



# Transplant Alliance

**Pre-Heart Transplant Education Guide**

[WVUMedicine.org/Transplant](http://WVUMedicine.org/Transplant)



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**WVU Medicine Transplant Alliance Contact Numbers**

**Transplant Office**

WVU Medicine J.W. Ruby Memorial Hospital  
1 Medical Center Drive  
Box 8301  
Morgantown, WV 26506

Phone: 304-974-3004

Toll free: 1-844-988-7267 (1-844-WVTRANS)

Fax: 304-598-4899

[WVUMedicine.org/Transplant](http://WVUMedicine.org/Transplant)

**Transplant Clinic Hours**

Monday through Friday  
8 am to 4 pm  
Closed on weekends and holidays

For urgent calls and calls after hours, on weekends, and on holidays,  
**please call the Transplant Office main number and choose option 1,**  
which will take you to the Call Center. Choose option 1 again and ask to be  
put in contact with the Transplant Coordinator on call.

For routine questions, please contact the office during normal business  
hours or send a message through MyWVUChart that will be addressed the  
next business day.

# WELCOME

Transplantation is a complicated process that includes much more than just the surgery. Evaluation, the waiting period prior to transplant, and recovery following surgery are all part of a long journey for the transplant candidate and family. Even after full recovery, some lifestyle changes are necessary for continued health.

The goal of a successful transplant is to help recipients feel better, become more active, and enjoy a better quality of life. The main benefits of a successful transplant are:

- // Increased feeling of well-being
- // Fewer restrictions on diet and activities
- // Increased energy level
- // Return to work or school
- // Longer life

Please review the information we have provided you in this Pre-Transplant Education Guide. This guide contains important information that is necessary to understand before starting your journey to transplant. Read it thoroughly, and share it with interested family and friends. We encourage you to bring this guide with you to each visit. If you have any questions prior to your evaluation, either write them down or feel free to call the Transplant Office at 304-974-3004.

Within this guide are several forms you will need to **complete prior to** coming in for your evaluation. Also included in this guide is information about MyWVUChart. We encourage you to utilize this tool throughout your transplant journey.

**Your evaluation day is:** \_\_\_\_/\_\_\_\_/\_\_\_\_

If you are receiving this guide while inpatient, your course may be slightly different, but the Transplant Team will help to guide you. The information is still very important to understand.

*Please remember to bring completed forms, this guide, questions, and any medical records from outside of the WVU Medicine health system with you to your evaluation appointment.*

We look forward to meeting you!

**The Transplant Team**

# Who is on the Transplant team?

**TRANSPLANT TEAM-** A group of professionals at the transplant center who work to make a transplant successful. Each person on the team is an expert in a different area of transplantation.

Member	Role
<b>You</b>	<ul style="list-style-type: none"> <li>/// Learn about heart transplantation and decide if you wish to proceed</li> <li>/// Participate in the evaluation process</li> <li>/// Discuss needs and concerns with team</li> <li>/// Complete all required testing</li> <li>/// Continue to communicate with the team</li> <li>/// Care for yourself before and after transplant</li> </ul>
Family/Support Team	<ul style="list-style-type: none"> <li>/// Learn about transplant, and ask questions</li> <li>/// Accompany candidate to appointments</li> <li>/// Participate in educational sessions</li> <li>/// Support candidate decisions</li> <li>/// Notify Transplant Team with any questions or concerns</li> </ul>
Transplant Surgeon	<ul style="list-style-type: none"> <li>/// Surgical evaluation, including medical history, physical exam, and ordering tests</li> <li>/// Educate you and your support team on the transplant surgery</li> <li>/// Perform the transplant operation</li> <li>/// Monitor your post-surgical progress during hospital stay and following discharge</li> <li>/// Assist Transplant Team in developing your post-transplant plan of care</li> </ul>
Transplant Cardiologist	<ul style="list-style-type: none"> <li>/// Medical evaluation, including medical history, physical exam, and ordering tests</li> <li>/// Educate you and your support team on transplant process</li> <li>/// Care for you after transplant</li> <li>/// Monitor and address all of your transplant medical needs during hospital stay and in post-transplant clinic</li> <li>/// Assist the Transplant Team in developing your post-transplant plan of care.</li> </ul>
Transplant Coordinator <b>Your point of contact at            WVU Medicine Transplant            Alliance</b>	<ul style="list-style-type: none"> <li>/// Provide education about the transplant process</li> <li>/// Be your advocate throughout the transplant process and answer any questions you may have</li> <li>/// Organize information about your case for the Transplant Selection Committee</li> <li>/// Register you on the UNOS transplant waitlist</li> <li>/// Monitor routine testing while on the waitlist</li> <li>/// Coordinate your admission for heart transplant</li> <li>/// Coordinate post-transplant care</li> </ul>

