thead>
<tbody>
<tr>
<td>If you have any of these symptoms, call the transplant coordinator:</td>
</tr>
<tr>
<td>• Low-grade fever</td>
</tr>
<tr>
<td>• Feeling excessively tired or fatigued</td>
</tr>
<tr>
<td>• Shortness of breath</td>
</tr>
<tr>
<td>• Overnight weight gain greater than 2-3 pounds</td>
</tr>
<tr>
<td>• Loss of appetite, nausea, or vomiting</td>
</tr>
<tr>
<td>• Change in pulse rate or heart rhythm</td>
</tr>
</tbody>
</table>
INFECTION
As a heart transplant recipient, you will be more susceptible to infection because you will take immunosuppressant medications to help prevent rejection. The risk of infection from bacteria and viruses is greatest in the early period after transplant when dosages of medicines are at their highest. That’s why it is important to protect yourself from exposure to infections while in the hospital. Here’s how:
- Anyone entering your room must wash their hands.
- After transplant, take your temperature twice a day and keep a record in the daily log that we give you.
- Avoid large crowds of people in the first month after transplant.
- Avoid people with colds or the flu.
- Carefully clean any cuts or scrapes that you receive with antibacterial soap (such as Safeguard or Dial) and water.
- Always call the transplant coordinator if you suspect an infection or develop a fever.

HYPERTENSION/HIGH BLOOD PRESSURE
Many transplant recipients take medications to control hypertension or high blood pressure since prednisone and cyclosporine, two of the medications used to limit rejection, can raise blood pressure.

Blood pressure is recorded as a top (systolic) and bottom (diastolic) number. Normal blood pressures range from 100/70 to 130/80. After transplant you will take your own blood pressure regularly and keep a record in a daily log we give you. We will also provide blood pressure guidelines and will expect you to call us if your blood pressure goes above or below the guidelines. Untreated high blood pressure can eventually damage your heart and other organs.

POST-TRANSPLANT DIABETES
Some of the immunosuppressant medications that you take may increase the likelihood of diabetes. Diabetes is an increased level of sugar in your blood. Signs of diabetes may include excessive thirst, frequent urination, blurred vision, drowsiness or confusion. Notify the transplant team if you notice any of these signs.
In some cases, high blood sugar can be reduced and managed by weight loss, careful diet, and exercise; however, you may need an oral diabetes drug or insulin injections. If you get diabetes, you will be given special teaching about how to deal with this problem.

CYTOMEGALOVIRUS (CMV)
Cytomegalovirus or CMV is a very common virus. About 70 % of adults have been exposed to CMV at some time. It usually causes a flu-like illness with fever, general body aches, and a decreased appetite which lasts for two or three days. After exposure to the
CMV virus, your body forms antibodies in your blood to protect you from future exposures to CMV. This is similar to what happens after you have chicken pox. We are able to do blood tests to check both the transplant recipient and donor for the presence of CMV antibodies.

Because of the immunosuppressant medications, you will be at risk for infection with CMV after transplant. During the first few months, while the immunosuppressant doses are highest and your immune system is especially weak, the CMV virus can "reactivate" or "wake up." A CMV infection can range from flu-like symptoms to more serious infections involving your stomach, kidney, or lungs (pneumonia).

If either you or your donor were positive for CMV antibodies, you will be given an antiviral medication for the first few months after your transplant. As your doses of immunosuppressants are lowered over time, your risk for CMV will decrease as well and the medication will be stopped. If you develop an active CMV infection, you will be treated with medication in the vein.

**GRAFT CORONARY DISEASE**

In some cases, the arteries in the transplanted heart narrow over time, resulting in *graft (transplant) coronary artery disease*. This may be caused by a different type of rejection of the heart by the body’s immune system.

Because this type of rejection cannot be detected by a heart biopsy, we use a test called cardiac catheterization, or left heart catheterization, to look at the heart’s arteries. This test is performed annually to check for narrowing of these vessels. If narrowed enough, blood cannot flow freely to all areas of the heart muscle, resulting in permanent damage and heart failure. If the vessel is blocked completely, then damage to the heart muscle, known as a heart attack, can occur.

Because the nerves around the heart are cut during the transplant surgery (denervation), patients with transplanted hearts often cannot feel the pain (angina) that usually occurs when the coronary arteries become blocked. In some cases, extensive damage or failure of the transplanted heart may require retransplantation.

To help reduce your chances of developing graft coronary artery disease, we recommend that you take aspirin and cholesterol-lowering medications daily. A diet low in sodium, cholesterol and fat may also help, as well as routine aerobic exercise.
Medications

After your transplant, you will have to take certain medicines for the rest of your life. These medicines are very important and must be taken exactly as prescribed and on time for the transplanted organ to work properly. Failure to do this will result in organ failure and death.

LEARNING ABOUT YOUR MEDICATIONS

While you are in the hospital recovering from your surgery, our pharmacists and nurses will teach you and at least one family member about all your medications. We will review with you the purpose, dosage and possible side effects of each medicine. To help you feel more comfortable taking these medications, we will ask you to begin administering your medications and keeping your own medication records in the hospital a few days before your discharge.

All transplant patients take immunosuppressants to help prevent rejection of their new organ. Most people take a combination of three immunosuppressants. Some generic names of immunosuppressants are cyclosporine, tacrolimus, mycophenolate, azathioprine and prednisone. Your transplant surgeon will determine which combination is right for you.

Since immunosuppressants reduce your ability to fight infection, you will receive a preventative antibiotic. Many patients will require additional medication for their blood pressure and to replace magnesium. Most patients also receive daily aspirin, a stomach acid reducer, a cholesterol-lowering agent, calcium supplementation and vitamins. Other medications will be prescribed based on patients’ individual needs.

WHERE TO GET YOUR MEDICATIONS

Soon after your transplant surgery, the social worker will ask you what pharmacy you will use to get your medications. You may use a pharmacy in your hometown or a mail-order pharmacy. Please try to plan ahead and make these arrangements before you get your transplant. You can contact your social worker for information about pharmacies and drug programs.

Prior to your discharge, a coordinator will call your pharmacy with your medicines. It is your responsibility to contact your pharmacy when you are about to run out of medications or to contact our office when you need new prescriptions, so that you will always have all of your medicines. Your prescriptions will either be for a month’s supply along with five refills or a 90-day supply with three refills depending on your insurance coverage requirements. We recommend that you keep a one or two week supply on hand.
If you are interested in a mail-order pharmacy, please let the social worker know. She can give you phone numbers to call. If you decide to use a mail-order pharmacy, it is your responsibility to call and initially set up the service, and then the coordinator will call in the prescriptions. Mail-order pharmacies will get medicine to you in a few days after you call them or can ship it to you routinely every month. After you contact them with your new medication dosages, the pharmacy asks us to verify the changed prescription. Mail-order pharmacies usually bill your insurance company directly.

Arrangements will be made prior to your discharge for delivery/pick-up of a 30-day supply of your medications.

If you experience difficulty with the cost of your medications, please do not hesitate to let your coordinator know. We will work together to seek assistance.

FREQUENTLY USED MEDICATIONS

Anti-Rejection Medications (Immunosuppressants)

You will take immunosuppressants for the rest of your life to protect your new heart from rejection. Immunosuppressants alter your immune system so that it will not reject your new heart. These medicines also make you more susceptible to illness and infection. All immunosuppressive drugs cause side effects, but not all of the side effects occur in everyone.

Cyclosporine (Gengraf®)

Gengraf® is a potent anti-rejection drug. It is taken in pill form. Gengraf® comes in 25 mg and 100 mg capsules.

