



HEART TRANSPLANT PROGRAM

# Before your transplant



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## HEART TRANSPLANTATION AT THE DUKE TRANSPLANT CENTER

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Your doctor referred you to the Duke Heart Transplant Program because there is a possibility that heart transplantation can help you. At this time, heart transplantation may be something you know very little about. The purpose of this booklet is to provide information about heart failure, the heart transplant evaluation process, and an idea of what to expect after a heart transplant.

The words “you may need a heart transplant” probably made you feel anxious and uncertain. You are not alone. This is a stressful time for most patients and their families. We expect you will have many questions, and we hope the information in this booklet will begin to answer some of them. As you go through it, please write down questions as you think of them so you can discuss them with members of the heart transplant team.

### How Your Heart Works

A healthy heart is about the size of a fist and is located in your chest, between your lungs. Your heart has four chambers, a left and right atrium and a left and right ventricle. There are also four valves in your heart to prevent blood from moving the wrong way. As your heart muscle contracts, blood moves from the right side of your heart, into your lungs where it picks up oxygen, and then to the left side of your heart. The left ventricle is the heart’s main pumping chamber. It pumps blood to your entire body — from your head to your toes. Once your blood leaves the left ventricle it moves through your arteries where it supplies your body with oxygen and nutrients. The blood then returns to the right side of your heart through your veins.

The healthy left ventricle is strong and thick, and pumps out 55%–65% of its blood with each beat. This percentage is called the “ejection fraction.” You may have been told that your heart is working at some percentage of normal, and your doctor was probably referring to the ejection fraction. To be considered for transplant, the percentage is usually less than 20%.

Your heart also has an electrical system that acts as a power source to coordinate the contraction and relaxation of the chambers. Your heartbeat is triggered by electrical impulses that travel down a special pathway through the heart. There are special cells in your heart tissue that are able to start this electrical impulse. When those cells or the pathway is damaged you develop arrhythmias, which are abnormal heart rhythms such as atrial fibrillation or ventricular tachycardia.

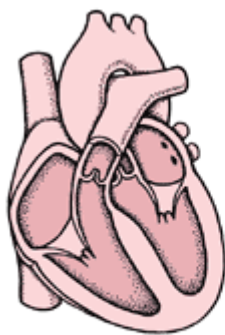
### Heart Failure

Cardiomyopathy is a term that means “weakness of the heart muscle.” The term “heart failure” usually refers to abnormal function of the left ventricle that causes symptoms. There are many reasons why the left ventricle cannot pump blood around your body effectively. For some people, blocked coronary arteries (the vessels that supply the heart muscle with oxygenated blood) have caused parts of your heart muscle to become injured and permanently weakened. For others, an infectious or inflammatory process may result in a permanently enlarged and weakened heart muscle. Heart failure may also result from the stress of pregnancy, exposure to poisonous



substances, congenital abnormalities (birth defects or hereditary conditions) or electrical instability resulting in abnormal heart rhythms. Despite our current level of understanding of heart failure, there may be no identifiable cause for an individual's heart failure.

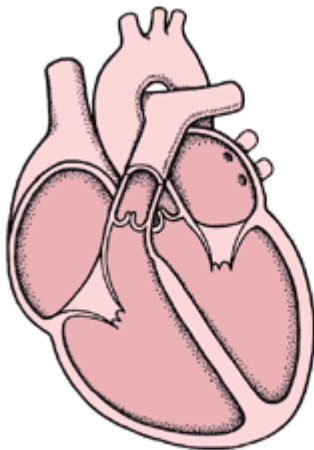
Most patients with heart failure can be effectively treated with medications. In some cases, surgery is required to fix blocked arteries or abnormal heart valves. Heart transplantation is an option only after all other available treatments have been tried and failed to improve heart function. Heart transplantation has been used to successfully treat many different types of heart failure. Each person's medical history must be evaluated individually to determine the best possible treatment, and the only way to determine if having a heart transplant is the best treatment for your heart failure is to undergo a heart transplant evaluation.



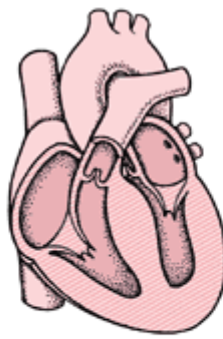
Normal

### Types of Cardiomyopathy

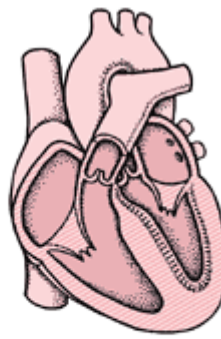
There are three main types of cardiomyopathy—dilated, hypertrophic, and restrictive. In dilated cardiomyopathy, the ventricles enlarge. In hypertrophic cardiomyopathy, the walls of the ventricles thicken and become stiff. In restrictive cardiomyopathy, the walls of the ventricles become stiff, but not necessarily thickened.



Dilated  
Cardiomyopathy



Hypertrophic  
Cardiomyopathy



Restrictive  
Cardiomyopathy

### What is Heart Transplantation?

A heart transplant is an operation during which your diseased heart is removed and replaced with a healthy heart. The new heart comes from a donor. A donor is a person who has died, and whose family has decided to donate his or her heart to someone who will benefit from it. Organ donation is an unselfish act of compassion and kindness that allows good to come from a loved one's unexpected death.

Heart transplantation is not considered an experimental operation. Since the early 1980s, it has been an effective, medically accepted treatment for heart failure. Approximately 4,000 heart transplants are performed worldwide each year. Duke's heart transplant program was established in 1986; and, as of July 2014, it has performed more than 1000 transplants. Most people who have a heart transplant are able to return to their jobs and families and to lead active, fulfilling lives.