Transplant Social Worker	<ul style="list-style-type: none"> <li>/// Evaluate your ability to cope with the stress of transplantation and your ability to follow a rigorous treatment plan</li> <li>/// Help you and your family with emotional concerns before and after transplantation</li> <li>/// Help you plan for the day-to-day and long-term needs, such as how and where to get your medicines</li> <li>/// Assist with evaluating your ability to cope with the stress of transplantation and your ability to follow a rigorous treatment plan</li> <li>/// Guide you with fundraising opportunities</li> <li>/// Help to connect you with local resources you may need after transplant</li> </ul>
Transplant Dietitian	<ul style="list-style-type: none"> <li>/// Assess your nutritional status and dietary knowledge</li> <li>/// Provide education and recommendations for your diet</li> <li>/// Help you to develop, begin, and maintain a nutritional program</li> </ul>
Transplant Pharmacist	<ul style="list-style-type: none"> <li>/// Evaluate your current medication list and identify any possible drug-drug interactions</li> <li>/// Educate you about your medications</li> <li>/// Assess compliance with your medication regimen</li> <li>/// Review any over-the-counter medications and/or supplements</li> <li>/// Review your vaccine/immunization history and provide recommendations</li> </ul>
Transplant Financial Coordinator	<ul style="list-style-type: none"> <li>/// Obtain authorization for heart transplant evaluation</li> <li>/// Review your insurance coverage and benefits information</li> <li>/// Help you understand your insurance policy (or policies)</li> <li>/// Discuss potential options for coverage during the transplant process</li> <li>/// <b>Needs to know</b> of any changes to your insurance coverage as soon as possible</li> <li>/// Obtain authorization for heart transplant</li> </ul>
Transplant Service Representatives (Administrative Staff)	<ul style="list-style-type: none"> <li>/// Schedule your evaluation, follow-up appointments, testing, and procedures</li> <li>/// Guides you during your out-patient clinic visits</li> <li>/// Answer Transplant Clinic telephone, takes a <b>detailed</b> message, and connect you with the appropriate Transplant Team member</li> </ul>
Support Personnel	<ul style="list-style-type: none"> <li>/// Collect and maintain data on each patient for research purposes and federal regulations</li> </ul>
Other Referrals	<ul style="list-style-type: none"> <li>/// Each patient is assessed to determine if other specialists are needed</li> </ul>

# **Your Transplant Journey**

As you go through this journey, the Transplant Team will be with you every step of the way. The following pages serve as a basic overview of what to expect throughout your journey from evaluation for transplant candidacy to being added to the waitlist for transplantation.



## HEART FAILURE OVERVIEW

The heart is the hardest working muscle in the human body. It is responsible for pumping blood throughout your body to supply body tissues with oxygen and nutrients.

Sometimes the heart muscle does not pump blood to the body as well as it should because the heart muscle cannot relax and fill with blood. This may cause blood and fluid to back up into the lungs and limit the amount of oxygen and nutrients supplied to body tissues. When the heart is not pumping effectively to meet the demands of the body, this is known as heart failure.

Heart failure may result from health problems that affect the heart. These health problems can include (but are not limited to):

- // High blood pressure
- // Coronary artery disease
- // Congenital heart disease
- // Active infection of a heart valve
- // Heart attack
- // Heart rhythm problems
- // Pregnancy

The severity of your heart failure depends on how much of the heart's pumping ability has been affected. Symptoms of heart failure may look like other health problems. Symptoms may be gradual or come on quickly. Common symptoms of heart failure include:

- // Shortness of breath while resting, exercising, or lying flat
- // Weight gain from water retention
- // Visible swelling of the legs and ankles from fluid build-up
- // Severe tiredness and weakness
- // Loss of appetite, nausea, and belly pain
- // Cough that doesn't go away

The cause of your heart failure will guide the treatment plan. Some causes are reversible, but for many causes of heart failure, there is no cure. Lifestyle changes and medications can aid in symptomatic relief. Untreated heart failure may lead to fluid build-up in the lungs (pulmonary edema), kidney and liver failure, stroke, abnormal heart rhythms, and death.

In some cases, the diseased heart must be replaced with a healthy one from a donor. This is known as a heart transplant. You have been referred for a heart transplant evaluation because your doctor feels your heart failure symptoms can no longer be managed effectively with medication or less-invasive options.

## BEFORE THE TRANSPLANT

The pre-transplant process involves the following steps:

- // Referral
- // Evaluation
- // Patient Selection Committee review
  - Approved for transplant listing
  - Declined (not a transplant candidate)
  - Deferred for transplant listing (further evaluation is needed)

## REFERRAL

You have been referred to WVU Medicine Transplant Alliance because your heart failure is not responding to treatment, and your cardiologist believes you could be a good candidate for heart transplant. Before anything can begin, insurance authorization needs to be obtained.

## EVALUTION

Once your insurance company has approved heart transplant evaluation at WVU Medicine, the evaluation will begin. The transplant team will guide you through the formal evaluation process to determine if you are suited for transplant or whether other therapies are available to you.

Goals of the evaluation process:

- // Determine if a heart transplant is your best treatment option
- // Establish your baseline medical condition
- // Identify any health conditions that need treatment or investigated before transplant surgery
- // Educate you and your family about the heart transplant process
- // Assess your readiness for and your commitment to the transplant process
- // Determine if you would not benefit from heart transplantation or if the risks would be too great

The evaluation process involves numerous tests and assessments to determine if you meet criteria for heart transplantation. This requires assessing your physical health, your mental readiness, and other factors that would influence the success of transplant.

The evaluation may be done on an outpatient or inpatient basis depending on your health status and tests that are required. A list of possible diagnostic tests required for the evaluation process can be found on page 10 of this guide. The transplant team will determine what testing you will need.