**Special instructions:**
- Must be taken every 12 hours.
- Do not store capsules out of foil wrappers.
- Do not store in refrigerator or leave in hot sun.
- The capsules have a funny smell. You may take your dose out of the foil and let the capsules stand for five to ten minutes if the smell offends you.
- Take each dose with a full glass of water.
- If possible, take your cyclosporine first thing in the morning on an empty stomach an hour before breakfast. This allows your body to absorb the medicine better and in lower doses.
- Take cyclosporine at the same times each day and in the same relationship to meals (if not an hour before meals) since food can alter how cyclosporine gets absorbed in your body.

**IMPORTANT:**

Do NOT eat or drink ATMNYTHING after midnight except blood pressure medicine and water before having your blood drawn.

Do NOT take cyclosporine or Prograf the morning before your blood draw.

TIPS FOR TAKING MEDICATIONS

- **Know the medicines that you are taking and their side effects.**

- **Tell the transplant coordinator if you experience any side effects.**

- **Keep a record of medicines you are taking, including the frequency and dose.**

- **Talk to the transplant coordinator before adding, stopping or changing any medicine, including those prescribed by other physicians such as your local doctor.**

- **Keep medicines in a dry place, away from heat or light, and out of the reach of children.**

- **If you miss a dose, DO NOT double the dose; take the next dose as directed.**

- **If you miss two doses, notify the transplant coordinator.**
• Do not consume grapefruit or grapefruit juice while you are on cyclosporine; the interaction can dangerously increase the medicine’s level in your blood.

Potential side effects:
• Increased risk of infection
• Damage to kidneys
• Elevated blood pressure
• Headaches
• Trembling hands and voice

• Tingling of hands and feet
• Increased body hair
• Thickening of gums
• Anemia

Tacrolimus (Prograf®)
Prograf® (formerly known as FK 506) is a very potent anti-rejection drug that comes in 1 mg and 5 mg capsules. It is used for patients having difficulty tolerating cyclosporine. You will not be taking cyclosporine and Prograf® at the same time.

Special instructions:
• Must be taken every 12 hours.
• Should be taken one hour before eating or two hours after eating.

Potential side effects:
• Increased risk of infection
• Damage to kidneys
• Increased potassium
• Increased blood pressure
• Increased blood sugar
• Trembling hands and voice
• Headache

Mycophenolate Mofetil (CellCept®)
CellCept® is a very potent anti-rejection medication. The usual dose of CellCept® is 1000 mg to 1500 mg twice a day. CellCept® comes in 250-500 mg tablets.

Special instructions:
• Must be taken every 12 hours.
• Should be taken on an empty stomach one hour before or two hours after a meal.

Potential side effects:
• Nausea, vomiting, diarrhea
• Constipation
• Leg cramps, weakness
• Headaches

• Bring a list of your medications including their frequency and doses each time you see a health care professional.

• Never take over-the-counter medications or herbal remedies unless you check first with the transplant coordinator to prevent possible dangerous interactions.

• Do NOT take aspirin or ibuprofen for pain relief unless approved by the transplant coordinator. Use other medications such as Tylenol.
Sirolimus® (Rapamune®)
Sirolimus® (Rapamune®) is an anti-rejection medication often prescribed in combination with a steroid medicine (i.e. prednisone) and cyclosporine (Gengraf®). The usual dose is 1-3 mg per day. Sirolimus® comes in 1 mg tablets.

Special instructions:
• Do not consume grapefruit or grapefruit juice during treatment.
• Sirolimus® is usually taken once a day.
• Sirolimus® can be taken either with or without food, but it is very important to take every dose of Sirolimus® in the same relation to food.

Potential side effects:
• Decreased white blood cells and platelets

Infection Prophylaxis

Antibiotics
The antibiotic trimethoprim-sulfamethosazole (Bactrim®) is prescribed to prevent a life-threatening pneumonia called pneumocystis carinii (PCP).

Potential side effects:
• Damage to kidneys
• Lowered white blood cell count

OTHER MEDICATIONS

Anti-hypertensives
Anti-hypertensives are drugs that help control blood pressure. The most commonly prescribed is amlodipine (Norvasc®).

Potential side effects:
• Low blood pressure
• Dizziness
• Weakness
• Fatigue
• Possible sexual dysfunction
• Fluid retention

Mineral-based Replacement Drugs
Magnesium is prescribed to replace this normal body salt that is wasted in your kidneys when you take certain immunosuppressive medications.
Going Home
From the Hospital

Going home with a new organ is very exciting. However, it can also be overwhelming because of all the medications you must take and risks involved with transplant. Before you go home, we will thoroughly review with you and your family what you need to do to keep your transplanted organ healthy.

The transplant coordinator, physical therapist, pharmacist and your nurses will begin preparing you for discharge the day you transfer from the intensive care unit to the surgery floor. It is very important that you and at least one family member understand the information provided here, so if you have any questions, please ask them.

As noted earlier in the Medications section, at this time you will learn about your medications, how to take them, how to keep your own medications, records, and where to purchase medications. Refer to the Medications section for additional information on your medications.

VITAL SIGNS

Vital signs provide useful information to the doctors and coordinators about the status of your health. After leaving the hospital, we ask that you check your temperature, heart rate and blood pressure every morning and every evening. A thermometer and automatic blood pressure cuff will be ordered for your home use before your discharge. The nurses will teach you how to check these vital signs so that you will feel confident doing this before you go home.

The coordinator will give you a diary to record your daily vital signs and will tell you acceptable ranges for the vital signs so that you will know when to call if a reading is abnormal. If there is a problem after your discharge, the coordinator may ask you what your vital signs have been running for the past few days. Please have the diary available when you call the office.

DAILY WEIGHT

We ask that you weigh yourself every morning. Please try to do this at the same time every day (preferably in the morning after you use the restroom) and while wearing the same amount of underclothes. Write the weight in your logbook every day. If you have gained more than two pounds overnight or more than three or four pounds over two to three days, we ask that you call the transplant office. You may be retaining some fluid. This is more likely due to a side effect of your medications than to poor heart function.
MEDIC ALERT IDENTIFICATION
We request that you obtain a special Medic Alert bracelet or necklace. In case of a car accident or other type of emergency, this will alert health care professionals that you have had a transplant, as well as how to contact the transplant team. The identification bracelet or necklace costs a nominal fee. To enroll, complete the order form that the coordinator provides at the time of discharge.

DISCHARGE FROM THE HOSPITAL
You will be discharged to go home if you live in the Atlanta area. If you live more than 45 minutes from Emory, we will ask you to stay in Atlanta three weeks post-discharge so we can monitor your progress closely.

The Mason Guest House of Emory University offers private, low-cost lodging for organ transplant candidates, recipients and families. Individuals from out of town coming to a transplant evaluation or follow-up care may also stay at the Mason Guest House. (See section on Mason Guest House.)

WHEN TO CALL THE COORDINATOR
Call your transplant coordinator if you experience any of these symptoms:
• Temperature of 100° Fahrenheit or greater
• Blood pressure greater than 160/90 or less than 90/60
• Heart rate greater than 130 or less than 70 (or varying 10 beats per minute from your average heart rate)
• Weight gain of more than two to three pounds in 24 hours or more than four to five pounds in two to three days
• Irregular heart rate or rhythm/palpitations
• Cough, shortness of breath, sore throat, chills, breathing fast or mucous production
• Nausea, stomach pain or decreased appetite that lasts more than 24 hours
• Diarrhea or vomiting
• Blood in the urine or bowel movements; painful urination
• Decrease in urine output
• Excessive fatigue
• Persistent headaches or flu-like symptoms
• Any unexplained rash
• Excessive swelling of the ankles and feet
• Dizziness or “blackout” spells
• Other signs of infection: pus draining from incisions, sores in or around the mouth, painful sores on other areas of the body
• Skin blisters (shingles)
Going for Check-Ups

After your transplant, all appointments at Emory Hospital will be scheduled by the personnel in the Heart Transplant office. The doctor and coordinator will see you for your office visit in Outpatient Transplant Services, which is located on the second floor, D-wing of Emory Hospital.

