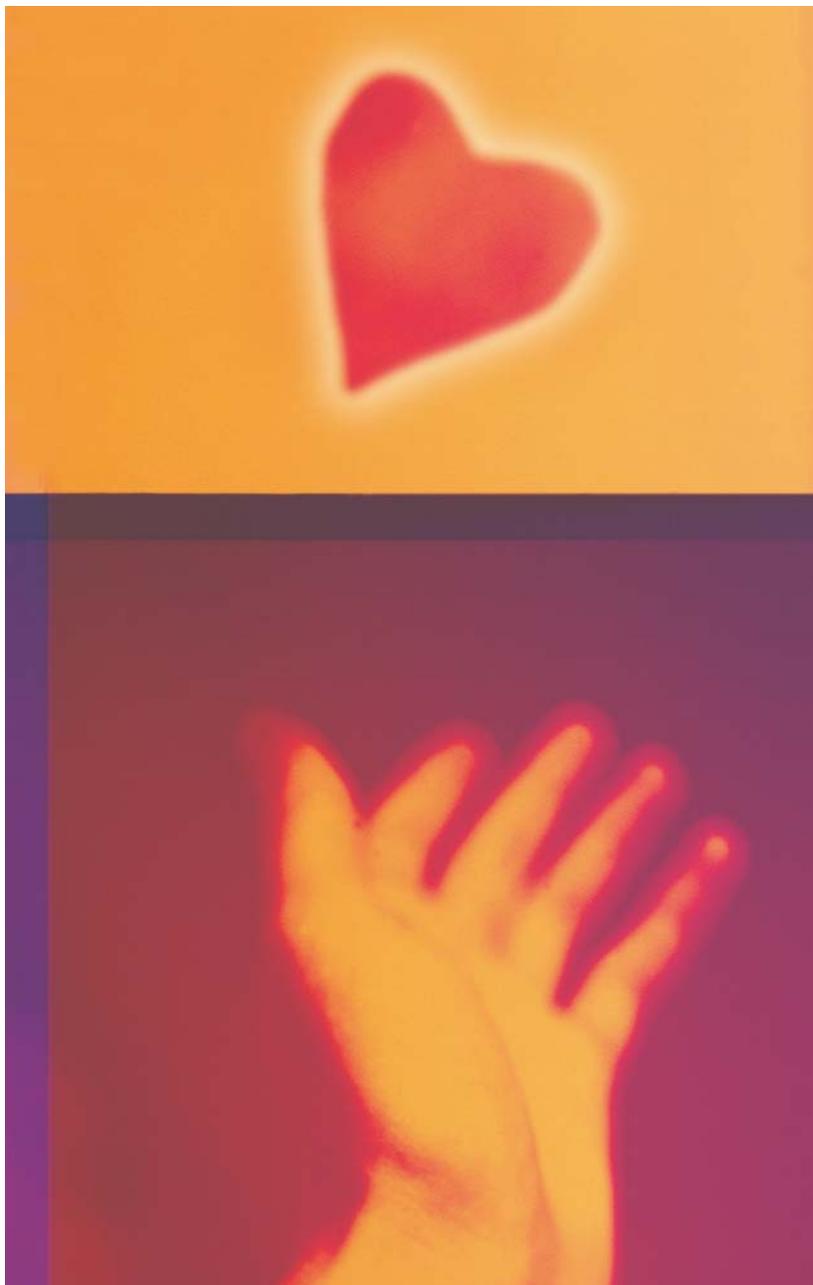


Emory Transplant Center

MAKING A DIFFERENCE IN THE LIVES OF OUR PATIENTS AND OUR COMMUNITY



Your Heart Transplant
AT EMORY UNIVERSITY HOSPITAL
A Journey for Life

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The most important information you may ever read