Heart transplant is not a cure; it is a lifelong commitment of caring for your gift of life. Lifelong responsibilities after a heart transplant include:

- // Attending follow-up appointments
  - Clinic visit and heart biopsies
  - Blood work
- // Taking antirejection medications twice a day every day
- // Taking care of all of your routine health needs

## EVALUATION PROCESS

Preparations **PRIOR** to evaluation

- // Make sure to read all information provided.
- // *Complete all of the forms that are located under Tab 7 - Forms to be Completed in this manual.* This will help make the evaluation day move more quickly.
- // It will be a long day, so plan accordingly and expect the visit to last approximately 4-6 hours:
  - Wear comfortable clothes/shoes.
  - Bring all medications with you that you might need during that time (make sure your support person has their medications as well).
  - Bring snacks/lunch, or be prepared to buy something from the cafeteria. You are not required to fast for your evaluation
- // Bring any medical records/reports from outside of the WVU Medicine system that have not already been provided to the Transplant Office.
- // It is not recommended to bring children or other dependents with you to your appointments.

If you need to cancel your scheduled evaluation appointment, please let the Transplant Office know as early as possible. We will then work to get your appointments rescheduled.

## EVALUATION DAY

Please arrive to the Transplant Alliance Clinic at least 15 minutes prior to your scheduled appointment to allow for registration and paperwork completion.

*If you are running late, please contact the Transplant Office at 304-974-3004.*

The consults scheduled for you will attempt to stay on schedule, but each service will provide you with what you need and will answer all questions. On occasion, appointments may run over the allotted timeframe.

Take notes, ask questions, and write down questions that come later.

- // Questions are important; do not hesitate to ask them.
- // If you did not understand what was said to you during a visit, ask that it be repeated and clarified for you at that time.

You are required to bring one of your primary caregivers with you to your evaluation appointment.

We will also be taking a photo of you at your evaluation appointment to reference during your transplant journey and to present you to the Patient Selection Committee.

### **What happens on Evaluation Day?**

On your initial evaluation day, you will meet with members of the Transplant Team, have a physical exam, receive education, and get a list of diagnostic tests that are required to find out if you are suitable for transplant. You may have blood work drawn, a chest x-ray, and EKG at the outpatient lab in the Physician Office Center (a short walk from the clinic). You may have additional tests performed that day.

**Diagnostic Tests** – Testing will be specific to what the team deems appropriate for your evaluation. These tests help determine if you meet criteria for a heart transplant. Your insurance company may need additional results before they can authorize transplant benefits. The Transplant Team needs the other tests. All of these tests must be completed before you can be added to the waitlist. If you delay or take a long time to complete testing, some test results may expire and have to be repeated.

Some testing is age and gender based. Some help to identify if you have cancer. You may not need all of the following tests.

<b>Test</b>	<b>Description</b>
Abdominal Ultrasound	Looks at the organs and other structures in the abdomen
Blood Tests	Determines your blood type; measure your sugar level; detects disease or medical conditions; assesses overall organ function; tests for infections
Cardiac Catheterization	Looks at blood vessels of the heart and measures the heart's pumping abilities
Carotid Artery Ultrasound	Measures the blood vessels that supply blood to your brain to determine if decreased blood flow is present
Chest X-ray	Picture of the lungs, looks for signs of disease
Colonoscopy	Assess your colon and rectum for signs of disease
CT Angiogram	Measures blood flow to certain parts of your body, including the heart or brain
CT Scan	A special x-ray showing detailed images of organs and other structures of your body
Desaturation Test	Checks your oxygen needs at rest and during exercise
Doppler-peripheral arterial of lower extremities	Special ultrasound technique used to evaluate blood flow through the vessels in your legs
EKG (Electrocardiogram)	Assesses the electrical activity of your heart
Echocardiogram	Records the position and movement of the walls of the heart, including the valves; can be either transesophageal, transthoracic, or both
Mammogram (Female only)	Detect the presence of breast cancer
MRI	Provides a picture of organs and other structures of the body in greater detail than a CT scan
Myocardial Volume Oxygen Stress Test	Assesses how well blood flows to the heart during physical activity
Pap Smear (Female only)	Screens for cervical cancer and other abnormalities of the female reproductive system
Pulmonary Function Test	A group of tests used to assess how well your lungs are working
Prostate Specific Antigen (PSA) (male only)	Screens for prostate cancer and other abnormalities of the male reproductive tract

## PATIENT SELECTION COMMITTEE (PSC)

All the information collected during the evaluation process will be reviewed at the PSC meeting. The PSC consists of transplant physicians and surgeons, social worker, dietitian, financial coordinator, pharmacist, and transplant coordinators. The information collected throughout your evaluation will help the PSC determine if transplant is an appropriate treatment option for you. The criteria include (but are not limited to):

- // Patients 18 or older with a diagnosis of end-stage heart disease.
  - Advanced Heart Disease, such as, but not limited to, the following:
    - Severe coronary artery disease not amendable to intervention
    - Life threatening arrhythmias
    - Severe valvular heart disease
    - Congenital heart disease
    - Cardiac amyloidosis
  - Other medical and surgical options have been considered and utilized as appropriate
- // No active or ongoing cancers. Prior malignancies are evaluated on a case-by-case basis.
- // Other vital organ systems can support your physiology through the transplant process.
- // Financial and social resources appropriate to support long-term success of a heart transplant.
- // Weight that exceeds a BMI of 40 **prevents** transplantation.
- // Active smoking is **not** acceptable.