On the day of discharge, the coordinator will set up your next appointment for a heart biopsy, lab work and a follow-up office visit. This office visit includes seeing the coordinator, who will do a physical exam, review all of your medications, and ask questions about how you have been feeling. We will ask you specific questions about your vital signs, energy level, appetite, breathing, swelling of the feet, swollen gums and activities. This is a great opportunity for you to express any concerns or ask questions. After the coordinator sees you, the doctor will examine you as well.

Remember, do not take any medications except for blood pressure medication in the morning if you are having a biopsy or lab work done. Please bring all of your morning medicines with you to the hospital so that you can take them after the biopsy or lab work. Also, remember to bring your daily logbook and a complete list of all the medications you’re taking to all appointments for review.

ROUTINE BLOOD TESTS

We will check lab work with every biopsy and clinic visit. Monitoring your blood through lab tests is one way that we can make sure that you are taking the right amount of medicines. Do not take your morning medication (except for blood pressure medication) before coming for a scheduled visit because we will give you a special blood test to measure cyclosporine, Rapamycin or Prograf® levels in your blood. This test should be drawn approximately twelve hours after your last dose of medicine.

If your scheduled visits are more than two months apart, we will ask that you have your blood checked either at Emory Hospital or in your hometown every two months or sooner if medication changes are made. We have a special instruction form for laboratories other than Emory, which includes mailing a small sample of blood to Emory Hospital for your cyclosporine, Rapamycin or Prograf® level. It explains what blood work to draw and how to report the results.

If you have your lab work done at Emory Hospital, the appointment will be scheduled by personnel in the Heart Transplant office. You will report to the Outpatient Transplant Services on 2D and the personnel in that area will draw your blood. We ask that you
call our office and leave a message on the labs line (404-712-5850, option 2) that you had blood drawn. We will check for the lab results and within five days after the labs are drawn, a coordinator will call you with any medication changes and let you know when to have your blood checked again. If you have labs drawn at a lab other than Emory Hospital, remember to inform us of the name of the lab, the lab’s phone number and the date you had blood drawn. Please leave a message with this information on the lab line. If you have not received a call from a coordinator in five days after your labs are drawn, please call the office to check on your results.

HEART BIOPSY

You will have a heart biopsy on a regular basis to check for heart rejection. Generally, heart biopsies are done according to the following schedule, but they may be performed more frequently if you have been treated for rejection:
- Once a week for the first four weeks
- Every other week for the second month
- Once monthly for three to six months
- Once every other month after six months
- And gradually decrease in frequency until once every four to six months.

On the morning of your biopsy do not take any medications except for your blood pressure pills.

BIOPSY TIMES:
Monday, Tuesday, Thursday, Friday at 7 a.m.
Wednesday at 7:30 a.m.
On the morning of your biopsy do not take any medications except for your blood pressure pills, but bring these with you to your visit so you can take them after your blood work is drawn.

Biopsies are done either in the fourth floor Echo Lab, located in the 4D wing of Emory Hospital, or the Outpatient Cardiac Catheterization (Cath) Lab, located on the tunnel level of Emory Clinic Building A. For these biopsies done in the Echo Lab, a tube (catheter) is inserted through a large vein on the right side of the neck after numbing the area. If the vein in the neck is blocked and cannot be accessed, the biopsy will be performed in the Cath Lab where a small tube is inserted through a large vein in the upper leg.

After we insert a catheter into your vein, some routine blood samples will be drawn, then four to five tiny pieces of the inside of your heart muscle will be removed. The most uncomfortable part of the procedure is inserting the catheter. The heart muscle sample will be placed on a glass slide and read by a pathologist to determine if there is any evidence of rejection.

**Biopsies are graded by using the following scale:**

<table>
<thead>
<tr>
<th>Level</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>NO REJECTION</td>
</tr>
<tr>
<td>1A</td>
<td></td>
</tr>
<tr>
<td>1B</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
</tr>
<tr>
<td>3A</td>
<td></td>
</tr>
<tr>
<td>3B</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>SEVERE REJECTION</td>
</tr>
</tbody>
</table>

On the day of your biopsy, you will need to go to Outpatient Transplant Services (2D) on the second floor of the hospital at 7 a.m., except on Wednesdays when you may come at 7:30 a.m. After checking in, the nurses will take your vital signs and send you to the Echo Lab (4D) where the biopsy will be performed. If your biopsy is done in the Cath Lab then the Cath Lab staff will call you with instructions on when and where to arrive. It is very important to arrive on time as these procedures are *only* done during these hours.

After the biopsy is complete, you will return to 2D where a nurse will take your vital signs for one hour (if the biopsy was done through the neck) or two hours (if the biopsy was done through the leg). During that time, a coordinator will examine you and assess your progress. Afterward, a cardiologist will see you. You can probably go home by 11 a.m. or noon, depending on when your biopsy is scheduled and how long it takes for you to recover from the biopsy.

Biopsy results are usually available by early evening on the day of the procedure. After a physician has looked at the results of both your blood work and biopsy, a coordinator will call you with your results (usually the same day of the biopsy). The coordinator will tell you what, if any, medications to change, when your next biopsy is scheduled, and when we will need for you to have more lab work. It is important that we are able to communicate your results
to you the day that they are available. Therefore, if you will not be available by phone, please call our office before 4:30 p.m. that afternoon for the results. We will send you a letter with the information to keep in your files for reference.

ANNUAL EXAMS

Every year, around the anniversary of your transplant, you will have your annual exam. Plan to be here a full day for this examination. We will do a heart biopsy and a full cardiac catheterization to look at the coronary arteries. A chest X ray will also be done. You will not need to spend the night in the hospital unless complications occur, but bring someone with you to drive you home.

Cyclosporine and Prograf® can cause the formation of gallstones. We will periodically recommend a gallbladder ultrasound to look for gallstones. If you develop gallstones, we will recommend surgery to have the gallbladder removed. If your gallbladder is not removed, a stone could possibly be released from the gallbladder and cause it to rupture. Since your immune system is suppressed, this could lead to a life-threatening infection.

Patients who had their transplant more than five years ago and have not had any coronary artery disease may only need a cardiac catheterization every two years. Prior to coming for your annual exam please read the Cath Lab instructions on the following page.

CARDIAC CATHETERIZATION INSTRUCTIONS

It is important to follow these instructions prior to and on the morning of your annual cardiac catheterization:

One week before cath:
• If you are taking coumadin, stop taking your daily dose three days before your catheterization. Resume taking coumadin the day following the catheterization.
• Someone will call within five days of your appointment to confirm the date and time. If you cannot be reached, your appointment may be cancelled. Call (404) 778-3417 if you have not spoken with someone two working days before the procedure.

Night before cath:
• Eat a regular meal the evening before your catheterization.
• Take your regular medications as directed unless your physician otherwise instructs you.
• Do not eat or drink anything after midnight the evening before the procedure. We encourage you to eat a bedtime snack.

REMEMBER:
Call your insurance company within two weeks of your annual catheterization to determine whether pre-authorization is required.
The Financial Coordinator is available for additional questions, 404-712-4601.
Morning of cath:

DON’TS
• Do not take your insulin dose or oral hypoglycemic (diabetic) medications since you won’t be able to eat for a while. Please bring these medications with you to the Cath Lab.
• Do not eat or drink unless instructed to do so by the Cath Lab staff.
• Do not take your coumadin dose. You should be off your scheduled dose for 3-5 days prior to this procedure.
• Do not take your other medications until after your blood is drawn at the hospital. Please bring these with you to your visit to take afterwards.