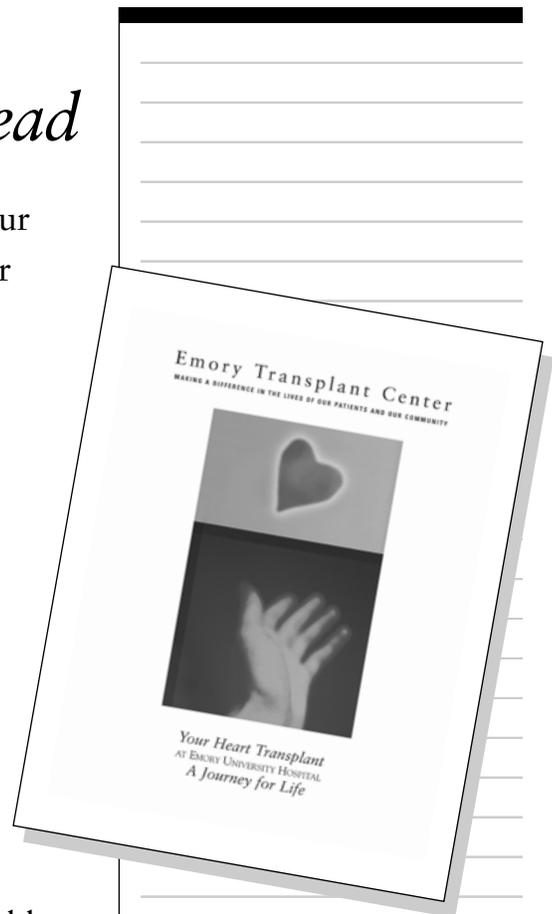
Now that you are considering a heart transplant, your success as a transplant recipient may depend on your understanding of what to expect before, during and after your transplant. The purpose of this book is to provide you and your family with that information. Please read each section carefully. Feel 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 meeting 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.



Bring your Heart Transplant manual with you to each visit. Use these margins to jot down notes or questions.

Why You May Need a Heart Transplant

THE HEALTHY HEART

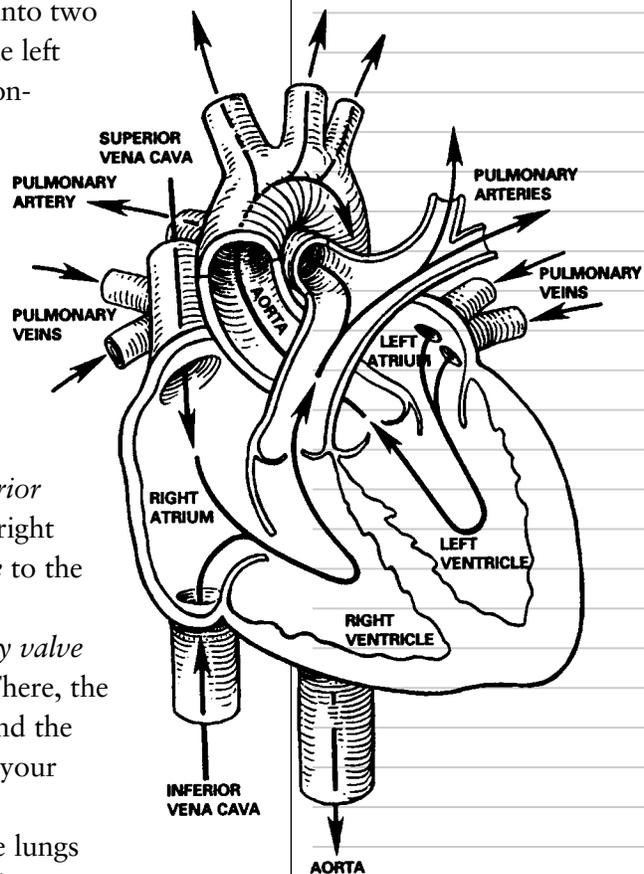
The heart is a very strong muscle that forcefully pumps oxygen-rich blood to all parts of the body. Located in the middle left of the chest, the adult heart is about the size of a man's fist and has four chambers. The two upper chambers are the right and left *atria*. The two lower chambers are the right 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)