Active illegal substance use/abuse and alcohol abuse are both contraindications to candidacy; such determination is made in conjunction with social work, and when appropriate, a psychiatrist, psychologist, or addiction specialist.

Every transplant center has a different set of selection criteria. You must meet the selection criteria in order to be listed for transplant. This means you may be a candidate at one center and not another. You may request a copy of the WVU Transplant Alliance Selection Criteria from your Transplant Coordinator.

The PSC will meet regularly to discuss candidates who have completed the evaluation testing. Test results and consult findings will be used to determine a plan for each candidate. There are multiple outcome options:

- **Approved for Listing**- Decision made to place on UNOS and WVU Medicine Transplant Alliance waitlist
- **Declined for Listing**- Decision made to not place on UNOS and WVU Medicine Transplant Alliance waitlist
- **Deferred for Listing**- Inability to make determination to place on UNOS and WVU Medicine Transplant Alliance waitlist pending further clinical testing and/or documentation

A Transplant Coordinator will notify you regarding the decision of the committee by telephone and by mail within 10 days. Your referring physician will also receive a letter detailing the outcome of the Patient Selection Committee's decision.

If you are not a candidate for transplant, you will receive detailed information regarding this decision. If you are accepted for transplant candidacy, the team will need to get insurance authorization for heart transplantation. Once this authorization is obtained, you will be notified and placed on the UNOS and WVU Medicine Transplant Alliance waitlists. You and your referring physician will receive a letter detailing the outcome of the Patient Selection Committee's decision within 10 days.

If you have questions, please contact your Transplant Coordinator at 304-974-3004.

### **What are UNOS and the OPTN?**

The United Network for Organ Sharing (UNOS) is a non-profit organization that manages our nation's organ transplant system under contract with the federal government. UNOS uses data and technology to continuously strengthen the system, increase the number of transplants in the United States, and ensure that patients across the nation have equitable access to transplantation through policy, regulation, and education.

UNOS provides a toll-free patient services line to help transplant candidates, recipients, living donors, and family members understand organ allocation practices and transplantation facts and data.

The Organ Procurement and Transplantation Network (OPTN) is the name of the transplant system in the United States. The OPTN brings together medical professionals, transplant recipients, donor families, and representatives from transplant associations to develop organ transplantation policy. UNOS serves as the OPTN under contract with the Health Resources and Services Administration of the U.S. Department of Health and Human Services. The OPTN regulates how organs are distributed in this country and maintains the official national waitlist of transplant candidates awaiting organ offers.

Visit their websites at **[UNOS.org](http://UNOS.org)** and **[OPTN.Transplant.HRSA.gov](http://OPTN.Transplant.HRSA.gov)**.

### **The Wait List**

You will be notified via phone and in writing when you are officially listed for transplant. The transplant waitlist is managed by OPTN, a private, non-profit organization that is responsible for matching organs and ensuring organ allocation policies are followed. Organ allocation is complicated but primarily based on blood type and size.

UNOS uses a computerized database (UNet) that stores your information so that when a donor heart becomes available, it can be matched with a recipient. Working with UNOS, organ procurement organizations (OPOs) are responsible for the evaluation and procurement of deceased donor organs for organ transplantation. The OPO works with donor hospitals to ensure that organs are allocated to the appropriate recipients based on the national transplant waitlist. OPOs also educate the public to increase awareness of organ donation. In West Virginia, our local OPO is the Center for Organ Recovery and Education (CORE).

### **While you are waiting...**

Waiting for an organ can be stressful. The length of time you wait varies and depends on many factors. There is no way of knowing when an organ offer may occur. You must **always** have a working phone with you, and you must answer it anytime day or night. The Transplant Team must be able to contact you. If contact information for yourself or your caregiver(s) changes, the Transplant Team needs to be notified immediately. We ask that you and your caregiver(s) be able to travel to WVU Medicine J.W. Ruby Memorial Hospital quickly if you receive a call for organ transplant.

While you are waiting, you will need to keep in contact and follow up with the transplant team. Intermittent testing, blood work, and routine health maintenance will continue while you are waiting. It is important that you keep up with all of these things in order to stay active on the transplant waitlist.

While you wait, it is important to keep yourself as healthy as possible. Staying active during your waiting period is especially important. Set aside time each day to get a little exercise. Take a walk outside, or engage in an exercise program that has been approved by your cardiologist. Sometimes it is hard to make yourself walk or do physical activity when you don't feel good. Do not push yourself past your limits. Keeping yourself as active as possible before your transplant may have a positive impact on your recovery and regaining your strength post-transplant.

Please make sure to keep the KidneyHeart Transplant Team aware of any of the following:

- Hospitalization
- New physician consult/testing
- Visits to the Emergency Department/Urgent Care
- Traveling
- Moving
- Change of insurance

## TIPS FOR PREPARING FOR YOUR TRANSPLANT SURGERY

Make sure your Transplant Team knows how to reach you at all times. When an organ offer becomes available, the Transplant Team needs to be able to contact you as soon as possible.