DO’S
• Report to The Emory Clinic information desk on the T (tunnel) level in Building A at your scheduled time. If you cannot make your appointment or will be late for any reason, please call our office at (404) 778-3417. We may need to reschedule your appointment if you are late.
• Take your morning blood pressure medications with a small sip of water.
• Wear casual, loose clothing.
• Bring your health insurance card and all information related to your health insurance, including insurance company, policy number and group number.
• Bring a family member or friend with you to the Cath Lab. There is a special waiting area for visitors, and they can visit you before and after the procedure. You will be given a sedative, and therefore, you must make definite arrangements for someone to drive you home at the time of your dismissal.
• Bring a complete list of your medications, including their dosages and frequencies, and a record of your vital signs since your last visit.

After the cath:
• Your procedure will last approximately thirty minutes to one hour.
• Your recovery period will follow and consist of one to two hours of complete bed rest. You may eat or drink during that period.
• Your complete stay in the Emory Clinic Outpatient Cath Lab will be approximately four to six hours.
• The Emory Clinic offers valet parking services for patients and visitors at a cost of about $7 a day. We encourage you to use this convenient service.
**Staying Healthy**

Now that you have had your transplant, you can expect to have a relatively healthy life ahead of you. We encourage you to resume your normal activities as much as possible and take good care of yourself. Here are some suggestions:

**YOUR DAILY ROUTINE**

Developing and adhering to a daily routine of checking vital signs, weight and taking your medications as directed is the best way to stay healthy and detect post-transplant problems early.

- Take your vital signs (temperature, blood pressure, heart rate) first thing in the morning while at rest. Record them in your logbook daily.
- Weigh first thing in the morning and record your weight in your logbook. Weigh around the same time and in the same amount of clothing. You may use bathroom scales, but remember to use the same scales each day.
- If possible, take your cyclosporine or Prograf® first thing in the morning on an empty stomach an hour before breakfast. This allows your body to absorb the medicine better and in lower doses.
- Take your other medications with breakfast.
- Check vital signs again in the evening once you are rested.
- Take your evening cyclosporine dose 12 hours after your morning dose and at least two hours after dinner.

**BATHING**

You may shower or bathe once your pacing wires have been removed. You may feel weak when standing to shower, and it may be a good idea to put a stool in the shower stall. You may also feel tired or dizzy after bathing, so take it slowly. Try not to use excessively hot water; it may dramatically lower your blood pressure and cause you to feel dizzy.

**DRIVING**

You will not be allowed to drive for six weeks after your transplant. Your reaction time is decreased because of the surgery, anesthesia, medications and bed rest. It also takes about six weeks for your incision to heal properly. You may ride in a car during this time, but you must always wear a seatbelt.

---

**HELPFUL HINTS**

- Keep all clinic appointments.
- Never run out of medications.
- Report changes in vital signs listed in section called “When To Call the Transplant Coordinator.” Also report any symptoms of illness to your transplant coordinator.
- Never take cyclosporine before having blood drawn or before a biopsy.
- Never take over-the-counter drugs without checking with the transplant coordinator. They may interfere with your transplant medications.
- Never smoke.
- Avoid smoke-filled areas. Ask family members not to smoke.
- Avoid lifting heavy objects and strenuous physical work for at least six weeks after transplant.
**EXERCISE**

After your transplant, you will begin an exercise program in the hospital. After you are discharged, you must continue this program that may be periodically modified.

Exercise helps counteract the weakening effects of your pre–transplant illness and offsets possible side effects of the immunosuppressive drugs you must take after transplant. Those side effects may include weight gain, water retention, high blood pressure, elevated cholesterol and blood sugar, and weakened bones. Regular activity also promotes confidence and a sense of well-being. The following information will help you through a safe and successful recovery.

A transplanted heart is described as “denervated” because the nerves that normally quickly speed up and slow down the heart rate have been cut during your surgery. These nerves rarely grow back. Therefore, changes in heart rate depend on slower mechanisms such as stimulation by chemicals in the blood and changes in the amount of blood returned to the heart from other muscles.

For example, you might feel very tired if you suddenly ran hard after sitting still. The denervated heart may not increase pumping fast enough in this situation to deliver sufficient amounts of oxygen-rich blood to the exercising muscles.

Five to ten minutes of warm-ups and cool-downs will allow time for the heart rate to adjust to your exercise intensity without causing excessive weakness or fatigue. Walking and stationary cycling are excellent warm-up and cool-down activities.

This scale can help you gauge the right intensity level of your activity. Aim for an intensity of “fairly light” to “hard.” Your breathing rate should increase, although you should remain able to talk without breathlessness.

---

**Exertion Scale**

<table>
<thead>
<tr>
<th>EXERCISE INTENSITY</th>
<th>EXERCISE INTENSITY</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>Very, very light</td>
</tr>
<tr>
<td>7</td>
<td>Very light</td>
</tr>
<tr>
<td>8</td>
<td>Fairly light</td>
</tr>
<tr>
<td>9</td>
<td>Somewhat hard exercise</td>
</tr>
<tr>
<td>10</td>
<td>Hard</td>
</tr>
<tr>
<td>11</td>
<td>Very hard</td>
</tr>
<tr>
<td>12</td>
<td>Very, very hard</td>
</tr>
</tbody>
</table>

*Modified from “Borg 20 Point Scale.”*
Stop the exercise if you become dizzy, short of breath, nauseated, extremely tired or if you are sweating excessively. Avoid these activities during the first six weeks after transplantation:

• lifting more than 10 pounds
• forceful pushing or pulling
• use of a regular bicycle
• contact sports

Limit your activity level to the warm-up or cool-down intensity if you have an infection, rejection, fever or if your resting heart rate is more than 20 beats per minute higher than your usual resting heart rate.

Contact your physical therapist if you have any questions about your exercise program.

SEXUAL ACTIVITY

Sexual activity may be resumed after discharge from the hospital. This will not harm your new heart. For the first six weeks after surgery, while the breastbone is healing, we advise taking a passive position that will not put pressure on your sternum. You should expect your sex life to be healthy and enjoyable. If problems develop, discuss this with your primary care physician or with the transplant team.

PREGNANCY

Please talk to the transplant team if you are thinking about becoming pregnant. We can discuss pregnancy and birth control with you. Since there is little current data on transplant patients and pregnancy, recommendations on whether or not to become pregnant must be made on an individual basis.

SMOKING

If you smoked before your transplant, you were required to quit before being considered for a transplant. If past cravings return, please discuss this with your physician or transplant coordinator. Otherwise, avoid smoke-filled areas, and ask family members not to smoke.

PROTECTING YOURSELF FROM INFECTION

In the first month after transplant, you will be on the highest doses of your immunosuppressant medications. This is the time when you will be more likely to get an infection, but there are certain things you can do to protect yourself:

• Wash your hands carefully and frequently with antibacterial soap. This is the single most effective way to decrease the spread of germs and to prevent infection.
• During your first month in Atlanta, avoid large crowds of people in areas such as church, airports, movie theaters and malls. You may go to the grocery store or a restaurant during times when these places are less crowded.

• After returning home, you may go out in public and have visitors.

• Avoid anyone who has any kind of infection that might be contagious. Avoid friends or family who have a cold, the flu, a virus or any other illness until they are well.