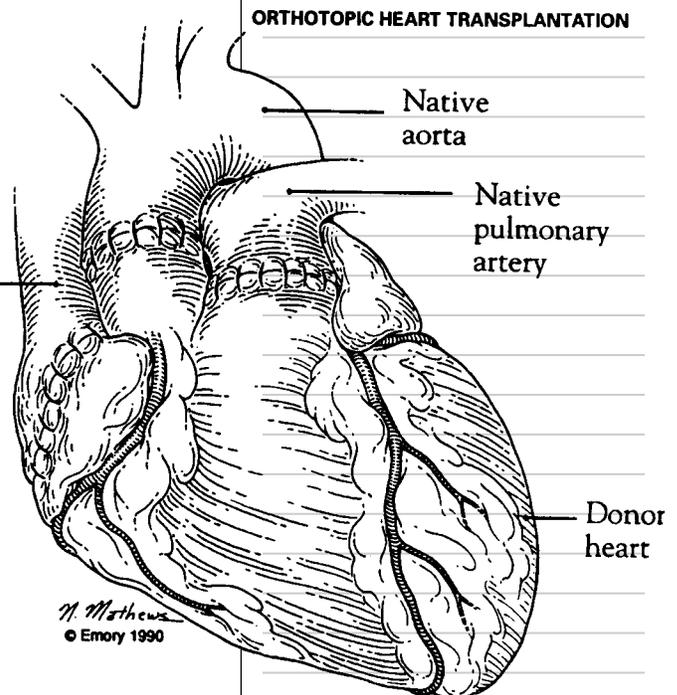
Regardless of what has caused your heart function to deteriorate, the result is the same: your heart becomes weak and unable to pump enough oxygen-rich blood through the vessels of your body. Over time, fluid can build up in your lungs, abdomen or legs and feet. This is called *congestive heart failure* (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.

Native
superior
vena cava



When your heart deteriorates, it can't pump enough oxygen-rich blood to the vessels of your body.

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.

TESTS:

- Blood work
- Breathing test
- Echocardiogram
- Exercise treadmill
- Heart pressures
- Urine collection

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.



My transplant surgeon is

My cardiologist is

My transplant coordinators are

My social worker is

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.

My psychiatrist is

My psychiatric clinical nurse specialist is

My clinical nutritionist is

My pharmacist is

My physical therapist is

My chaplain is

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.

My staff nurse is

FINANCIAL QUESTIONS?

Call the financial coordinator at 404-712-4601

DISABILITY QUESTIONS?

Call the social worker for heart transplantation at 404-712-5524

My insurance case manager is

Phone:

REMEMBER:

Bring to your evaluation a copy of your benefits for heart transplantation, including deductible and co-payment amounts.

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 and physician 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 \$88,751.
- Physician charges from the date of discharge, including 90 days of follow-up care, average \$20,849.
- 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). All Emory Clinic charges will be billed on one account.

MORE ABOUT OUR FEES

Our fees reflect the fact that the physicians and transplant team members are specialists in this area and bring to your case training, expertise, and experience of the highest level.

YOU WILL RECEIVE SEPARATE BILLS FROM:

- *Emory Hospital for inpatient and outpatient hospital services*
- *Emory Clinic for doctors’ fees and medical services*

PAYMENT

ARRANGEMENTS

Emory University Hospital and The Emory Clinic provide services to you with the expectation that you will make the payment in full, not your insurer.

If you will not be able to pay the balance on your account in full, the hospital and clinic business offices will be happy to work with you to set up payment arrangements.

To arrange a payment plan, please call the financial coordinator at 404-712-4601.

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 usual 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?

WRITE ANSWERS HERE

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.



Heart transplantation puts great demands and stress on recipients and their families. Call on the transplant team to help.

Support Groups:

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.



Do not have anything to eat or drink except sips of water with your routine medicines after we call you for transplant.

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.



A heart-lung machine will work as your heart and lungs during the transplant surgery.

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.