- // Have your cell phone on you with the ringer on the loudest setting at all times.
- // Keep your phone charged and carry your charger with you at all times.
- // Provide the Transplant Team with contact information for close family and friends, in case we are unable to reach you at your main contact numbers.



Have your caregiver team in place. Your caregiver team will consist of your primary and back-up caregiver as well as other family and friends.

- // Choose at least 2 primary and 2 back-up caregivers. Your caregivers should be people you feel comfortable with and who have the time and flexibility to help care for you.
- // Be clear with your caregivers about what you are asking them to do for you and what will be expected of them. (See “Caregiver Expectations” section of the guidebook.)
- // When developing your caregiver team, consider where they will stay while you are in the hospital for transplant surgery. The Transplant Social Worker has information about local lodging. Before you are discharged our team will want to meet with your caregiver to do discharge education.

Consider setting up a phone/email tree or blog to keep your loved ones up to date and limit the amount of calls you and your caregiver are receiving while you are trying rest and recover after surgery.

Get your personal affairs in order.

- // Fill out your advanced directives and healthcare power of attorney forms and provide them to the Team to add to your records.
- // Make a plan for how your bills, mail, and emails will be managed while you are unable to do so.

Keep in mind that your call for transplant could come at any time, so you will need to have a plan for childcare and pet care in place.

Have a transportation plan in place. When you get the call for an organ offer, you will need to be able to get to WVU Medicine J.W. Ruby Memorial as directed by the Transplant Coordinator. This call could come any time day or night, weekends, or holidays.

- // Have gas in the car.
- // Always keep some cash available.
- // Have a driver and a back-up driver who are willing to bring you into the hospital at any time.
- // Always have the address/directions to the hospital available.  
**1 Medical Center Drive, Morgantown, WV 26506**
- // Have alternative directions to the hospital in case of road closures/traffic.
- // During home football games, additional travel information will be provided.

Pack your bags. When you are called in for transplant, you will need to be ready to go fairly quickly.

// You should have your transplant bag packed ahead of time or at least a checklist to work off while packing.

// Things to pack include:

- Loose/comfortable clothing and pajamas
- Good supportive shoes (for when you do physical therapy)
- Hygiene items
- Your current medication list
- Insurance information
- Phone chargers
- Diabetic supplies
- Glasses
- PD Supplies

// Support person should also have their bag with same items as above plus their medications if they will not be returning home nightly

Learn as much as you can about transplant and what to expect throughout the process. As you learn what to expect, you may feel more comfortable. Knowledge is power, and empowered patients are more likely to be active participants in their care. We want you to be at the center of your Transplant Care Team.

// Review this transplant guide completely and often until you are called for transplant.

// Consider joining a transplant support group either in person or online

## **Transplant**

Once you are called in for transplant, you will be asked to report to WVU Medicine J.W. Ruby Memorial Hospital. Upon arrival, you will be assessed and have blood work drawn, and x-rays may be obtained. You may have to wait some time before going to the operating room. Once the donor organ arrives at the hospital and the surgical team is ready, you will go to the operating room. The length of the surgery will vary from patient to patient. Heart transplant surgery typically lasts between four to six hours.

After surgery, you will recover in the Cardiovascular Intensive Care Unit (CVICU). Once you are stable, you will be moved to a step-down floor. This may take a few days. During recovery, you and your caregiver team will receive education on how to care for your new organ. Doctors and nurses will monitor your vital signs, urine output, fluid status, laboratory results, overall recovery, and how you are feeling. During recovery, you and your caregiver team will receive education on how to care for your new organ. The average hospital stay is 10-20 days.

## **“Dry Run”**

Sometimes, the heart transplant surgery is cancelled. This is called a “dry run.” This can occur because the organ was not suitable for transplant once a surgeon looked at the heart, or it was not a good organ for you. It can be frustrating when this occurs. However, know that even though you did not receive that particular organ, you will remain on the waiting list and continue to receive other offers.

## **After the Transplant**

After you are discharged from the hospital, you may be asked to stay closer to the hospital for a period of time. You will have frequent follow-up appointments, lab work, and scheduled heart biopsies. During the six weeks following transplant, you will not be able to drive and will also have other physical restrictions (you may not lift more than 7 pounds for 3-6 months). You will need to have a 24/7 caregiver available during the first few weeks after transplant. This does not have to be one person, but someone will need to be available to help you during this time.

## **Caregiver Expectations**

During this journey, it is important to develop a team of caregivers that you can rely on to provide support when it is needed. Emotional, physical, mental, and spiritual support will be needed throughout your transplant journey.

