

# Pre-Heart Transplant Patient Guide





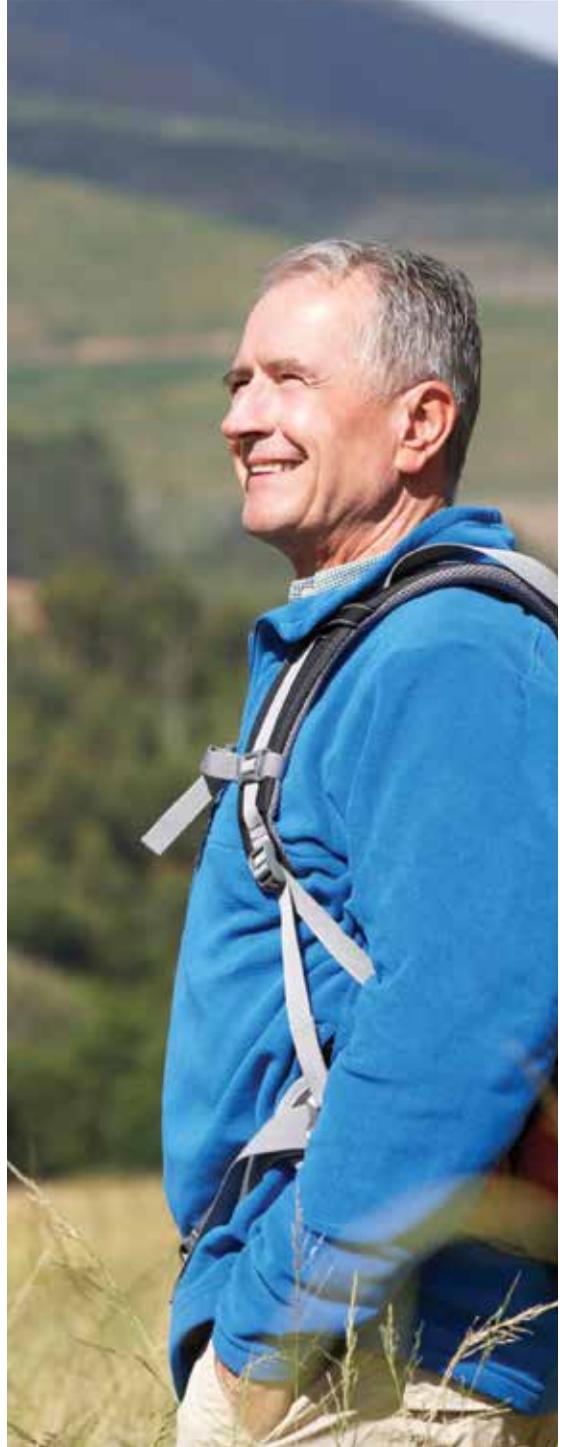
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# Pre-Heart Transplant Patient Guide

## Introduction

Your doctor has referred you to the Transplant Center at UK HealthCare to see if a heart transplant can help you. It is normal to be anxious because heart transplantation may be something you know very little about. The purpose of this booklet is to provide you with information about the transplant process and what to expect after a heart transplant. As you go through this journey, write down questions that you have for the heart transplant team. Our doctors, nurses and other staff members are happy to help.



# How your heart works

A healthy adult heart is about the size of a clenched fist and weighs about 11 ounces. It is located in the middle of your chest behind the breastbone, between the lungs.

Your heart has four chambers, or open spaces, that fill with blood. Two of these cavities are called atria and they form the curved top of the heart. The other two are called ventricles and meet at the bottom of the heart to form a pointed base toward the left side of your chest. Each side of the heart has an upper atria and lower ventricle. A wall, called the septum, separates the right and left side of the heart. A valve connects each atrium to the ventricle and its job is to make sure that the blood moves in the right direction.

When your heart contracts, blood moves out of the right side of the heart, into your lungs where it picks up oxygen and then to the left side of your heart. The left ventricle pumps blood to your entire body. A healthy left ventricle pumps 55-65 percent of its blood with each beat. This percentage is called the “ejection fraction.”

Electrical impulses travel down pathways in the heart to coordinate the contraction and relaxation of each chamber. If your heart tissue is damaged, then the electrical impulses can't travel down the right pathway and you develop abnormal heart rhythms, also known as arrhythmias. A healthy heart muscle contracts and relaxes about 60 to 90 times per minute.