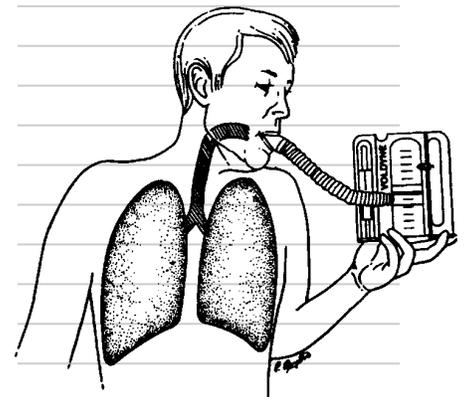
DEEP BREATHING AND COUGHING

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.

HOW TO USE THE INCENTIVE SPIROMETER:

1. Assume a comfortable relaxed sitting position.
2. Attach one end of the tubing to the unit and one end to the mouthpiece.
3. Slide the pointer to your target volume as instructed by the respiratory therapist or nurse.
4. Hold the unit in an upright position.
5. Exhale normally, then place your lips tightly on the mouthpiece.
6. Breathe in slowly to raise the piston to the target volume.
7. Avoid raising your shoulders as you inhale.
8. Remove the mouthpiece and hold your breath for about five seconds until the piston falls to the baseline.
9. Slowly exhale through your mouth.
10. After each breath, cough and breathe deeply. Do not just clear your throat.
11. Relax and pace yourself in order to avoid excessive fatigue or dizziness.
12. Repeat steps 5-9 at least ten times.



INCENTIVE SPIROMETER

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 and Prevention (CDC) and the United Network for Organ Sharing (UNOS). However, transplant recipients may be at risk for contracting certain diseases from the organ donor, such as various types of infectious diseases, which are not detected during the organ donor 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.

REJECTION WARNING SIGNS

If you have any of these symptoms, call the transplant coordinator:

- *Low-grade fever*
- *Feeling excessively tired or fatigued*
- *Shortness of breath*
- *Overnight weight gain greater than 2-3 pounds*
- *Loss of appetite, nausea, or vomiting*
- *Change in pulse rate or heart rhythm*

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 anti-bacterial 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 you developing 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.

INFECTION WARNING SIGNS

If you have any of these symptoms, call the transplant coordinator:

- *Fever, chills, sore throat*
- *Nausea, vomiting, diarrhea*
- *Headache, sinus drainage*
- *Productive cough*
- *Wound redness, swelling, or pus*
- *Pain or burning while urinating*

CYTOMEGALOVIRUS (CMV)

Cytomegalovirus(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 that lasts 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 and lungs (pneumonia).

If your donor was positive for CMV antibodies and you were not, you will be monitored for the development of CMV regularly through blood tests for several weeks following your transplant. As your doses of immunosuppressants are lowered over time, your risk of CMV will decrease as well and the testing will be stopped. If you develop an active CMV infection, you will be treated with medications 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 and keeping your own medication records in the hospital a few days before your discharge.

All transplant patients take *cyclosporine*, *CellCept®* and *prednisone* to help prevent rejection of their new organs. The following pages explain what's important to know about these medicines. You may be placed on medications other than these after transplant. Please ask your transplant coordinator for information about those medications.

WHERE TO GET YOUR MEDICATIONS

Soon after your transplant surgery, the coordinator 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.

Prior to your discharge, a coordinator will call your pharmacy with your medicines. It is your responsibility to contact your pharmacy when you run low on medications or to contact our office when you need new prescriptions, so that you will always have all of your medicines. Your prescription usually will be for a month's supply along with five refills. 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.



PLAN AHEAD:

Before you have your transplant, arrange for your medications with the pharmacy of your choice.

My home pharmacy is

Their phone number is

My Atlanta area pharmacy is

Their phone number is



IMPORTANT:

Please bring your medications in their bottles with you to your first follow-up visit.

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.
- 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

IMPORTANT:

Do NOT eat or drink ANYTHING 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.*

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

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

• *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.*

Other Helpful Information

MASON GUEST HOUSE

The Mason House is a private retreat that offers low cost housing for organ transplant candidates, recipients, living donors, 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, TV's 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.

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.

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
- Enrollment in Ticket to Work program

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 Heart Transplant Program

www.transplant.emory.edu

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