### **The Role of the Caregiver**

- // Your Caregiver Team can have many people, but one person should be identified as your primary caregiver. We recommend that your caregiver team consist of at least four members: two primary caregivers and two additional caregivers that can act as back-up caregivers if needed.
  - We recommend that one of your primary caregiver(s) must attend your evaluation appointment.
  - We encourage primary caregivers to attend all appointments with you.
  - If a primary caregiver is unable to attend appointments, a back-up caregiver should accompany you.
- // Caregivers can be family members or friends, neighbors, or other community members. They do not have to have a medical background or perform medical care but should be people who are committed to help you with a variety of activities, such as:
  - Support/companionship
  - Making meals and snacks
  - Reminding you of medication times
  - Assisting with transporting to clinic/testing
  - Noticing changes in your behavior and notifying the Transplant Office
  - Monitoring your incision and notifying the Transplant Office with any changes
- // You should have a caregiver coverage plan to provide 24 hours a day for at least one week after discharge or as long as needed. Remember this does not need to be just 1 person.
- // Caregiver coverage will continue after the first week of discharge but may not require 24-hour coverage.
- // Your Caregiver Team will also be needed to provide transportation while you are unable to drive.

- /// The caregiver(s) should be able to notice changes in your behavior or wounds and notify the Transplant Office.

Use the Caregiver Contact Information form to help gather information and form your caregiver team.

## Center for Organ Recovery and Education (CORE)

CORE is an Organ Procurement Organization (OPO) located in Pittsburgh, Pennsylvania. This OPO works with UNOS to coordinate all organ donations and allocations. CORE coordinates the surgical recovery of organs, tissues, and corneas for transplantation. It is also responsible for facilitating communication between donor and recipient families. CORE promotes organ donation, education, and research for the purpose of saving and improving lives through transplantation.

### DONATE LIFE

As you begin the process of evaluation for transplantation, we request all candidates talk with their families and friends regarding organ donation. At the start of your transplant journey, you should consider the following:

- /// Are you registered as an organ donor?
  - Just because you have an organ at end stage, there is still the possibility to donate other organs, corneas, or tissue.
- /// Are your family members registered as organ donors?
- /// You can take this opportunity to discuss with friends to see if they have registered as organ donor.

There are nearly 106,000 men, women, and children on the waiting list for organ transplants in the United States. In addition, others await cornea or tissue donation to improve their quality of life. You can register to be an organ donor when obtaining or renewing your driver's license or by visiting [RegisterMe.org/WVUMedicine](http://RegisterMe.org/WVUMedicine).

Register to be an organ donor at:  
[www.registerme.org/wvumedicine](http://www.registerme.org/wvumedicine)

Talk with the Transplant Team regarding how you can help with raising awareness about organ donation.



# Frequently Asked Questions (FAQs) Transplant

## Who pays for the costs of transplant?

- // Each patient's insurance coverage is different. A financial coordinator at WVU Medicine will work with your insurance company to obtain approval for some or all of:
  - Evaluation/testing of the recipient and donor
  - Surgery of the recipient and donor
- // The financial coordinator will discuss with you the findings from the insurance company and your responsibility.
- // Questions for you to consider and understand your insurance coverage:
  - What part of the transplant cost is covered?
  - How does this apply to my deductible?
  - What is the cap on my insurance coverage?
  - What happens if my financial coverage runs out?
  - How can I cut down on insurance expenses to make sure my coverage lasts as long as I need it?
  - How will a change in my job status affect my insurance?
  - What would the increase be in my deductible?
  - What pre- and post-transplant tests are covered?
  - Do I need to go to a certain facility for these tests to be covered?
  - Does my plan cover the expenses incurred by my organ donor?
  - Are assistive breathing devices covered by my insurance plan?
  - Are expenses for food, housing, and transportation covered while I wait for my transplant?
  - How much coverage will I receive for post-transplant medications?
  - What is the co-pay amount?

## What other expenses should be expected?

- // Possible out-of-pocket expenses:
  - Transportation/fuel (gas)
  - Hotel/lodging
  - Childcare
  - Food
  - Co-pays/deductibles
  - Follow-up testing/appointments
- // Medications
  - Monthly drug costs will vary and can range from \$0 - \$3,500 per month
  - Medicare Part B coverage at 80%

// Other

- Loss of income due to leave of absence from work
- Household management

**Where should my family stay while I'm in the hospital for my transplant?**

- // The Transplant Team will be able to assist with putting in a request with the Rosenbaum Family House and/or provide contact numbers for local hotels with hospital discounts.

**What medications will I have to take afterward?**

- // Anti-rejection (immunosuppression) medications are taken lifelong:
- Multiple medications to prevent rejection
  - Decreased dose of medication over time
  - Medications for other health issues (blood pressure, insulin, etc.)

**How does a person's quality of life change if he/she gets a transplant?**

- // Most patients say that having a transplant improves the quality of their lives. Patients say that they feel better and have more energy to spend time with their family, do their hobbies, travel, and go back to work.

**Will I be able to have children?**

- // Yes, neither the transplant procedure itself nor the drugs needed postoperatively impair fertility for either men or women. We advise women to delay childbearing until after the first postoperative year, when their health status is generally quite stable. Pregnancy should be planned and managed by a team, including experienced high-risk obstetricians working with their transplant physician since drug dosages and rejection surveillance will need to be coordinated. Drug levels can change during pregnancy and will need to be monitored closely and kept in the therapeutic range. There is no track record of the drugs commonly used causing babies to be abnormal. The one exception to this rule is mycophenolate (Cellcept®), which has some history of abnormalities in babies of mothers taking it. The drug should be replaced with an alternative medication prior to becoming pregnant.
- // Babies of women with transplants are often a few weeks premature and somewhat small for their gestational age, but grow and develop normally.
- // Fertility is not impaired in men having had a transplant. Also, there is no known increase in abnormalities in the children they father.
- // The methods for contraception available to men and women who have transplant are the same as those used by anyone.