## Heart failure

The term “heart failure” refers to a weakened heart that can no longer pump oxygen-rich blood to the body. When this happens, the heart ventricles may enlarge, get thicker or become stiffened. You may start to feel tired, have shortness of breath and not be able to enjoy everyday activities. Sometimes we don't know what causes the heart to fail, but the most common causes of heart failure are blocked coronary arteries, an infection, pregnancy, exposure to toxic substances, heart defects present at birth or electrical disturbances.

Lifestyle changes, heart failure medications and surgery to fix blocked arteries or damaged valves can improve your quality of life. However, if the heart continues to worsen after trying medical and surgical options, a heart transplant may be your only chance for a better quality of life.



# What is a heart transplant?

A heart transplant is a surgical procedure where your failed heart is replaced with a healthy heart from an organ donor. An organ donor is a person who has died, and either they or their family have decided to donate their organs to help someone else. Organ donation is an unselfish act of kindness, and the organs donated are a natural resource.

The heart transplant program at UK HealthCare was established in 1991, and since that time, we have performed more than 300 heart transplants. The Scientific Registry of Transplant Recipients is a national database of transplant information, which includes patient survival, organ donation and waitlist candidates. You can access this information at [www.srtr.org](http://www.srtr.org), and your transplant coordinator will also provide you with the most up-to-date information for UK HealthCare.

The goal of heart transplantation is to provide patients who have end-stage heart failure an opportunity to return to their jobs and families and lead an active life.

### Mechanical circulatory support

A ventricular assist device, or VAD, is a mechanical circulatory support device that is part of the surgical treatment for heart failure. It is a special pump that helps your heart pump blood to the rest of your body. The VAD, which is put in your body during surgery, is connected to a control unit that runs the pump. The control unit is outside your body and is connected to the pump by the driveline. The control unit can be worn on a belt around your waist. You will be given a booklet that gives you detailed information about the specific VAD that you will get.

VADs can be put in as either a “bridge to transplant” or as “destination therapy.”

- **Bridge-to-transplant** candidates are patients who are eligible for a heart transplant but have become too sick to wait until a suitable donor heart is available. The VAD is temporary for them and provides enough blood flow to the body while they are waiting for a transplant. It may also allow patients to exercise so they are as physically fit as possible when it is time for their transplant.
- **Destination therapy** candidates are patients who will have a VAD as their permanent treatment for heart failure. They have problems that make them unable to have a heart transplant, or they do not want to receive a heart transplant.

### UNOS

The United Network for Organ Sharing, or UNOS, manages the nation’s organ transplant system under contract with the federal government. UNOS manages the national transplant waitlist and matches donors with people waiting for a transplant. It also develops policies to make sure the transplant process is fair and provides education for transplant centers and organ procurement organizations. To learn more about UNOS, visit

[www.unos.org](http://www.unos.org).

# Heart transplant team members

### **Patient and family/caregivers**

As the patient, you are a vital part of the team and should actively participate in all decisions concerning your care. Support from family members and/or a friend is also essential for a successful transplant. Hearing from your doctor that you may need a heart transplant probably made you feel anxious. This is a stressful time for most patients and their families, but you are not alone. Our team is here to help you throughout the entire transplantation process.

### **Transplant surgeon**

One of our transplant surgeons will meet with you during the evaluation. They will update your family after surgery and participate in the management of your care while you are in the hospital after your transplant.

### **Transplant cardiologist**

At the time of your referral, you will meet with a transplant cardiologist in the transplant clinic. The transplant cardiologist will perform an examination and discuss with you your functional ability, medical history and surgical history.

Once the cardiologist determines that your medical condition is an indication for transplant, they will ask the coordinator to schedule you for transplant evaluation testing. Once you are evaluated, our team will discuss the results in a committee meeting to determine the best option of care for you. The transplant cardiologist will manage your care if you are admitted to the hospital prior to transplant, collaborate with the surgeon after the transplant and manage your care once you are discharged from the hospital.

### **Transplant coordinator**

The transplant coordinator is a registered nurse who collaborates with the transplant team throughout all phases of the transplantation process. In the pre-transplant phase, the coordinator will educate you and your family about the transplant process, schedule your evaluation and be your contact person with the transplant team.

If you are a transplant candidate, the coordinator will inform you of the plan of care, list you on the United Network for Organ Sharing waiting list and coordinate your transplant when an organ becomes available for you. If you are not a transplant candidate, the coordinator will inform you of your medical management options.