• Keep cuts and scratches clean and dry. Inspect these areas regularly for any sign of infection and notify the transplant team if you see any of these signs: redness, swelling, tenderness or drainage.

• Normal sore throats and ear infections can turn into bigger problems in transplant patients because your immune system is suppressed. Please notify the transplant coordinator of any signs of infection such as fever, shortness of breath, cough, sore throat, fatigue, headache or flu-like symptoms.

• You will need to take antibiotics prior to dental and oral work, as well as respiratory tract or esophageal procedures.

RETURNING TO WORK

One of the goals of our transplant program is to help patients return to work when they are physically and emotionally ready. Returning to work can be as easy as returning to a previous job.

However, you may not have worked for a long time, lack current job skills, or need to change occupations because of physical or other limitations. You may benefit from career counseling. We can refer you to the Georgia Transplant Foundation’s JobLink Program, and they can assist you in a number of ways:

• career interest testing
• coaching for job search and interview techniques
• skill training
• resumé development
• career counseling
• social security and benefits counseling
• placement in a job that matches your interests, capabilities and functional limits.

When you are ready, the social worker will be happy to assist you with a referral to the JobLink program.

TRAVEL TIPS

If you choose to travel long distances for an extended period of time after your transplant, please notify the transplant coordinator. We can tell you the location of the transplant center nearest your destination in case any problems should arise.

If you plan to travel overseas, alert the transplant team. Some required vaccinations might be harmful to transplant recipients.
Always take your medications with you on the plane, in case your luggage is lost in flight. Also remember to bring extra medications in case you were to lose some of yours.

We suggest that you wear a Medic Alert bracelet or necklace and carry an ID card that identifies you as a transplant recipient. This identification should have the contact number of the transplant team. In case of emergency, it is also a good idea to carry a list of your current medications.

**ROUTINE MEDICAL CARE**

Routine medical care is important for early detection and treatment of disease. We recommend routine medical care not only because it makes good sense, but also because some of the medications transplant patients take can affect other body systems. All transplant patients should have an *annual check-up* by their local physician, including a complete history and head-to-toe physical exam. If you do not have a primary care physician (PCP), please choose one so that you will have access to care for your routine health needs after transplant.

**Immunizations**

Transplant recipients may resume their vaccination schedule approximately three months after transplant. We recommend the pneumonia vaccine every five years, the flu shot every year and the tetanus booster every 10 years. *Live vaccines should be avoided.* This includes the measles, mumps and rubella (MMR) vaccine, the oral polio vaccine (OPV), and the varicella and smallpox vaccines. Household contacts should not receive either the oral polio vaccines (OPV) or smallpox vaccine because they are easily transmitted. OPV is no longer recommended for use in the United States. The inactivated vaccine, or IPV, is commonly used. Household contacts may receive MMR and varicella vaccines.

**Dental Exams**

It is important that you resume routine dental care, but we recommend that you wait three months after transplant before making a dental appointment except in cases of emergency. Some transplant patients on cyclosporine experience problems with tender, swollen gums. To avoid tooth and gum problems, we recommend a dental visit every six months and sometimes every three months. If problems do arise, you may need to see a periodontist (a dentist specializing in gum problems).

You will need to take one dose of antibiotics before any dental procedure, including cleanings, fillings or oral surgery. This is to protect your transplanted heart from *endocarditis*, an infection of
the inner lining or valves of the heart caused when bacteria from the mouth gets into the blood stream. The transplant coordinator will provide you with a prescription for the appropriate antibiotic, based on American Heart Association recommendations.

**Vision Screening**
We recommend regular vision screening at least every two years or annually if you wear glasses or contacts. Prednisone and other medicines can cause changes in eyesight, including blurry vision, cataracts or glaucoma. Tell your ophthalmologist that you had a transplant so he or she may specifically test for these conditions.

**Cancer Prevention and Early Detection**
As a transplant patient, you may be more susceptible to cancer because of your altered immune system. We recommend that you see your PCP annually for all routine preventive health screenings.

**Dermatology**
One of the complications frequently seen in transplant recipients is skin lesions. You will be taking medications for the rest of your life and they will make your skin more sensitive. Because your immune system will be suppressed, you may also be more likely to develop skin cancers.

Skin cancer is the most common cancer in the United States. The cause of skin cancer is well known. Prolonged exposure to the sun, especially if it results in sunburn and blistering plays a key role in beginning skin cancer. The majority of skin cancers occur on parts of the body not protected by clothing, such as the face, neck, forearms and back of hands. Most skin cancers are easily treatable if detected early enough. Therefore, we recommend:

- wearing a broad-brimmed hat, a shirt, and sunglasses when you are outside in the sun.
- using a sunscreen with a SPF of 30 or higher and reapplying it often when out in the sun.
- avoiding tanning beds or sun lamps.
- conducting monthly self-exams.

If lesions do develop or you notice a change in a mole or freckle, you will need to see a dermatologist. You may also be more prone to developing mouth sores and ulcers. Please let the transplant coordinator know if you notice any unusual lesions or ulcers on your skin or any sores or white patches in your mouth. A physician should always examine suspicious lesions.
**Colorectal Screening**
Beginning at age 50, you should follow one of the five screening options below:

- Yearly fecal occult blood test (FOBT)
- Flexible sigmoidoscopy every five years
- Yearly fecal occult blood test plus flexible sigmoidoscopy every five years
  
  *(Of the options above, the American Cancer Society prefers yearly FOBT combined with flexible sigmoidoscopy every five years)*
- Double contrast barium enema every five years
- Colonoscopy every 10 years

Talk to your primary care physician about beginning colorectal screening earlier and/or more often if he or she thinks it is necessary based on your individual history and risk factors.

**FOR WOMEN ONLY:**

**Pap Smears**
Women taking transplant medications may be at increased risk of getting cervical cancer. Regular pap smears are an excellent method for early detection and treatment of cervical cancer. A pap smear is the primary test for detecting cervical cancer, because there are usually no physical signs of this problem. Cervical cancer is 100 percent curable if it is detected early enough.

The transplant team and the American Cancer Society recommend annual pap smears and pelvic exams for all women over the age of 18. This should include a rectal exam to check for blood in the stool. Women who are or have been sexually active should have yearly exams regardless of age. A urinalysis should be included in this yearly exam.

We also recommend good health practices such as prompt treatment of vaginal and cervical infections, limiting the number of sexual partners, using condoms to avoid sexually transmitted diseases, and reporting abnormal uterine bleeding, discharge, spotting, or painful intercourse.

**Breast Self Exam (BSE)**
As many as 95 percent of breast cancers are accidentally discovered. All women should perform regular exams 7–10 days after each menstrual period as a routine good health habit. We join the American Cancer Society in recommending that all women over age 20 perform monthly breast self-examinations. Your local physician or gynecologist should be able to instruct you in this practice. We also recommend breast exams by a physician every three years if you are between 20 and 39 years old and annually for women over the age of 40.

**PAP SMEAR SCHEDULE:**
*Annual pap smear and pelvic exams.*

**BREAST HEALTH SCHEDULE:**

**Self-exam:** *every month*

**Doctor’s exam:**
*every three years (ages 20-40)*
*every year (over age 40)*
Mammography
A mammogram uses a very small, safe amount of radiation to detect masses or tumors in the breasts. The American Cancer Society recommends that all women have a baseline mammogram done between the ages of 35 and 39. Women ages 40 and older should have a mammogram every year. However, if you have a strong family history of breast cancer, follow the recommendation of your physician regarding frequency of testing.

FOR MEN ONLY:
Testicular Exams
Men themselves discover most testicular cancers first. We do not know how to prevent testicular cancer, but if treated early enough, there is an excellent chance for its cure. The American Cancer Society recommends that all males over the age of 15 perform testicular self-examinations monthly on a set date. Your local physician can instruct you on this practice.