### UNOS

The United Network for Organ Sharing (UNOS) is the company that manages solid organ transplant in the United States. UNOS is responsible for maintaining the national transplant waitlist and matching potential donors with people waiting for a transplant. They make the policies that make the best use of the limited number of donor organs and make sure the transplant process is fair. In addition, they manage information on every transplant that takes place in the United States and provide education to the public about organ donation.

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## DETERMINING IF YOU ARE A CANDIDATE FOR HEART TRANSPLANTATION

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### Evaluation for Transplantation

There are four reasons for the heart transplant evaluation:

1. To determine the extent of your heart disease.
2. To find out the health of your other body systems (lungs, liver, kidneys, etc.).
3. To allow you and the team to decide if transplantation is right for you.
4. To allow you to meet members of the transplant team.

We will want to know more about you, and we expect you will have many questions for us. Evaluation consists of several tests, blood work, and interviews with transplant team members. The tests and interviews require several days to complete. If some of the tests have already been performed, let the transplant team know. You may not need to repeat them. The entire evaluation will take about two to four weeks. During this time, the test results are gathered, analyzed, and presented at a transplant team meeting.

### Standard Criteria Program

Heart transplantation is considered for men and women less than 65 years old who, except for heart failure, have no other major disease or health problems. Individuals considered for heart transplantation have had maximum medical and surgical treatment for their heart disease, but their heart function continues to decline, and recovery of heart function is not expected. Individuals who use tobacco products, drink alcohol excessively, or use illicit drugs, and who are unable to change their lifestyle, would not do well after a heart transplant; they will not be accepted into the program. Smoking greatly increases the chance of infections and heart disease, and substances such as alcohol or street drugs interfere with function of the medications needed to

keep you healthy after transplantation. Persons who are able to lead a healthy lifestyle are likely to do well after a heart transplant.

### **Expanded Criteria Program**

The Expanded Criteria Program at Duke University Hospital (DUH) is a program for individuals who do not meet the criteria for the standard program. As with the standard program, candidates cannot use tobacco products, drink alcohol excessively, or use illicit drugs. However, candidates in this group can be over 65 years of age, or have other conditions that would exclude them from the Standard Criteria list.

Individuals in the expanded criteria program must be willing to accept a donor organ that has good, but somewhat compromised function. The age of the donor may be over 45 if male or over 55 if female, the donor's ejection fraction may be 35%–45% at the time of the offer, the echocardiogram (ECHO) may indicate moderate enlargement of the left ventricle, the donor may have coronary artery disease that can be repaired during transplantation, or the donor may be on intravenous (IV) medicine to help the heart to pump.

### **Mechanical Circulatory Support**

Ventricular assist devices (VADs) are mechanical devices/machines that can provide an extended period of support for a failing heart. The support offered by VADs is more than the short-term capabilities of traditional support devices like an intra-aortic balloon pump (IABP). The surgery to place a VAD is similar to other types of heart surgery. Support times on the VADs can range from a month to several years, depending on the type of device used. Also, depending on the type of ventricular assist device an individual has, it may be possible to return home after recovery from surgery, and while waiting for heart transplantation. Individuals who are considered for this therapy will be referred to the VAD team.

### **Heart Transplant Team Members**

#### **Transplant Cardiologist**

This team member is a physician who specializes in evaluating and treating patients with end-stage heart failure. The transplant cardiologist is central to determining the timing of the need for transplantation and continues to follow you through the evaluation phase while you are waiting and at regular intervals after transplantation. The transplant cardiologist will also talk to you about whether you need a VAD as a bridge to transplantation.

#### **Transplant Surgeon**

This specialist performs the transplant operation. You will meet a transplant surgeon during the evaluation. This is a good time to ask any questions you may have about the surgery itself. The transplant surgeon is most involved in your care while you are still in the hospital after your heart transplantation.

### **Transplant Coordinator**

Your main contact with the transplant team is the transplant coordinator. Transplant coordinators are also nurses. The transplant coordinators follow you through the evaluation phase, the transplant operation/surgical recovery phase, and after transplant. A transplant coordinator will talk with you and your family in depth about the evaluation process and provide you with information on what life is like after heart transplantation.

### **Transplant Social Worker**

A social worker will help you determine your ability to deal with the impact of heart transplantation on you and your family. The social worker will ask questions about your family life, social habits, and financial concerns. The social worker will assist you with coping skills, family issues, adjustment to transplant, substance abuse, and relocation resources.

### **Transplant Psychologist**

The psychologist will talk to you about the stress and anxiety you may feel during both the heart transplant evaluation process, and — after surgery — as you adjust to your life following transplantation. The psychologist will also ask you to complete questionnaires that will help assess your ability to adjust to heart transplantation.

### **Transplant Financial Coordinator**

During the evaluation and post-transplant care you will need to consider financial, housing and transportation needs. The transplant financial coordinator will contact your insurance company and inform you of the extent of your coverage for the transplant operation. They can assist you in determining your out-of-pocket expenses in both the short term and the long term and suggest ways of meeting these expenses. While it will be your responsibility to manage your own financial matters, the financial coordinator can be a useful resource.

### **Transplant Dietitian**

A registered dietitian will meet with you to review your nutritional state, dietary habits and provide you with nutritional education based on your own health situation. If you need to lose weight, the dietitian will work with you to develop a plan for weight loss.