After the transplant, your transplant coordinator will teach you how to take care of your new heart. The coordinator will schedule your follow-up appointments, refer you for any consults you need and remain your main contact person at the transplant center.

### **Social worker**

Social workers are an integral part of the health care team and will work closely with you and your family. A social worker is assigned to all heart transplant patients and is available throughout the transplant process. You will meet with the social worker in the evaluation phase for a psychosocial consultation. At this time, the social worker can identify social, mental and financial needs prior to transplant.

Anxiety, fear and frustration are often experienced and, through supportive counseling, these concerns can be expressed and often eased. If the social worker identifies a need for you to see the transplant psychiatrist, we will refer you for a consultation. It is very important for your mental health to be addressed before transplant because this can be a very emotional process. It is not uncommon for our patients to require antidepressant and/or anti-anxiety medications to cope with their emotions. After transplant, the social worker will also assist you with lodging, community resources and support services.

### **Financial coordinator**

After you are referred for a transplant, the financial coordinator reviews and verifies your insurance benefits. They will notify you if they need additional information or if you need to contact your insurance carrier. The financial coordinator will help you understand your expected out-of-pocket expenses. It is their responsibility to help you with any insurance matters and to direct you to the proper departments when you have billing questions. If at any time during the transplant process your insurance situation changes, it is **very important** for you to tell the financial coordinator. This will allow the financial coordinator to verify your benefits and coverage. The financial coordinator will also provide you with fundraising options prior to transplant.

### **Pharmacist**

The transplant pharmacist will ensure that you are on the correct medication regimen, review your medications for any interactions and educate you about your new medications. The pharmacist will meet with you before and after your transplant.

### **Dietitian**

To ensure a positive outcome, you must follow a diet that includes adequate amounts of foods that contain vitamins and minerals necessary for healing and electrolyte balance.

The dietitian will review your weight, lab results and your current eating habits during the evaluation phase. Then, they will develop your individualized plan of care and review it with you to maximize your potential as a transplant candidate.

While you are in the hospital after your transplant, the dietitian will review your diet to ensure that you are receiving adequate nourishment and review your lab results to evaluate electrolyte balance. He or she will also provide education to you before going home.



# The transplant process

Heart transplantation is not only a surgical procedure. It is a process that includes a referral phase, evaluation phase, waiting period, hospitalization for transplant and continuance of care after surgery. It is important that you and your family have as much information as possible about each step of the transplant process. s

### Referral

You will be referred by your doctor to the UK Transplant Center's heart transplant program to see if a transplant is an option for you. Once you have been referred to our facility for a transplant, we will schedule an appointment for you at the transplant clinic to meet with the transplant cardiologist and transplant coordinator. The transplant cardiologist will decide whether a heart transplant is a suitable option for you based on your degree of heart failure.

### Evaluation

In order to be considered for a heart transplant, you must complete a thorough evaluation. Multiple tests and procedures are performed to evaluate the function of every vital organ in your body. The overall goal of this evaluation is to be sure that a heart transplant is the best treatment for your heart problem and to be sure that you do not have any other health problems that would prevent you from having a good outcome after transplant.

During this phase, you will meet multiple health care specialists: doctors, nurses, pharmacists, physical therapists, dietitians,

social workers and the financial coordinator. Each of these specialists will ask for information about you and give you information about heart transplantation.

To help you remember some of the people involved in your care, we will provide you with a list of the members of the heart transplant team. We also encourage you to add names of people who are not on the list.

The evaluation requires a 23-hour admission to the hospital. You will have to stay overnight in the hospital to ensure that all tests have been completed in a timely manner. Patients begin the process in the cardiac catheterization lab and are taken from test to test until all testing is complete.

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 with you what tests are ordered.

The heart transplant team will also need to be familiar with your medical and surgical history. If you have had any heart procedures in the past, we will request a copy of your medical records from the facility where they were performed. Also, if you have a history of cancer, bleeding disorders or any other illnesses that may impact your transplant outcome, please notify us so that we can request a copy of those medical records.

## 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, HIV and the hepatitis viruses. We may need to adjust your medications after transplant based on these results.

## Left heart catheterization

This test gives us information about arteries that supply your heart with blood.

If you take Coumadin or any other medicine to thin your blood, you may need to stop taking it temporarily 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.

After your skin is numbed, 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 whether 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.