Prostate Exams
All men should have a rectal exam yearly. During this exam, the prostate is examined to see if it is enlarged or infected and the stool is checked for blood. All male patients over the age of 50 should get a special blood test called a prostate-specific antigen (PSA) to screen for prostate cancer. If anyone in your family has ever had prostate cancer, start having this blood test at age 45.

BREAST HEALTH SCHEDULE:

Mammogram:
baseline at age 35; every year after age 40

TESTICULAR/PROSTATE HEALTH SCHEDULE:

Testicle self-exam:
every month

Rectal, stool and prostate:
exam annually

PSA exam (after age 50)
**NUTRITION AND DIET**

Proper nutrition is necessary before and after your transplant. A balanced, low-fat diet will help you maintain a healthy body weight as well as reduce high blood cholesterol levels. A low-salt diet will help reduce fluid retention. You may need to eliminate sugar in your diet to help control high blood sugar.

Our clinical dietitian will meet with you and your family to evaluate your diet and teach you about the right foods to eat to meet your special needs. While waiting for an organ and after your transplant, the dietitian will adjust your diet as necessary. Our dietitian is also available to answer any questions you or your family may have and to help with meal planning at home.

*Before your transplant*, it will be important for you to reach and maintain a healthy body weight and to eat a balanced diet to keep your strength up while waiting for your transplant. We will ask you to reduce the table salt and sodium in your prepared food to prevent your body from retaining too much fluid or water. Some patients have poor appetites and need special attention to ensure good nutrition. A healthy diet will improve your healing process post-surgery.

*After your transplant*, you will continue to follow a strict diet as well as take many medications. Some of these medications may cause side effects, such as elevated blood sugar, elevated blood cholesterol, fluid retention and especially weight gain. You will enjoy food much more now that you feel better, but you must make a special effort to follow your diet.

Our dietitian will develop individual guidelines and menus to fit your specific needs. It helps if your family members take part and follow your heart healthy diet with you.

Here are some good-for-your-heart recipes from *The Low Salt Cookbook*, published by the American Heart Association.

**VEGETABLE SOUP**

Serves 4; approximately 8 ounces per serving

1 tablespoon olive oil
1/2 cup chopped onions
1/2 cup diced celery
1/2 cup sliced carrots
1/2 teaspoon oregano
1/2 teaspoon thyme
2 cloves garlic, minced
4 cups low-sodium beef broth
Freshly ground black pepper to taste
1/2 cup cut fresh green beans
1/2 cup chopped fresh tomatoes
Place oil in a medium stockpot over medium heat. Add onions, celery, carrots, oregano, and thyme and sauté until soft, about 5 to 7 minutes. Add garlic and cook for another minute. Add beef broth, pepper and the rest of the vegetables. Simmer 30 to 45 minutes or until vegetables are soft.

**POTATO SALAD**

Serves 6

5 medium, red potatoes, cooked, peeled and diced  
3/4 cup chopped celery with leaves  
1/2 cup sliced radishes  
2 green onions, diced  
2 tablespoons mayonnaise  
2 tablespoons plain nonfat yogurt  
1 teaspoon dry mustard powder  
1 tablespoon sugar  
1/4 teaspoon turmeric  
1/2 teaspoon celery seed (optional)  
21/2 tablespoons white vinegar  
3 tablespoons skim milk

Combine potatoes, celery, radishes and onions. In a separate bowl, mix together mayonnaise, yogurt, mustard powder, sugar, pepper, turmeric and celery seed. Add vinegar and milk and stir until mixed. Combine with potato mixture and stir well. Chill before serving.

**REDUCED-CALORIE RANCH DRESSING**

Makes 1 1/2 cups; serves 24; 1 tablespoon per serving  
1 cup low-fat buttermilk  
1/2 cup plain low-fat yogurt  
1 tablespoon Dijon mustard  
2 tablespoons minced onion  
1 tablespoon fresh dill  
1 tablespoon chopped fresh parsley  
1/2 teaspoon garlic powder  
1/4 teaspoon freshly ground black pepper

In a jar with a tight-fitting lid, combine all ingredients. Shake well to blend. Refrigerate for at least 2 hours.
OVEN-FRIED FISH

Serves 4
Vegetable oil spray
2 tablespoons acceptable margarine, melted
1 tablespoon fresh lemon juice
1/4 teaspoon freshly ground black pepper
1/4 teaspoon paprika
1/4 teaspoon basil
1/8 teaspoon garlic powder
1 pound fillet of flounder or other fish
1/4 cup dry breadcrumbs

Lightly spray a shallow baking dish with vegetable oil spray. Preheat oven to 475o F. Combine margarine, lemon juice, pepper, paprika, basil and garlic powder. Mix well. Dip fish in margarine-herb mixture and roll in breadcrumbs. Arrange fish in a single layer in a baking dish. Spoon remaining margarine mixture over fish. Bake uncovered 15 minutes or until fish flakes easily with a fork. Do not overcook.

HASH-BROWN POTATOES

Serves 6
1/4 cup acceptable vegetable oil
1/4 teaspoon freshly ground black pepper
1/8 teaspoon onion powder
1/8 teaspoon garlic powder
6 cups chopped or grated peeled potatoes
1/4 teaspoon paprika

Heat oil, pepper and onion and garlic powders in a large, nonstick skillet over medium-high heat. Add potatoes and paprika. Cook until potatoes are crisp and browned, stirring frequently. Drain on paper towels and serve immediately.
**SPAGHETTI WITH MEAT SAUCE**

Serves 6

1 pound lean ground beef
1 medium onion, chopped
1 clove garlic, minced
5 medium fresh tomatoes, peeled and chopped,
   or one 28-ounce can no-salt-added tomatoes, chopped
1 6-ounce can no-salt-added tomato paste
1/2 cup dry red table wine
1/2 teaspoon oregano
1/2 teaspoon basil
1/2 teaspoon fennel seeds
1/8 teaspoon freshly ground black pepper
1 8-ounce package spaghetti

Brown ground beef in a large nonstick skillet. Pour off fat. Add remaining ingredients except spaghetti. Cover and simmer over low heat 1 1/2 hours, stirring occasionally. If sauce appears too thick, add water. Cook spaghetti according to package directions, omitting salt. Drain. Pour sauce over spaghetti and serve.

**VEGETABLE MEDLEY**

Serves 4

1 tablespoon acceptable margarine
2 medium yellow summer squash, diced
1 medium zucchini, sliced
1 medium yellow onion, diced
3 medium fresh tomatoes, diced
1/2 cup frozen corn
1 clove garlic, minced
1/2 teaspoon oregano
1/2 teaspoon basil
1/4 teaspoon freshly ground black pepper

In a large pan over medium heat, melt margarine. Add squash, zucchini and onion. Sauté 3 to 4 minutes. Add tomatoes, corn, garlic and seasonings and cook another 2 to 3 minutes. Serve immediately.
APPLE CRISP

Serves 8

Vegetable oil spray
1 1/2 pounds (5 medium) apples, cored and sliced, unpeeled
2 tablespoons fresh lemon juice
1/4 teaspoon ground cinnamon
2/3 cup all-purpose flour
1/2 cup firmly packed brown sugar
1/2 cup uncooked oatmeal
1/3 cup acceptable margarine

Preheat oven to 375°F. Lightly spray a 2-quart casserole dish with vegetable oil spray. Arrange apples in prepared dish. Sprinkle with lemon juice and cinnamon. In a medium bowl, combine flour, brown sugar and oatmeal. Cut in margarine with a fork or pastry blender until mixture is crumbly. Spread over fruit. Bake 40 minutes or until apples are tender.
Glossary

Anesthesia: medicine given by injection or mouth that causes partial or complete loss of feeling for a period of time, usually during surgery.