### **Transplant Pharmacist**

The transplant pharmacist reviews your medications and works with the transplant team to recommend medications. The pharmacist will also meet with you and your caregivers after transplant to teach you about your new medications.

### Heart Transplant Evaluation Testing

The transplant cardiologist along with the transplant coordinator will decide what tests you need based on your history and your current condition. You may not need all the tests described below or you may need more tests not described here. Your transplant coordinator will discuss what tests are ordered with you.

#### Left Heart Catheterization

This test gives us information about arteries that supply your heart with blood. After numbing your skin, a catheter is inserted through an artery in your arm or leg and advanced into the left side of your heart. Dye is then injected to determine if blockages are preventing blood flow to your heart muscle. You will lie on a table for a short period until the test is completed, and the catheter is removed. After the test, you will be asked to lie still, and pressure may be applied to prevent bleeding. You will remain in bed for two hours after the procedure. If needed, medication will be given to help you relax before the procedure. If you take Coumadin, or any other medicine to thin your blood, you may need to hold it prior to the procedure. The dye used in this test contains iodine, so if you have an allergy to either iodine or shellfish, please tell your cardiologist or transplant coordinator. You should discuss this with a member of the transplant team.

#### Right Heart Catheterization

This test measures the pressures inside the right side of the heart and can be done at the same time as the left heart catheterization. After numbing the skin, a catheter is inserted through the vein and into the right side of your heart. There is no dye used in this test, and you will not be able to feel the catheter as measurements are taken. After the catheter is removed, pressure will be applied to the insertion site for a few minutes to prevent bleeding. You will be able to resume normal activities within an hour of this test. You will also need to hold Coumadin or any other medicines to thin your blood before this test. You should discuss this with a member of the transplant team.

#### Level 1 Exercise Test (CPX Test)

The purpose of this test is to determine your heart's response to exercise. The results tell your doctor the amount of oxygen your heart can provide to your muscles during exercise. If your heart cannot respond to exercise, you may be sick enough to need a heart transplant. You will be asked to breathe through a small snorkel-like device both at rest and during exercise. This test takes about two hours to complete.

#### Ventilation-Perfusion Scan (V/Q Scan)

The purpose of this test is to look for evidence of a blood clot in your lungs, called a pulmonary embolus (PE). You will be asked to breathe a special gas mixture through a mask. You will also receive a small injection into an arm vein. A large machine called a Ventilation-Perfusion Scanner will then record data about your blood supply to your lungs while you lie on a table.



### **Pulmonary Function Testing (PFT)**

This is a group of tests that measures how well your lungs take in and release air, and how well they move oxygen from the air into your blood stream. You will be asked to breathe in and out, using your best effort, while a technologist measures your lung volumes, and compares the results with typical values for a person of your size and age.

### **Blood Tests**

We will draw blood to check the function of your kidneys, liver, and immune system. We will determine your blood type to match you with a compatible donor heart. We will also draw blood that tells us if your immune system has a memory of different viruses you may have been exposed to throughout your lifetime. Some of the viruses we check include chickenpox, mononucleosis, and the hepatitis viruses. We may need to adjust your medications after transplant based on these results.

### **Echocardiogram**

This test uses sound waves to give us a moving picture of your heart. The picture gives us information about your heart valves and the ability of your heart to pump blood throughout your body (the ejection fraction). This test is painless and does not use radiation. Clear gel is used to help the ultrasound wand obtain pictures of your heart and slides easily over your chest.

### **Gallbladder Ultrasound**

This test also uses sound waves to see the organs in the right side of your abdomen, including your gallbladder and liver. It tells us if you have gallstones and if you have inflammation in your liver or the ducts (connections) between your liver, gallbladder and intestines. Clear gel is applied to the abdomen to help the ultrasound wand slide easily.

### **Carotid Ultrasound**

Again, sound waves and clear gel are used in this test. This time, they are used to view blood vessels in your neck. This test is used to determine if there is a blockage or a narrowing in the arteries supplying blood and nutrients to your brain. If there is significant blockage or narrowing, procedures may be done before or at the time of your transplant to reduce the risk of stroke.

### **Arterial Brachial Index Test (ABIs)**

This is a test used to screen for peripheral arterial disease (PAD) of your legs. It is done by measuring your blood pressure at your ankle and your arm while at rest. The blood pressures are repeated after a few minutes of walking on a treadmill.

### **CAT Scan of Chest**

If you have already had heart surgery or there is concern about underlying lung disease, we may ask you to have a CAT Scan of your chest to determine the amount of scarring in your lungs and the position of your heart relative to your breastbone. During this test a small IV may be placed in

your arm to administer dye. Individuals with an allergy to iodine or shellfish should alert the transplant coordinator prior to the CAT Scan.

### **Routine Health Maintenance Testing**

If you are 50 years or older you will need a colonoscopy if you have not had one done in the last five years. If you are female you will need a PAP smear, and if you are over 40 you will also need a mammogram if you have not had one done in the last year. You will also need clearance from a dentist that says you do not have any active infections in your mouth. These tests can all be done by local doctors or we can arrange to have them done at DUH. Your transplant coordinator will discuss this with you.

### **Your Responsibility in the Evaluation**

As you talk to various members of the transplant team, you will need to think about the impact heart transplantation will have on you and your family. You will want to learn all you can about what life will be like after transplant. Please write down any questions you may have, and plan to discuss them with members of the transplant team as you meet with them. You can also contact your coordinator through the transplant office.