**Can I swim in a public pool?**

- // Yes, you can do most anything if you are aware of your surroundings and mindful of the situations where being immune compromised can put you at risk.
- // Do not swim in dirty water.
- // Do not swim until your incision is healed.

**Can I eat sushi? Raw meat?**

- // No – unless it's cooked or smoked. Seafood and meat must be cooked.

### Can I travel outside of the US?

- ✓ Yes, to most places but it is recommended that you talk with your Transplant Team regarding your plans. You will need to consider what vaccinations you need to travel out of the country. Things to keep in mind:
  - Proximity to a transplant facility
  - Checking with your health insurance regarding requirements
  - Expense of vaccines needed
  - Ensure you have enough medication for your entire trip
  - Pack your medications in your carry-on luggage

### Will I take on memories or traits from my donor?

- ✓ No – not according to the most current available scientific research

### What can I find out about my donor? Can I contact the family?

- ✓ Many transplant recipients want to know more about their donor and may want to express gratitude for the donation of their new organ. A protocol for contacting your donor's family has been created in order to protect each party's safety and privacy. Respect for the privacy of your donor's family also impacts the ability of medical personnel to provide details about your donor. WVU Medicine Transplant Alliance will provide a "Thank You" card following your transplant that you can sign and the transplant team will forward to the Organ Procurement Organization (OPO).
- ✓ Any correspondence to the donor family should go through the Transplant Office. The team will document the letter in your electronic medical record and then forward to the OPO, which will then make your letter available to your donor's family.

### Do I need to wear a seatbelt?

- ✓ A transplant patient should always wear a seatbelt when in the car.

# Frequently Asked Questions (FAQs) Heart Transplant

## How do I know if I need a heart transplant?

- // Some patients with severe heart disease may benefit from transplantation. A discussion with your cardiologist will help to determine if it might be appropriate to undergo an evaluation by a multidisciplinary team.

## Is the evaluation process very difficult?

- // The transplant evaluation process is very thorough. In addition to heart testing, tests will be performed to assess the function of all major organ systems. Screening tests for infectious diseases and cancers will be performed. In addition to the physicians on the team, you will be assessed by multiple other disciplines to try and predict how well you and your family will cope with the rigors of the transplant regimen.
- // The multidisciplinary team will meet weekly to discuss the patient evaluations and make decision on appropriate treatment. The outcomes can range from approved for listing, needing additional testing, or declined for stated reasons.

## If approved for listing, when will I be added to the UNOS waiting list?

- // Following committee approval, the Financial Coordinator will submit to your insurance company for approval.
- // All health maintenance results will need to be completed/submitted to the Transplant Office prior to listing.
- // Once all results and insurance clearance is received, you will be contacted and added to the UNOS waiting list.

## What does it mean if additional testing is needed?

- // The transplant coordinator will relay what testing the committee has requested. He or she will help you to schedule or send a prescription for the needed testing. Once the results come back to the transplant office, you will again be presented to the Patient Selection Committee. You will be notified following that discussion.

## If I am declined, what does that mean?

- // If the Patient Selection Committee decides that transplant is not the best option at this time, it will provide you a detailed rationale for this decision. Sometimes this occurs because you are too well for transplant, or it can be that there are issues that make you an inappropriate candidate at this time.
- // You can always request that your evaluation records be forwarded to another transplant center for consideration there.

## How long is the waiting list?

- // Unfortunately, the waiting times for heart transplant are long – often more than six months. Each patient on our waiting list returns for outpatient visits to our transplant clinic as medically indicated.
- // While many patients can wait at home, sometimes it is necessary for patients to be admitted to the hospital in order to remain in satisfactory condition until transplantation.



### What happens when an organ offer is available?

- ✓ The Transplant Team will review donor organ offers to determine if suitable for the identified recipient. The Transplant Coordinator will notify you when an organ has been accepted for you. You will be asked questions regarding your health status and be informed about when you need to report to the WVU Medicine Transplant Alliance Clinic.
- ✓ You will be provided a time to arrive to begin pre-op procedures. You can wait in the clinic for 6 to 24 or more hours. Home medications for you and your support person should be brought in with you.

### How long will transplant surgery last?

- ✓ On average, surgery can take 4-6 hours once begun. Family may feel time is longer as you may actually be waiting in the Pre-op/OR room for a period of time.

### How long will I be in the hospital?

- ✓ Although this will vary person to person but on average discharge will occur 10-14 days after the transplant procedure.

### Will I have pain after surgery?

- ✓ Many heart transplant patients state that they do not have pain after transplant but some discomfort. The incision can cause pain and/or discomfort when you cough. Pain medication will be provided to help control that pain as it will be very important for deep breathing and coughing to prevent infections in your lungs.

### Can my family stay with me?

- ✓ We encourage your family to be present while waiting for the transplant surgery to begin. Following surgery, you will be in the Intensive Care Unit (ICU) to start your recovery. Family will be permitted in for short periods of time according to the ICU guidelines. WVU Medicine has very open visiting hours at which time family is encouraged to provide emotional support – but be aware that rest is an important part of recovery.
- ✓ The Transplant Team can help to direct to local accommodations for family members to get their own rest/relaxation.
- ✓ Anyone who is ill, such as a cold or flu, should not visit.