Angina: severe pain when the heart does not receive enough oxygen.

Antirejection medicine: (See immunosuppressants.)

Antibiotics: drugs taken to prevent infections and kill bacteria.

Antihypertensive: medicine that prevents or controls high blood pressure.

Aortic valve: heart valve between the left ventricle and the aorta (leading from the heart to the body).

Aspirin: pain reliever taken by mouth; also helps to prevent blood clot formation.

Atria: the two upper chambers of the heart.

Azathioprine: immunosuppressive drug used mainly to prevent the body from rejecting an organ or tissue transplant. (See Imuran®.)

Bradycardia: condition where the heart beats slower than normal.

Breast self-exam: monthly check of the breasts for lumps or tumors that could be cancerous.

Bronchioles: small air passages from the trachea to the lungs.

Cancer: disease in which abnormal cells multiply out of control and disrupt normal cell or organ function.

Cardiac biopsy: removal of a small amount of heart tissue to check for any evidence of rejection.

Cardiac catheterization: a procedure in which a small tube is guided through a vein or an artery into the right or left side of the heart to check the function of the heart and the coronary arteries.

Cardiologist: doctor who studies and treats diseases of the heart.

Cardiomyopathy: disease of the heart muscle (myocardium) causing it to weaken over time.
Cardiovascular: relating to the heart and the blood vessels or to the circulation of blood.

Cataract: thickening of the eye lens in one or both eyes that impairs vision and often leads to blindness.

Catheter: tube, generally small and flexible, inserted into the body, to infuse medications, monitor organ function and drain fluid.

CellCept®: immunosuppressant drug used mainly to prevent the body from rejecting an organ or tissue transplant. (see also mycophenolate mofetil)

Cervical cancer: cancer of the cervix.

Chemotherapy: the use of drugs to destroy cancer cells.

Cholesterol: fat substance found in animal meats, dairy products and produced by the liver; a high level of cholesterol in the blood is a risk factor for developing heart disease. Blood cholesterol can be elevated by cyclosporine.

Clinical nutritionist: specialist in selecting foods that repair or maintain the body.

Congenital: existing at birth.

Congestive heart failure: when the heart becomes too weak to pump enough blood through the body and fluid builds up in your organs and tissues.

Coronary artery disease: narrowing of the coronary arteries that usually result from a build-up of a substance called plaque or from atherosclerosis.

Coronary arteries: blood vessels that supply oxygenated blood to the heart.

Cyclosporine: drug that helps keep the body from rejecting a transplanted organ. Brand names include Neoral® and Gengraf®.

Dermatology: study and treatment of skin.

Denervation: cutting or blocking the nerve supply.
Diabetes: the body’s inability to control the amount of insulin or blood sugar it produces for energy.

Diastolic blood pressure: bottom number of the blood pressure reading that shows the amount of resistance in the blood vessels that the heart has to overcome.

Diuretic: medication that assists the kidneys in ridding the body of excess fluid.

Donor: person who gives an organ to be used in another person.

Echocardiogram: diagnostic test that uses reflected sound wave images to see the heart and provides information regarding the structure and function of the heart.

Edema: swelling of body tissue caused by fluid leaking from blood vessels.

Endocarditis: an infection of the inner lining or valves of the heart.

Endotracheal tube: long tube used to provide an airway into the lungs. This tube is generally connected to a breathing machine.

Enzyme: protein that helps complete chemical reactions without being changed in the process.

Fluid retention: condition in which the body stores excess fluid.

Foley catheter: tube inserted into the bladder to drain urine.

Gallbladder: organ that stores bile.

Gallstones: stones that form when the bile has too much cholesterol.

Glaucoma: eye disease in which increased pressure on the eyeball damages the optic nerve and eventually can lead to blindness.

Graft coronary disease: condition in which the arteries in a transplanted heart narrow.

Heart attack: blockage of a vessel that feeds the heart muscle, causing sudden tissue death (myocardial infarction).

Heart biopsy: (See cardiac biopsy.)
Heart failure: (See congestive heart failure.)

Heart monitor: a device that records and displays information about the heart, including condition and number beats.

Idiopathic: arising from an unknown or obscure cause.

Immune system: your body’s natural defense system against foreign invaders such as viruses, bacteria, some types of cancers, and sometimes transplanted organs or tissue.

Immunization: giving antibodies or other agents to protect against disease.

Immunosuppressants: drugs that help treat or prevent the immune system from rejecting an organ or tissue transplant.

Immunosuppression: process of preventing the body’s immune system from rejecting an organ or tissue transplant.

Imuran®: immunosuppressive drug used mainly to prevent the body from rejecting an organ or tissue transplant.

Infection: condition in which the body is invaded by a disease-causing micro-organism.

Intravenous (IV): a catheter (small tube) inserted into a vein so that fluid, blood or medicine can be received.

Lab draw: process of taking blood or urine for laboratory analysis.

Laboratory (lab): place where blood and specimens are studied and identified.

Laxative: food or chemical substance that acts as a stool softener.

Lesion: injury or wound to skin or tissue.

LifeLink: organization that matches organs and tissues with potential recipients.

Magnesium oxide: white, odorless powder in tablet form used after transplant to counteract cyclosporine’s tendency to lower magnesium levels in the blood; low magnesium can cause heart rhythm problems or muscle cramps.
Mammography: screening process for early detection of breast cancer.

Medic Alert: nonprofit organization that provides a bracelet or necklace with your personal medical information that can be used by medical personnel in case you have a car accident or other type of emergency.

Mg: milligram.

Mitral valve: largest of the four heart valves; allows blood to flow on the left side of the heart.

Monopril: drug that lowers blood pressure.

Mycelex troche: anti-fungal agent that lowers the growth of yeast that can cause infection.

Mycophenolate mofetil: generic trade name for the drug CellCept®. (See CellCept®.)

Mycostatin®: trade name for the drug Nystatin. (See Nystatin.)

Mylanta: common over-the-counter drug used to relieve upset stomach.

Native heart: your diseased heart; the heart you were born with.

Neoral®: (See cyclosporine.)

Norvasc®: drug used to prevent heart spasms and lower blood pressure.

Nystatin: antifungal agent used to prevent infections.

Ophthalmologist: physician who studies and treats the eye.

Osteoporosis: condition where the body loses bone mass; this can lead to bone fractures and disk breakdown in the spine.

Pacemaker: electrical device that stimulates or steadies the heartbeat or re-establishes the rhythm of an arrested heart.

Palpitations: rapid throbbing of the heart, usually with an increase in frequency or force, with or without irregularity in rhythm.
Pap smear: test in which cells from the vagina and cervix are collected then analyzed to detect cancer.

Pathologist: specialist who diagnoses abnormal changes in tissue removed during an operation.

Pneumococcal: bacterial microorganism that causes pneumonia.

Pneumonia: infection of the lungs.

Post-transplant: after transplantation.

Postpartum cardiomyopathy: heart disease that develops after childbirth.

Pravachol: drug that lowers cholesterol.

Prednisone: medication used to limit rejection of a transplanted organ or tissue.

Prograf®: (See tacrolimus.)

Prostate: gland around the neck of the bladder and urethra in males that secretes ejaculatory fluid.

Prostate-specific antigen (PSA): special blood test recommended for men over the age of 50 to screen for prostate cancer.

Psychiatric clinical nurse specialist: nurse specially trained to help you and your family deals with behavioral and mental issues such as stress, anxiety, depression and addiction.