A new heart will mean new responsibilities. If it is determined that a heart transplant is the best treatment for your heart disease, you will be asked to commit to follow-up care. The main areas of commitment to consider are: taking daily medications for the rest of your life, keeping clinic appointments, and living a healthy lifestyle after a heart transplant. You will be asked to record your blood pressure, temperature, and weight each day, and bring your records with you to each clinic appointment. Initially, you will return to the Duke Outpatient Clinic every week for outpatient tests and clinic visits. As time passes, the visits become less frequent, but you will return to DUH for follow-up every six months for the rest of your life. We will also expect you to keep in close contact with the transplant team regarding any changes in your health because of the potential impact on your transplanted heart. Life after transplant means a commitment to close follow-up with the transplant team.

Please think about who will be available to stay with you after your heart transplant to provide you with emotional support and help you while you recover from surgery. You will also need to think about who will be available for transplant learning sessions with you. You will also need someone to drive you to your clinic appointments after your transplant until you are well enough to drive yourself, usually about six weeks. Be prepared to talk about your plans with the transplant coordinator and the social worker.

### **Evaluation Results**

When all the test results are available, the transplant team will meet to decide if heart transplantation is the best treatment for you. A member of the transplant team will discuss your test results with you and give you the team's recommendations. If it is determined that a transplant is the best treatment for your heart disease, you will be asked to commit to follow-up care. You may also be asked to make a written commitment to abstain from smoking or alcohol use. If it is determined that transplant is not the best treatment option for you, the transplant team will provide you with recommendations for further treatment of your heart failure.

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## WAITING FOR YOUR TRANSPLANT

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Once you and the transplant team have decided heart transplantation is the best choice for you, your name will be placed on a national waiting list with the United Network of Organ Sharing (UNOS). Hearts are matched by body size, blood type and clinical status. When a donor heart is found, it is given to the person who best matches the donor's size and who has been on the waiting list the longest at the highest clinical status. The sickest patients receive transplants first. The wait for a heart transplant ranges from several days to more than a year. The transplant team will talk to you about how long you can expect to wait for a heart transplant and which status matches your situation.

The following are the definitions for the different statuses on the waitlist as defined by UNOS:

**1A:** the highest priority on the waiting list; patients who are on two or more IV medications, a mechanical assist device (LVAD) that is not working correctly, a ventilator or who have a short term life expectancy

**1B:** the second highest priority on the waiting list; patients who require continuous infusion of one IV medication or a mechanical assist device at home

**2:** the lowest priority on the waiting list; patients who are managed on oral medication

**7:** temporarily inactive on the waiting list

Sometimes, patients must wait in the hospital for their new heart so they can receive extra medical support for their heart failure. Waiting for a new heart can be frustrating and stressful. Please understand that no one has any control over when a donor heart becomes available and that this can be a very difficult time for you and your family.

Support from your family and friends will be very important during your wait. Learning relaxation techniques and talking with the social worker or psychologist may help. The DUH Heart Center Support program can also schedule visits with volunteers who have had heart surgery or even a heart transplant. Many people find it helpful to talk to someone who has been through the transplant process.

The social worker can provide you with information on the heart transplant support group and caregiver support group.

If you are at home when a donor heart becomes available, you must be ready to come to the hospital right away. This means you must be available for the transplant call at all times. You must notify the transplant office if any of your contact information changes. You will need to be on your way to DUH within 30 minutes of notification by the transplant coordinator. The amount of time that will be available for you to reach the hospital will vary from one donor situation to another; however, we generally ask that you be able to reach the hospital in four hours. If you cannot get to the hospital in four hours, you may need to relocate closer to DUH during your wait for a donor heart.

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### THE TRANSPLANT OPERATION

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After you receive a call that we have a donor heart for you, you must not eat or drink anything, or stop for any reason except refueling or restroom breaks unless there is a true emergency. You should bring your medication list with you, an extra bag of medicine if you are on an IV infusion or extra batteries if you have a VAD. The transplant coordinator will tell you where to go, the DUH Emergency Room, Duke North Admitting or the Duke Medical Pavilion. Where you go depends on the time of day and the day of the week. From there, you will be taken to a hospital room or to the pre-operative holding area. When you arrive in your room, you will be prepped for surgery. A chest X-ray, EKG, and routine blood tests will be done. A member of the transplant team, including the surgeon who will perform your transplant, will talk with you and the family members accompanying you. You will also meet an anesthesiologist, the doctor who will put you to sleep for the surgery. The anesthesiologist will take you to the operating room in your bed or on a stretcher. The amount of time between when you arrive at DUH and go to the operating room for your transplant varies from case to case. Delays are common due to the complex nature of coordinating a transplant procedure at the donor hospital.

On arrival in the operating room preparation area, you will be given medication to make you sleepy and relaxed before you are put to sleep. The heart transplant operation takes between four and six hours. Your family will be shown where to wait and will be informed about your condition when the surgery is finished. During surgery, you will have an incision made down the length of your breastbone (sternum). Your diseased heart is removed when the donor heart arrives in the operating room. Your new heart is then sewn into place. There are four main connections to attach the new heart. If you have a pacemaker or defibrillator, this will also be removed. You can talk to the surgeon during your transplant evaluation if you have any questions about how the surgery is performed.



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### AFTER YOUR SURGERY

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Once your new heart is sewn in and begins to beat, you will be taken to the Cardio-thoracic Intensive Care Unit (ICU). After the nurses settle you in, they will let your family members visit. This settling in will generally take an hour or longer. You will still be asleep, because the anesthesia takes several hours to wear off. Once you wake up, it is normal to be confused. You will have many IV lines and tubes; you will be in a room with many monitors and machines. Your hands may be tied down until you are fully awake and able to follow directions. The restraints are a safety measure to prevent you from accidentally pulling out any of your critical tubes before you are fully awake. You will be given medication to control your pain and to help you relax. You may not remember much of the first day after your surgery.