## 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. You may need to temporarily stop taking Coumadin or any other medicines to thin your blood before this test.

The skin is numbed and then 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.

## Exercise stress test (CPX)

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 one hour to complete.

## Pulmonary function testing (PFT)

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 one hour to complete.

## 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 non-invasive and does not use radiation. Clear gel is used to help the ultrasound wand slides easily over your chest and obtain pictures of your heart.

## Abdominal ultrasound

This test uses sound waves to see the organs inside of your abdomen, including your gallbladder and liver. It tells us if you have gallstones, liver abnormalities or dilated blood vessels. 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.

## Ankle brachial index test (ABIs)

This is a test used to screen for peripheral arterial disease (PAD) in your legs. You will lie on a table on your back and a technician will measure your blood pressure in both arms and both ankles.

## CT scan of your chest

This test is done to look for signs of lung damage and to look at the position of your heart related to your breastbone if you have had heart surgery in the past.

## Consults

In addition to testing, it is mandatory that you also meet with the heart transplant pharmacist, dietitian and social worker. Based on their findings, you may also have neurocognitive testing done to measure your ability to learn and retain information. If you have an underlying mental illness and you do not have a psychiatrist, you will be referred to meet with the transplant psychiatrist to ensure that you are receiving appropriate mental health care.

The heart transplant team will also have a physical therapist evaluate your functional ability and discuss with you precautions related to your sternum that may arise after your surgery. The palliative care team will meet with you to discuss the goals of your care. A dental consult will be required if there are any abnormalities noted on the X-ray of your teeth, also called a panorex of the mandible.

## Routine health maintenance testing

A colonoscopy is required for **all patients over the age of 50** if you have not had one in the last five years. Women must have a Pap smear, and if you're over age 40, you must also have a mammogram if you have not had one in the last year. You can schedule these tests to be done near your home. If you have had these tests done within the appropriate timeframe, please ask the medical facility where they were done to fax results to the heart transplant program at **859-257-7402** or bring a copy of the results with you to your initial appointment. The transplant coordinator will discuss this with you.

# Transplant candidacy

On a weekly basis, our team meets to discuss new referrals, evaluations, listed patients and patients who have received a mechanical circulatory device. The purpose of this meeting is to discuss your need for a heart transplant, review the results of your evaluation and discuss the best treatment option we can provide for you.

In addition, the team will discuss any problems that could make transplantation too risky for you. Sometimes, additional tests may be required to resolve questions about your candidacy for transplantation. We will make all the arrangements necessary to complete these additional tests as quickly as possible. After a decision is made about your plan of care, the transplant coordinator will call you to discuss the plan.

### **National waiting list**

Transplant candidates are placed on a national waiting list with the United Network for Organ Sharing, which is an organized process that is fair to transplant patients. The Organ Procurement and Transplant Network, or OPTN, develops policies for the transplant community. OPTN policy allows you to be listed at multiple transplant centers, but each individual transplant center will decide whether to accept you as a candidate. Also, if you decide to transfer your listing to another center, your waiting time can be transferred as long as it is coordinated with both programs. See the brochure, "Questions and Answers for Transplant Candidates About Multiple Listing and Wait Time Transfer," from

the United Network for Organ Sharing for more information about this process.

Once you are listed as active on the UNOS waiting list, your wait for a donor heart begins. You will be matched with a donor based on your blood type and body size. The transplant team also reviews your antibody levels to ensure that you are an appropriate match with the donor. There can be donor risk factors that affect your outcome, such as the medical and social history of the donor, condition of the organ and the risk of contracting a disease if it is not detectable at the time of donation. All organ donors are evaluated and screened for transmissible disease. If the donor meets the guidelines for an increased risk of transmissible disease as specified in the US Public Health Services Guidelines, the surgeon will discuss the specific risk with you.

You will not be given any personal information about your donor. Prior to discharge, the transplant coordinator will give you a preprinted card for your donor family and a pamphlet about writing to your donor family. This is not mandatory. If you choose to send the card, give it to your transplant coordinator and they will give it to the social worker, who will ensure that the donor family receives it. The social worker will contact you if the donor family sends a card or letter to you.

A donor heart 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 days to more than a year. The transplant team can explain to you how long you can expect to wait and what listing status matches your clinical status.