### When can I drive?

- ✓ After heart transplantation, you can drive when your sternum (breastbone) is fully healed. This takes about six weeks.

### When can I return to work?

- ✓ Depending on your line of work, typically you can return in two to three months following heart transplant. You may wish to discuss career counseling with the Transplant Team's social worker.

### How long does it take to fully recover?

- ✓ Generally, it takes three to six months for full recovery from surgery. Keep in mind that age and previous medical problems may cause a longer recovery.

*This information is for educational purposes only and not intended to replace the advice of your Transplant team. Please contact the WVU Medicine Transplant Alliance Office at [304-974-3004](tel:304-974-3004).*

# Your Quick Guide to WVU Medicine

Below is a list of locations you may visit during your transplant journey.

<b>Main Hospital- J.W. Ruby Memorial Hospital</b>	
<b>Cafeteria</b> Breakfast 6:00 to 10:00 am Lunch 11:00 am to 3:30 pm Dinner 4:00 to 7:30 pm Grab and Go 9:00 pm to 5:00 am	4 <sup>th</sup> floor
Discharge Pharmacy	1 <sup>st</sup> floor (Lobby)
Endoscopy/GI lab	2 <sup>nd</sup> floor
Gift Shop	1 <sup>st</sup> floor (Lobby)
Information Desk	1 <sup>st</sup> floor (Lobby)
Pulmonary Function Test	2 <sup>nd</sup> floor
Radiology	3 <sup>rd</sup> floor
Registration	1 <sup>st</sup> floor
Same Day Surgery	2 <sup>nd</sup> floor
Starbucks	1 <sup>st</sup> floor

<b>WVU Heart and Vascular Institute (Southeast Tower)</b>	
Cardiac Catheterization	2 <sup>nd</sup> floor (2SE)
Heart Failure Clinic	4 <sup>th</sup> floor (4SE)
Cardiac and Pulmonary Rehabilitation	4 <sup>th</sup> floor (4SE)

<b>Physician Office Center</b>	
<b>Outpatient Laboratory</b> Monday through Friday 6:30 am to 6:00 pm Saturday 8:00 am to 12:30 pm <i>Closed on football game days</i>	1 <sup>st</sup> floor
<b>Outpatient Medical Center Pharmacy</b> Monday through Friday 7:30 am to 6:00 pm Saturday 10:00 am to 2:00 pm <i>Closed on football game days</i>	1 <sup>st</sup> floor

**Valet Parking-** In addition to self-parking, valet parking is available at all locations listed above. Valet parking is free, and tipping is not required. Valet parking is available 7 am to 5 pm Monday through Friday.

## IMPORTANT TELEPHONE NUMBERS

Admission	304-598-4000 ext. 75040
Billing	800-516-5548
Cardiac Catheterization Lab	304-598-4012
Cardiac Rehabilitation	304-598-4648
Echocardiogram Lab	304-598-4395
Rosenbaum Family House	304-598-6094
Heart Transplant Office	304-974-3004
Heart Transplant Office Toll-Free Number	1-844-988-7267
WVU Heart and Vascular Institute	304-598-4478
J.W. Ruby Memorial Hospital Main Number	304-598-4000
Medical Records	304-598-4110
Outpatient Lab (Physician Office Center)	304-598-4870
Patient Registration (J.W. Ruby Memorial Hospital)	1-800-324-1468
Pulmonary Lab (J.W. Ruby Memorial Hospital)	304-598-4147
Security (J.W. Ruby Memorial Hospital)	304-598-4029

# Glossary

**Active Candidate:** A transplant candidate eligible to be considered for organ offers.

**Candidate:** A person registered on the organ transplant waiting list.

**Deceased Donor:** An individual from whom at least one organ is recovered for the purpose of transplantation after the declaration of death.

**Evaluation:** The process of gathering information about the potential transplant candidates

**Inactive candidate:** A candidate who is temporarily unable to receive a transplant at a given time and appears inactive on the transplant waiting list.

**Informed Consent:** A person's voluntary agreement, based upon adequate knowledge and understanding of relevant information, to participate in research or to undergo a diagnostic, therapeutic, or preventive procedure.

**Match:** When a donor organ is compatible with a recipient for transplant.

**Organ Offer:** When a deceased donor organ becomes available for an active candidate that is a match. The transplant team is notified with possible organ offers and assesses if the organ is appropriate for the active candidate. If the organ is appropriate, the active candidate will be brought into the hospital to proceed with transplant.

**Organ Procurement Organization:** An organization authorized by the Centers for Medicare and Medicaid Services to procure organs for transplantation.

**Recipient:** A candidate that has received an organ transplant.

**Transplant Team:** A group of professionals at the transplant center who work to make a transplant successful. Each person on the team is an expert in a different area of transplantation.

**Waiting List:** A computerized list of candidates that are waiting to be matched with a specific deceased donor organ for transplant. When a donor organ becomes available, the matching system generates a new, more specific list of potential recipients based on specific criteria.

**Waiting Time:** The amount of time a candidate is on the Wait List. Waiting times can vary depending on many factors.