Initially, you will have a breathing tube in your mouth and throat. This tube will be connected to a ventilator that will assist your breathing until you are fully awake. You will not be able to talk while the breathing tube is in place, but it will be removed when you are fully awake and no longer need help breathing.

As soon as the breathing tube is removed, it will be important to take deep breaths and cough to fully expand your lungs and remove any mucous that might cause a lung infection. You can play a big role in preventing a lung infection (pneumonia) after your operation by taking very deep breaths as often as you can.

You will have another smaller tube in your nose or mouth that goes to your stomach. It is called a nasogastric (NG) tube. This tube drains your stomach juices to help prevent you from feeling nauseated. The NG tube will be removed when your anesthesia wears off and your stomach and intestines begin to work normally again.

You will have a large intravenous (IV) catheter in a vein in the side of your neck. This catheter allows monitoring of your heart function and guides the medical team in making changes to the medications that are helping your new heart recover. You will also have two or more IVs in your arms for fluids and medications. There will be pumps beside your bed with bags of IV fluids hanging overhead. These fluids contain medications to help your new heart beat stronger for the first few days after your operation. You will also receive medications to prevent rejection of your new heart.

Although your pacemaker or defibrillator was removed during the operation, you will have temporary pacemaker wires coming out of your chest and attached to a pacemaker machine. It is normal for the heart to be sluggish for the first few days after transplant so this temporary pacemaker helps your new heart pump effectively. The wires will be removed before you go home.

You will also have one to four chest tubes that drain blood and fluid from the surgical area in your chest to containers stored at the side of the bed. Once the drainage has stopped or diminished to a low level, the chest tubes will be removed.

There will also be a catheter in your bladder to drain your urine. Initially, the ICU nurse will measure urine output every hour. The bladder catheter (Foley) is typically removed in a few days when you are able to go to the bathroom on your own, and the team is confident that your kidneys are functioning effectively.

You will be assisted out of bed to a chair within 24 hours of your transplant if you are able. A physical therapist will start working with you on a walking program. When you are ready to leave the ICU (usually three to five days), you will be transferred to a thoracic surgery step-down unit. On the step-down unit you will continue to recover and regain your strength. The transplant team will work with you and your family to get you ready to go home.

Every patient experiences some pain after a major operation, but for each person, the experience is different. Your bedside nurses in both the ICU and later in the step-down unit will work with you to make sure you receive the proper type and amount of pain medication to keep your pain well-controlled. This enables you to rest comfortably, and it also allows you to get out of bed so you can begin your recovery as soon as possible.

### **Recovery**

Each person recovers at their own rate, but patients who were active before transplant are usually ready to go home seven to ten days after the transplant procedure. When they are ready to leave the hospital, most patients are able to walk several laps around the hospital floor without difficulty. Patients who were bedridden and very weak before transplant may take longer to recover.

For the first four to six weeks after transplant, you will have some restrictions on your activity while your incision heals on both the inside and the outside. For example, you should not drive or lift heavy objects for six weeks. The transplant team will review everything you need to know about taking care of your new heart before you leave the hospital.

### **Possible Complications**

Complications after heart transplantation may include failure of the new heart to beat or pump effectively, stroke, bleeding, blood clots, infection, rejection, damage to nerves, increased risk of cancer, renal failure, blocked coronary arteries in your new heart and side effects from the anti-rejection medications. There are treatments for these complications, but it is possible that some complications may be fatal. The transplant coordinator will talk to you in greater depth about these potential complications.

### **Rejection**

After the donor heart is sewn into your body, your body's immune system will recognize that the cells in the new heart are not exactly like the rest of your body's cells. Without immunosuppressive medication, the immune system, the body's natural defense system, will begin

to attack the new heart because it “sees” the heart as a harmful foreigner. Without immunosuppression, your immune system would send special cells to the new heart to destroy it. This process is called rejection. To prevent the body from rejecting the new heart, you will take medications to suppress, but not disable, your body’s natural immune response. The body will always try to reject the new heart, although it generally tries hardest in the first few months after your transplant. The amount of immunosuppressant medication needed varies for each individual, and the amount of medication in your bloodstream will need to be monitored regularly to make sure you have a good level. The immunosuppressant medication must be taken at regular intervals every day for the rest of your life.

While you are in the hospital after your transplant, you will be given the post-transplant information manual that will provide more detail about anti-rejection medications and how to take care of your new heart. One of the transplant coordinators, with assistance from the transplant pharmacist, will teach you about these new medications.

Most of the time, rejection does not cause symptoms which is why we monitor your new heart with blood work and heart biopsies (see below). Signs of rejection include shortness of breath or swelling in your legs or belly. Rejection can usually be treated by increasing the dose of your anti-rejection medication or with high-dose steroids at home. If this does not stop the rejection, you may need to be admitted to the hospital for more aggressive treatments.

### **Biopsies to Monitor for Rejection**

Biopsies are done on your new heart to monitor for rejection. The transplant cardiologist uses lidocaine to numb the right side of your neck, then uses a needle to access a vein in your neck that leads into your heart. Several small pieces of heart tissue are removed from your right ventricle and sent to the pathologist. The pathologist looks at the tissue under a microscope to see if any of your immune system cells are activated and injuring your heart. Heart biopsies are graded on a scale from zero to four.