## Listing status

Each organ has a different listing process. For the heart, you may be listed as a **Status 1A**, **Status 1B**, **Status 2** or **Status 7**. Each status has a criteria outlined that is based on medical urgency. According to the OPTN, the criteria for heart transplant listing statuses are as follows:

**1A:** The highest priority on the waiting list. Patients listed as 1A must be admitted to the hospital and have continuous hemodynamic monitoring. They must also be on one or more continuous IV medications to support their heart function or have a mechanical circulatory device in place. These devices include extracorporeal membrane oxygenation (ECMO), Total Artificial Heart or intra-aortic balloon pump. The patient may also require continuous mechanical ventilation or biventricular assist devices. A patient who has a mechanical assist device (LVAD) with a complication meets 1A listing criteria and can be inpatient or outpatient.

**1B:** The second highest priority on the waiting list. Patients listed as 1B require continuous infusion of one IV medication or have a mechanical circulatory device in place at home.

**2:** The lowest priority on the waiting list. Patients listed as 2 are managing their condition with oral medication.

**7:** Temporarily inactive on the waiting list.

## Waiting for your new heart

Some patients must wait in the hospital for their new heart so that they can receive additional medical support for their heart failure. Waiting for a new heart can be frustrating and stressful, but it's important to

remember that no one has any control over when a donor heart becomes available.

We will provide support during this time by offering music therapy, chaplaincy services and scheduled visits with volunteers who have had a heart transplant. Many people find it helpful to talk to someone who has been through the transplant process. Additionally, support from your family and friends is vital and the social worker can provide you with information about a heart transplant support group for patients and their caregiver(s).

The period of time after being listed for a heart transplant may be the toughest part of the transplant process. It is natural to wonder whether you will get your new heart in time. Although the waiting period may seem unbearably long, there are a few things you can do during this time that may help to lower your anxiety:

- Talk about your feelings with your family and friends.
- Remember that the transplant coordinator, social worker and other team members are available to help you through the waiting period.
- Meet with the transplant psychiatrist or another psychiatrist to discuss ways to manage anxiety and/or depression while waiting.
- Attend support group meetings, connect with other transplant patients on social media or let your team know that you would like to meet a transplant patient.

## The transplant surgery

When a donor heart becomes available, the on-call transplant coordinator will contact you to come to the hospital. Once contacted, you should come to the hospital as soon as possible. Drive safely and be careful, as we will already have taken into account your travel time before you were notified. Once you are contacted, do not eat or drink anything. Bring

a current medication list with you and if you have a VAD, bring your VAD equipment with you.

The transplant coordinator will tell you where to go when you arrive at UK HealthCare.

Once you are in your room, the nurse will insert an IV and draw blood to send to the lab for testing. You will also have a chest X-ray performed.

The transplant surgeon will meet with you to discuss the procedure and potential risks and complications. An anesthesiologist, the doctor who will put you to sleep for the surgery, will talk with you and your family before you are taken to the operating room. The time between when you arrive and when you go to the operating room will vary, and delays are common due to the complexity of coordinating a transplant procedure at the donor hospital.

During most of time before your operation, your family will be allowed to stay and visit with you. Once you go to the operating room, your family will be given a pager and taken to a waiting room. The operating room nurse will update your family periodically during the surgery.

### **During the surgery**

The start time of your surgery will depend on the progress of coordinating your transplant procedure with the donor hospital. Specialists from the donor hospital will keep the surgeons at UK HealthCare informed of their progress with getting your new heart. Delays are common because of the complex nature of coordinating a transplant. Once the donor team decides that the new heart is right for you, they will contact the team at UK HealthCare. Because of the fragile nature of the heart tissue, the donor heart may become unacceptable for transplant at any time during this process. If this occurs, your procedure would be canceled.

In the operating room, the anesthesiologist will give you medicines to help you relax and sleep. After you are asleep, a plastic breathing tube is placed in your mouth and passed into your airway. The breathing tube is taped to your cheek and connected to a ventilator. The ventilator breathes for you during and after your surgery until you are strong enough to breathe on your own. When the tube is removed, an oxygen mask may be used to supply you with additional oxygen. A nasogastric tube, or NG tube, will be put in place to keep air and fluid from collecting in your stomach. This plastic tube is passed through your nose and into your stomach. The NG tube will be removed as soon as you are able to eat and drink.