Psychiatrist: physician who diagnoses and treats mental disorders.

Pulmonary artery: blood vessel that carries blood from the right ventricle of the heart to the lungs.

Pulmonary artery catheter: A long, flexible tube inserted through your neck vein into the pulmonary artery; used to measure pressures in your heart and lungs, and evaluate your heart function.

Pulmonary valve: structure between the right ventricle and pulmonary artery; regulates movement of fluid into the pulmonary artery.
Ranitidine: (See Zantac®.)

Rectal: lower part of the colon or large intestine.

Rejection: condition in which recipient’s body rejects tissue or organ transferred from a donor.

Rheumatic heart disease: condition in which the heart valves are damaged by rheumatic fever.

Status: patient’s current condition.

Sternum: narrow, flat bone that connects the ribs or the shoulder girdle or both; also referred to as the breastbone.

Swan-Ganz catheter: (See pulmonary artery catheter.)

Systolic blood pressure: amount of force used by the heart to eject blood out of the heart; “systolic” refers to the top number read as part of blood pressure.

Tachycardia: condition where the heart beats faster than normal.

Tacrolimus: drug the helps keep the body from rejecting a transplanted organ. Brand name is Prograf®.

Testicular: Relating to the male reproductive glands that produce reproductive cells and the hormone testosterone.

Tetanus: infectious disease that causes painful muscle contractions; also known as lockjaw.

Transplant coordinator: specially trained, registered nurse who coordinates care for patients before and after transplantation.

Transplant surgeon: highly trained doctor who performs the transplant operation.

Transplantation: transfer of living tissue or organs from one person to another.

Tricuspid valve: heart valve between the right atrium and the right ventricle.

Ultrasound: device that uses ultrasonic waves to outline the shape of various tissues and organs of the body.
UNOS: United Network for Organ Sharing, a national agency that maintains a national computerized transplant waiting list and helps locate donor organs.

Vaccination: injection that builds your body’s resistance to an infection.

Valvular disease: disease that causes the heart valves to malfunction and permit fluid to flow in the wrong direction.

Vena cava (superior and inferior): two large veins that bring blood that has been used by your body to the right side of the heart; the superior vena cava drains the upper portion of the body, while the inferior drains the lower portion of the body.

Ventilator: mechanical device that controls and monitors flow of air to the lungs.

Ventricle: Either of two lower chambers of the heart. The right chamber pumps blood to the lungs to be oxygenated, while the left ventricle is a powerful muscle that pumps the oxygenated blood throughout your body through your arteries.

Vital signs: temperature, pulse, respiration and blood pressure.

Zantac®: drug used to treat stomach problems like peptic ulcers and heartburn.
Other Helpful Information

MASON GUEST HOUSE
The Mason House is a private retreat that offers low cost housing for organ transplant candidates, recipients and families. Guests who book one of the 15 bedrooms, each with a private bath, will find a comfortable bed-and-breakfast environment. In addition, a two bedroom suite is available with its own kitchen, living area and private entrance. Several bedrooms and bathrooms are wheelchair accessible. Continental breakfast is provided, but guests may cook their own meals. Other amenities include laundry facilities, TVs in the gathering rooms, private phones, a VCR, stereo and a computer. The Mason House is a home-away-from-home, created to make transplant candidates, recipients and their families feel far away from a hospital environment, yet close enough to feel secure should they need medical assistance. Please call 404-712-5110 for reservations.

THE MENTOR PROJECT
What is the Mentor Project?
The Mentor Project provides one-on-one contact between people living successfully with a transplant and people who are new to the world of transplantation. The project pairs a “veteran” organ transplant recipient, primary caregiver or living donor with someone who is waiting for a transplant, a recent transplant recipient, family members of a transplant recipient or a living kidney or liver donor. Through these connections, even the smallest questions get answered, experiences are shared, and support is provided to both patients and families.

What is the history of the Mentor Project?
The Mentor Project began in Georgia in 1996, serving adult transplant recipients in all solid organ groups — heart, kidney, kidney/pancreas, liver and lung. Since that time, mentors for pediatric transplant families and living donors have been added. Also the scope has been expanded to include people at all stages of the transplant process — from the earliest mention of transplant as a treatment option through post-transplant.
**Who are mentors?**
Mentors are organ recipients, parents or other supporting family members and living donors who are at least six months out from their transplant date or the transplant date of their loved one. Mentors attend a full day of training to learn how to draw on their personal experiences to address the needs of others that they mentor. Mentors are updated periodically on services and assistance available to transplant families within the transplant community, and the mentor network is an excellent connection to these resources.

**How do I get a mentor?**
If you live in Georgia, you can be referred to the Mentor Project by your social worker, transplant coordinator, clinical nurse specialist or physician. A mentor is never assigned without the consent of the potential mentee. Georgia residents may also call the Mentor Project and request a mentor directly.

**How do you match mentors and mentees?**
Mentors and mentees are matched by the things you have in common. Where you live, your age, hobbies, interests and occupation are all considered.

**How is the Mentor Project different from a support group?**
Participation in the Mentor Project is not meant to replace being part of a support group. The Mentor Project is an addition to this important means of support.

- It is easy to participate in the Mentor Project since it is tailored to meet your individual needs:
  - The mentee and mentor decide where to meet, what to discuss, and the amount of time you want to spend with each other.
  - Issues most important to each mentee can be talked about in a private setting.
  - There are no fixed schedules or locations for meetings.
  - Mentees are matched with mentors who live in or near their hometowns.

**Who sponsors the Mentor Project?**
The Mentor Project is a service provided by the Georgia Transplant Foundation. It evolved from a team effort of transplant recipients and transplant center healthcare professionals. Together, they review and revise the Mentor Project to meet the needs of transplant families.

For more information about the Mentor Project contact the Georgia Transplant Foundation at 1-866-(GATX411) or 770-457-3796.
JOBLINK

A career development and return-to-work program for transplant recipients in the state of Georgia

JobLink is an assistance program that helps Georgia transplant recipients and candidates return to the work environment. JobLink offers needed information and training in order for the transplant recipient to reach career goals.

The objective of JobLink is to provide transplant recipients and candidates a quick and successful re-entry into the work force. Skilled placement specialists evaluate work needs and provide both necessary skills training and access to the appropriate vocational and rehabilitation services.

JobLink offers access to the state's vocational rehabilitative services and provides a comprehensive return-to-work program — at no cost to you. The return-to-work program can be the link that completes the goal of transplantation in returning recipients to a productive lifestyle.

Services include:
- Career interest testing and development
- Assistance with Social Security issues
- Information on state vocational rehabilitation services
- Job skills training
- Resume development and interview techniques
- Job placement
- Early return-to-work programs
- Americans with Disabilities Act (ADA) awareness
- Post-placement intervention to ensure success

For more information, call 770-457-3796 or 1-866-428-9411. Your transplant social worker also will be happy to assist you with a referral.

HELPFUL RESOURCES AND WEB SITES FOR THE HEART TRANSPLANT PATIENT

American Heart Association
www.americanheart.org
1-800-242-8721
(national office in Texas)
770-952-1316 (Atlanta office)

Emory Healthcare Heart Transplant Program
www.emoryhealthcare.org/transplant_heart
404-712-5850

Georgia Transplant Foundation
www.gatransplant.org
770-457-7396

LifeLink of Georgia
www.lifelinkfound.org
404-266-8884

National Transplant Foundation
www.transplants.org
1-800-489-3863

Transplant Recipients International Organization, Inc.
www.trioweb.org
1-800-874-6386

TransWeb
www.transweb.org
734-998-7314

United Network For Organ Sharing (UNOS)
www.unos.org
1-888-894-6361