You will have biopsies done every week for the first four weeks after your transplant. Over time, your risk of rejection goes down so you will not need biopsies as frequently. This schedule allows your transplant team to detect rejection and treat it before your immune system does damage to your heart.

If you do not have many rejection episodes early after transplant, you might be able to switch from biopsies to Allomap testing, a blood test that checks for rejection. You can talk to your transplant team about whether the blood test is a good choice for you.

### **Infection**

The risk of infection is higher for transplant recipients than other surgical patients because the treatments needed to prevent organ rejection make the body less able to fight infection. Sites of infection may include but are not limited to wound, bloodstream, bladder and lungs (pneumonia). Infection is a major cause of hospital admission for heart transplant recipients and a leading cause

of death in the first year after transplant. You will be prescribed several antibiotics and anti-viral medications to prevent common infections in transplant patients.

### **Kidney Damage**

The medications used to prevent and treat rejection after transplant can cause damage to your kidneys. This affects more than 25% of patients in the first year after transplant and around 5% of patients will develop end-stage kidney disease requiring dialysis within seven years after transplant.

### **Cancer**

Suppressing the immune system puts you at risk for cancer. There is a 3% chance of developing all types of cancer in the first year after transplant, although the most common type of cancer is skin cancer. There is also a specialized form of lymph node cancer that can occur after transplant.

### **Cardiac Allograft Vasculopathy (CAV)**

CAV, also called transplant coronary artery disease, is a form of chronic rejection and is a progressive disease in which the walls of the transplanted heart's coronary arteries become thick, hard and narrow. This limits the amount of blood and oxygen being delivered to your new heart and can cause a heart attack, heart failure, arrhythmias and sudden cardiac death.

### **High Blood Pressure**

The medications to prevent rejection can cause high blood pressure. Hypertension develops in 70% of heart transplant recipients in the first year after transplant and in nearly 95% of patients in 5 years.

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## ADVANCE DIRECTIVE

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The heart transplant program at Duke is committed to achieving the best outcome for you, but we also realize there are many uncertainties ahead. During the waiting period, we ask that you discuss an Advance Directive with your family. An Advance Directive is a legal document that provides a set of directions to guide your health care if you are unable to make decisions for yourself. It can include a Living Will, outlining the level of care you would want for yourself in various medical situations. It may also include designating a Health Care Power of Attorney. The Health Care Power of Attorney indicates a person who would be legally able to speak for you if you are not able to speak for yourself. Some patients also take the opportunity to write a will regarding financial matters, concerns over minor children, or other personal affairs. We ask you to discuss these various issues with your family.

The office of Patient and Visitor Relations — 919-681-2020 — has Advanced Directive forms available that comply with North Carolina laws. If requested, the office of Patient Visitor Relations can help you complete the forms.

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## SUPPORT GROUPS

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### Cardiac Transplant Support Group

This support group is held monthly, on the second Wednesday of each month, in the outpatient clinic (Duke Clinic) for transplant candidates, recipients and their caregivers. The group is facilitated by clinical social workers and provides education on the heart transplant process as well as peer support for participants. There is a toll-free number which allows remote participation. Please contact the clinical social worker for more information.

### Solid Organ Transplant Caregiver Support Group

This support group is held weekly in the hospital and is facilitated by a clinical social worker. This group offers emotional and peer support for caregivers of all solid organ transplant candidates or recipients. Please contact the clinical social worker for more information.

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## WEBSITES

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United Network for Organ Sharing: [www.unos.org](http://www.unos.org)  
Scientific Registry of Transplant Recipients: [www.srtr.org](http://www.srtr.org)



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## LODGING

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### Duke Transplant Center Recommended

To assist our patients and their family members who are in the evaluation, waitlisting and post-transplant phases of care, the Duke Transplant Center contracts with the **Hilton Garden Inn Durham/University Medical Center** to set aside a limited number of guaranteed rooms from Sunday through Thursday nights for a discounted rate of \$60 per night plus tax. **Please contact the front desk regarding this Duke Transplant Center rate. At the time of check in you will need to provide the name of the transplant physician you will be seeing in clinic or your coordinator's name.** At the time of check in you will be asked to show your clinic schedule. Reservations cannot be processed online or through Hilton central reservations at this time.

The Hilton Garden Inn opened in early 2014 and is conveniently located between Duke University Campus and downtown Durham. The hotel has complimentary self-parking, internet, fitness and a free shuttle service to the Duke campus or to a location – such as the Croasdaile Commons – within a five mile radius. The hotel is also located next door to grocery shopping, restaurants and the 9<sup>th</sup> Street district.

**Hilton Garden Inn**  
**Durham/University Medical Center**  
**2102 West Main Street, Durham, NC 27705**  
**919.286.0774**  
**919.864.7102 Jennifer Watson**

While the Duke Transplant Center strives to make the accommodation information below as accurate as possible, the center makes no claims, promises, or guarantees about the accuracy, completeness, or adequacy of the information, and expressly disclaims liability for errors and omissions in the content of this information.

### Hotels within five miles of Duke

The following hotels are within a five mile radius of Duke University Medical Center and provide shuttle services to and from the hospital.