The surgeon will make an incision down the length of your breastbone. After your new heart has arrived, your old heart will be removed and replaced by the new heart. If you have a pacemaker or defibrillator, this will be removed. Once the surgery is completed, you will be taken to the cardiovascular intensive care unit, or CVICU, located on the eighth floor of the hospital. Your surgery will last about five to eight hours but can last longer if you have had previous open heart surgery or have an LVAD.

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## After your surgery

After your heart transplant surgery, you will be taken to the cardiovascular intensive care unit, or CVICU, for recovery.

It may take up to two hours to get settled in your room. Once you're settled, family is allowed to visit. Visitors will be limited to immediate family to help protect you from infection. More visitors can mean an increased risk of infection.

Most patients stay in the CVICU for three to seven days.

### **While you are in the CVICU, you will notice many bandages, lines and tubes.**

Here is what you can expect:

- There will be an IV line in the right side of your neck. The purpose of this line is to give medications and monitor your heart function.
- You will have a breathing tube until you are fully awake and can breathe on your own.
- During surgery, your chest wound is closed with staples or glue. A bandage covers it after surgery. We will change the bandage 48 hours after surgery.
- One or more chest tubes will drain blood and fluid. Based on how much fluid is draining, the surgeon will decide when to remove them.
- Stickers and leads will be near your shoulders and chest. These help us watch your heart rate and rhythm and your respiratory rate.
- You will have a small rubber tube in your bladder. This will empty your bladder during surgery. It will also help us see how well your kidneys are working. It usually stays in place for two to three days.

- You will have one or two IVs in each arm. One will measure your blood pressure and let us draw blood without a needle stick. Another will let us give you fluids and medicine.
- For your safety, we will restrain your hands with soft cotton straps until you are fully awake. It will keep your arms from moving and pulling out an IV or tube.
- You will have temporary pacing wires to help with any irregular heart rhythms. These will be removed after the first heart biopsy. If you had a pacemaker or defibrillator, the wires were removed during transplant surgery. If the generator was not removed, you will go back to the OR in a few days to remove the generator.

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.

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.

## Preparing for discharge

When you are ready to leave the ICU, you will be transferred to the cardiac step-down unit. On the step-down unit you will continue to recover and regain your strength. It is important to limit how many people come into contact with you because it will be easy for you to get infections. If your loved ones are sick, they should not visit you. No children under age 10 can visit unless the transplant team approves. Wear a mask anytime you leave your room.

There will be many things for you and your family to learn before you go home. Your post-transplant education begins once you are awake and able to participate. The transplant coordinator will bring you your transplant binder and review the information enclosed. In the binder there will be a diary to record your daily medications and vital signs, information on precautions and restrictions, diet, diabetes, complications, medications, support groups, the follow-up regimen, and various other details. The transplant coordinator will explain how to use your diary and review the other information in the binder. It is your responsibility to take accountability for the use of your diary to learn your medication regimen, not your family members or your nurses.

The bedside nurse will provide diabetes education. This education includes how to use a glucometer to measure your blood sugar before meals and at bedtime, how and when to give yourself insulin, what to do when your blood sugar is too low and what diet modifications you need to make to help regulate your blood sugar. Taking your medications, controlling high blood pressure and blood sugar, eating a diet low in fat and sugar, exercising on a regular basis, addressing any mental health issues, and attending all follow-up appointments will extend the life of your new heart. This is a big lifestyle change and our team is here to prepare you before and help you along the way.

The transplant pharmacist will teach you about your new medications and their possible side effects. The dietitian will review with you how to eat a healthy diet to protect your new heart. If you do not live locally, you will be required to stay locally for two to three weeks after you are discharged. The social worker will help you with lodging arrangements when a date of discharge has been decided. It is your responsibility to check your insurance coverage to see if lodging is covered.

## Possible complications after surgery

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, kidney failure, blocked coronary arteries in your new heart, and side effects from the antirejection 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 you receive your new heart, 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, your immune system, will begin to attack the new heart because it views 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. 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 antirejection 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 three.

You will have biopsies done every week for the first four weeks after your transplant. Over time, your risk of rejection goes down and 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.

### **Infection**

The risk of infection is higher for transplant recipients because the medications 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 antiviral 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 percent of patients in the first year after transplant, and around 5 percent 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-percent 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 percent of heart transplant recipients in the first year after transplant and in nearly 95 percent of patients in five years.