**Brookwood Inn**, 2306 Elba Street, Durham, NC 27705 919.286.3111, within walking distance to hospital.

**Durham Hilton**, 3800 Hillsborough Road, Durham, NC 27705 919.383.8033 or 800.445.8667

**Millennium Hotel**, 2800 Campus Walk Avenue, Durham, NC 27705 919.383.8575

**University Inn**, 502 Elf Street, Durham, NC 27705 919.286.4421 or 800.801.3441

**Washington Duke Inn**, 3001 Cameron Boulevard, Durham, NC 27705 919.490.0999 or 800.433.5853

### Hotels and Motels

**Budget Inn**, 2101 Holloway Street, Durham, NC 27703 919.682.5100, [www.budgetinn.com](http://www.budgetinn.com)

**Carolina Duke Motor Inn**, 2517 Guess Road, Durham, NC 27705 919.286.2771 or 800.438.1158, [www.carolinainn.com](http://www.carolinainn.com)

**Comfort Inn**, 1816 Hillandale, Durham, NC 27005 919.471.6100 or 800.426.7866, [www.comfortinn.com](http://www.comfortinn.com)

**Courtyard by Marriott**, 1815 Front Street, Durham, NC 27705 919.309.1500 or 800.321.2211, [www.marriott.com](http://www.marriott.com)

**Days Inn**, 33460 Hillsborough Road, Durham, NC 27705 919.383.1551 or 800.DAYS.INN, [www.daysinn.com](http://www.daysinn.com)

**Duke Tower Hotel**, 807 W. Trinity Ave, Durham, NC 27701 919.687.4444 or 866.385.3869, [www.duketower.com](http://www.duketower.com)

**Durham Hilton**, 3800 Hillsborough Road, Durham, NC 27705 919.383.8033 or 800.445.8667, [www.hilton.com](http://www.hilton.com)

**Durham Marriott at the Civic Center**, 201 Foster Street, Durham, NC 27701 919.768.6000 or 800.768.6000, [www.marriott.com](http://www.marriott.com)

**Econotel**, 2337 Guess Road, Durham, NC 27705 919.286.7746

**Holiday Inn Express**, 2516 Guess Road, Durham, NC 27705 919.313.3244, [www.hiexpress.com](http://www.hiexpress.com)

**Motel 6**, 3454 Hillsborough Road, Durham NC 27705 919.309.0037 or 800.466.5337

**Innkeeper – Durham South** (RTP I-40), 4433 Hwy 55 (I-40 Exit Hwy. 55), Durham, NC 27701 919.544.4579 or 800.466.5337

**LaQuinta Inn**, 4414 Chapel Hill Blvd (Hwy 15-501), Durham, NC 27707 919.401.9660 or 800.531.5900, [www.lq.com](http://www.lq.com)

**Quality Inn**, 3710 Hillsborough Road, Durham, NC 27705 919.382.3388 or 800.228.2800, [www.duke85.com](http://www.duke85.com)

**Radisson Governor's Inn – RTP**, I-40 at Davis Drive, Exit 280, Durham, NC 27709 919.549.8631 or 800.333.3333, [www.radisson.com](http://www.radisson.com)

**Red Roof Inn**, 1915 North Pointe Drive, Durham, NC 27705 919.471.9882 or 800.843.7663, [www.redroof.com](http://www.redroof.com)

**Residence Inn (Marriott)**, 1919 Hwy, 54 East (I-40 Exit 278), Durham, NC 27713 919.361.1266 or 800.331.3131, [www.marriott.com](http://www.marriott.com)

**Staybridge Suites**, Durham/Chapel Hill, 3704 Mt. Moriah Rd, Durham, NC 27707 919.401.9800, [www.staybridge.com](http://www.staybridge.com)

**Scottish Inn**, 5303 Hwy 70 West, Durham, NC 27705 919.383.2561 or 866.271.9880

**University Inn**, 502 Elf Street, Durham, NC 27705 919.286.4421 or 800.801.3441, [www.universityinnduke.com](http://www.universityinnduke.com)

**Wingate Inn RTP/RDU**, 5223 Page Road, Exit 282 at I-40, Durham, NC 27703 919.941.2854 or 800.228.1000, [www.wingatehotels.com](http://www.wingatehotels.com)

### Other Lodging Options

**Nearby camping facilities**

Duke Oversized Parking, Garage II, 919.684.5773

Birchwood RV Park, 919.493.5573, 5901 Wilkens Drive, Durham, NC 27705

Southern Country Inn, Hillsborough, NC 27278 919.732.8101

Spring Hill RV Park, 3500-1A Old Greensboro Road, Chapel Hill, NC 27516, 919.967.4268 or 800.824.8807

### Suite Hotels/Apartments/Extended Stay

<b>Clairmont at Hillandale</b> 2901 Bertland Avenue, Durham, NC 27705 888.429.1315. 1.7 Miles from Duke. 1, 2, 3 bedroom apartments, furnished available. Washer/Dryer in each and attached garage. 3, 6, 12-month leases.	<b>The Hamptons at RTP Apartment Homes</b> 300 Seaforth drive, Durham NC 27713 919.484.1321 or www.thehamptons.com Studio, 1, 2, or 3 bedroom furnished corporate suites. Pets, pool, fitness center, business center.
<b>Colonial Village at Deerfield</b> 910 Constitution Drive, Durham NC 27705 919.383.0345	<b>Hawthorne Suites</b> 300 Meredith Drive, Durham, NC 27713 919.361.1234 or 800.527.1133 AARP/AAA discount. Full breakfast, full kitchen services, separate living/dining and bedrooms.
<b>DoubleTree Guest Suites</b> 2515 Meridian Parkway, Durham, NC 27713 919.361.4660 or 800.222.TREE 15 minutes to Duke, continental breakfast.	<b>The Heights at LaSalle</b> 500 South LaSalle Street, Durham, NC 27705 919.309.1292 or leasinglasalle@worthingse.com Less than one mile from Duke. Short term lease, furniture rental available, pet friendly, pool, fitness center, elevators, washer/dryer in unit available.
<b>Edinborough at the Park</b> 200 Edinborough Drive, Durham NC 27703 919.941.9635 1, 2, 3 bedroom apartments, clubhouse, gated, swimming pool. 15 minutes from Duke.	<b>Homestead Studio Suites</b> 4515 Highway 55 (RTP) 1920 Ivy Creek Blvd, Durham, NC 27713 919.544.9991 or 919.402.1700 Includes kitchen, free local calls, wireless, pet-friendly and van to Duke.
<b>The Evergreens at Mount Moriah</b> 5512 Sunlight Drive, Durham, NC 27707 919.489.8788 1, 2, and 3 bedrooms, corporate apartments. Mail concierge service, valet dry cleaning, lap pool, tennis courts, fitness center.	<b>Homewood Suites</b> 3600 Mt. Moriah Rd., Durham, NC 27707 919.401.0610 or 800.225.4663 Six miles from Duke. All suites, fully equipped kitchens, complimentary breakfast and evening social hour, outdoor pool spa, exercise room, shopping and restaurants within walking distance.
<b>Extended Stay America</b> 3105 Tower Blvd, Durham, NC 27707 919.489.8444 or 800.398.7829 10-15 minutes from Duke, fully furnished studios, full kitchen, laundry, cable, data port, free voicemail and local calls.	<b>Oakwood Corporate Housing</b> 800.520.5288 1, 2, and 3 bedroom apartments.
<b>Forest Apartments</b> 800 White Pines Drive 919.383.8504	<b>West Village Corporate Lofts</b> 604 West Morgan Street, Durham, NC 27705 919.682.3690 or www.westvillagedurham.com

## Heart Transplant Program

Five minutes from Duke, fully furnished and accessorized studio, 1 and 2 bedroom suites, business center, laundry facilities, fitness center.	Fully furnished suites, cable and internet service, housekeeping, coffee bar, free local calls, business center, fitness center, laundry facilities, and pets.
<b>Studio Plus</b> 2504 NC Highway 54, Durham, NC 27713 919.361.1853 or 800.646.8000 Swimming pool, laundry, exercise room, fully equipped kitchens in all rooms, free local calls, data port, and extended cable.	<b>Wynne Residential</b> 1013 Southpoint Crossing, Durham, NC 27713 919.484.8999 or 800.477.6922 Two communities offering fully furnished accommodations with washer and dryer, pool, business center, fitness, and children's play area.
<b>Trinity Commons Apartments</b> 2530 Erwin Road, Durham, NC 27705 919.309.1409 or <a href="http://www.trinitycommons.com">www.trinitycommons.com</a> 1, 2 bedrooms, rental furniture plans, pets OK, walking distance to Duke, parking, many amenities.	

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## HEART TRANSPLANT PROGRAM MEMBERS

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Cardiologists	Michael Felker, MD Adrian Hernandez, MD Robert Mentz, MD Chetan Patel, MD Joseph Rogers, MD Paul Rosenberg, MD
Transplant Surgeons	Mani Daneshmand, MD Robert Jaquiss, MD Andrew Lodge, MD Carmelo Milano, MD Jacob Schroder, MD
Transplant Coordinators	Kathryn Hord, RN, BSN Tara Miller, FNP-BC, MSN, CCTC Erica Mitchell, RN, MSN Amy Porter, RN, BSN Melissa Williams, RN, BSN, CCTC Joanne Prinzhorn, RN, MSN (Pediatric)
Nurse Clinician	Amy Miller, RN, MSN
Ventricular Assist Device Coordinators	Laura Blue, MSN, RN, NP Kevin Cox, MSN, RN, FNP-BC
Transplant Program Specialist	TBA
Transplant Patient Financial Coordinator	Dora Berganzo
Transplant Pharmacist	Mara Watson, PharmD
Transplant Dietitian	Yen Lowder, RD
Heart Failure Nurse Clinicians	Jennifer Lewis, RN, BSN Martha Anders RN, BSN



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## CONTACTING THE HEART TRANSPLANT PROGRAM

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The members of the Heart Transplant Team want to assist you through the heart transplant process. Feel free to ask team members questions you may have. All communication about your heart transplant should come through the heart transplant office. The heart transplant office employs a secretary and a program specialist who can answer many of your scheduling questions and can direct your calls to the appropriate team member for any questions or concerns.

### **Office Hours: Monday–Friday, 8 am–4 pm.**

After hours, a recorded message will remind you how to contact the hospital operator for urgent issues. You may leave a message if your question is not urgent.

#### **Phone:**

Monday–Friday, 8 am–4 pm

Local: 919-613-7777

Toll free: 1-800-249-5864

#### **Evening, nights, weekends, and holidays for urgent issues:**

919-684-8111

Ask for the cardiologist on call for urgent issues.

#### **Mailing address:**

Duke Heart Transplant Program Office

DUMC Box 102347

Durham, NC 27710

#### **Physical address:**

Duke Heart Transplant Program Office

Hanes House, Room 132

330 Trent Drive

Durham, NC 27710

Fax: 919-681-8860

We hope the information provided in this manual has been helpful. Detailed information about how to care for your new heart will be given to you once you receive a heart transplant. Remember, the Duke Heart Transplant Team wants to help you through this process and achieve the best outcome for you. We know that this can be a difficult and confusing time. Again, please write down questions you might have and ask them when you see us. We look forward to working with you.

## NOTES AND QUESTIONS

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