## **Your responsibilities as a transplant patient**

As you begin this journey and talk with the transplant team, think about the impact transplant will have on you and your family. Take advantage of every opportunity to learn all you can about what life will be like after transplant. Please write down any questions you have and plan to discuss them with members of the transplant team as you meet with them. You can also contact the transplant coordinator to discuss your questions.

If you are a transplant candidate, you must be committed to follow-up care. The main areas of commitment to consider are: taking medications daily for the rest of your life, keeping all scheduled appointments, having labs drawn frequently and living a healthy lifestyle after transplant. You will also be asked to record your weight, heart rate, blood pressure, temperature and blood glucose testing each day and bring the results with you to each clinic appointment. We 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 transplant to provide you with emotional support and help you while you recover. It is important that this same person is available to be present when you learn about how to take care of your new heart before leaving the hospital. You will also need someone to drive you to your appointments until you are well enough to drive yourself, which usually takes about six weeks.



# Pre-Heart Transplant Patient Guide

## Helpful resources

A heart transplant is a life-changing event for you and your loved ones. The heart transplant team is here to guide you through this. We will help you set realistic goals for getting back to your normal life. Unrealistic goals can discourage you and keep you from working to get better. An optimistic outlook before transplant is the key to success after transplant. You must also have a support team in place before transplant. Your team will include people close to you, such as friends, family and coworkers.

### Advance directive

UK HealthCare is committed to achieving the best outcome for you, but we also realize there are many uncertainties ahead.

An advance directive is a legal document that outlines a set of directions to guide your health care if you are unable to make decisions for yourself. It can include a living will, which outlines the level of care you would want for yourself in various medical situations. It may also include designating a health care power of attorney. A health care power of attorney is a person who would be legally able to speak for you if you are not able to speak for yourself.

Some patients choose to make a will with concerns related to finance, children or other personal affairs. We ask that you discuss these personal matters with your family before you are listed for a transplant.

### Support groups

The heart transplant process can take a toll on both the patient and their caregiver. We offer support groups for pre- and post-heart transplant patients and their caregivers. This is a good place to meet other patients and caregivers to share concerns and advice.



Our heart transplant support group meets the first Wednesday of every third month in Room H133 of Albert B. Chandler Hospital, Pavilion H. Meetings are from 11:30 a.m. to 1:30 p.m. and a light lunch or snack is provided. The group meeting is casual, and we usually have a guest speaker. For questions about the support group, you may contact the heart transplant social worker at **859-323-2557**. For updates regarding the support group meetings, if you have questions about transplant and to meet other patients, visit our Facebook page, "UK HealthCare Cardiothoracic Transplant/VAD Support Group."

### Lodging

The social worker will provide you with a list of local short-term and long-term lodging options.

## Contacting the heart transplant program

The members of the heart transplant program are here to support you through the heart transplant process. Please don't hesitate to ask any questions you may have. Our heart transplant support staff support can answer questions regarding appointments and can direct your calls to the appropriate team member.

### Office hours: Monday-Friday, 8 a.m. to 5 p.m.

After hours, a recorded message will instruct you how to leave a message or contact the on-call transplant coordinator for urgent issues.

### General phone:

Monday–Friday, 8 a.m. to 5 p.m.

Local: **859-323-6497**

Toll-free: **800-333-8874**

Fax: **859-257-7402**

**If you are listed for a heart transplant or have received a heart transplant, you may call the following number on evenings, nights, weekends and holidays for urgent issues:**

**859-257-2211**

Ask for the on-call heart transplant coordinator for urgent issues.

### Mailing address:

Heart Transplant  
UK Transplant Center  
Kentucky Clinic  
740 S. Limestone, Suite J301  
Lexington KY 40536-0284

### Physical address:

UK Transplant Center  
Kentucky Clinic, third floor, Wing D, Suite J301  
740 S. Limestone  
Lexington

### UK Transplant & Specialty Clinic

Medical Plaza East  
3 Audubon Plaza Drive, Suite 150  
Louisville KY 40217  
**502-636-4950**

## Helpful websites

United Network for Organ Sharing Transplant Living

[www.transplantliving.org](http://www.transplantliving.org)

Scientific Registry of Transplant Recipients

[www.srtr.org](http://www.srtr.org)

Air Charity Network

[www.aircharitynetwork.org](http://www.aircharitynetwork.org)

GiveForward (Fundraising)

[www.giveforward.com/transplant](http://www.giveforward.com/transplant)

HelpHopeLive

[www.helphopelive.org](http://www.helphopelive.org)







