



Transplant Alliance

Post-Heart Transplant Education Guide

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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-WVT-RANS)

Fax: 304-598-4899

Transplant Office 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.

CONGRATULATIONS!

Welcome to the start of your new life post-transplant. Receiving a transplant is a marvelous gift and the Transplant Team is here to assist you in taking care of that gift.

Transplant Team members include transplant surgeons, transplant cardiologists, nurses, transplant coordinators, transplant dietitian, transplant pharmacist, transplant social worker, and transplant financial coordinators. Remember that YOU are the most important person on this team. Your heart transplant is a gift, and it is important for you to honor the organ donor and his/her family by taking care of yourself; therefore, taking care of your new heart.

This guide is designed to help you care for yourself following your heart transplant. Read this guide over carefully, and share it with your caregivers, as well as interested family and friends. Being familiar with the information in this guide will help you understand your recovery after transplant surgery and how to care for your transplanted heart going forward.

The information in this guide is generalized and may not answer all of your questions but serves as a good starting point. Be sure to communicate any additional questions you may have after reading this information with your Transplant Team. Team members will meet with you during your hospitalization to help you understand the information you will need to know prior to being discharged home from the hospital. Education after transplant is ongoing with phone calls and during clinic visits with the Transplant Team.

This information may seem overwhelming, but your education will be ongoing. Some suggestions to help you learn:

- /// Listen to the education the Transplant Team gives you and ask questions regarding what you do not understand.
- /// Read over this guide thoroughly and become familiar with the information.
- /// Ask a family member or friend to review this guide with you.

The goal is for you to return home in the best possible health with all of the necessary tools to lead a healthy, active, and productive life.

Remember, never hesitate to contact the Transplant Team with any questions/concerns. We are here to help you! No question is too small!

We look forward to helping you throughout this journey!
The Heart Transplant Team

How to Say “Thank You”

After transplantation, many people look to express their gratitude to the donor families. The Transplant Coordinator has “Thank You” cards and can provide one for you to sign. Once signed, the card will be forwarded to the Center for Organ Recovery and Education (CORE). Donor families often report that organ donation has helped them with their grief. Receiving a letter from a recipient provides the donor family with consolation and assurance that their loved one’s decision has improved lives.

Choosing to write to your donor family is a personal decision and not one that needs to be made immediately. Understand that all families grieve differently, and some take more time than others to respond. There is no time limit for corresponding with your donor’s family and what you say in your card is completely up to you.

Some suggestions to help write your card:

- // Be sensitive to the family’s feelings and be aware that they are coping with loss and grief of a loved one.
- // Acknowledge and express sympathy for the family’s loss.
- // Express gratitude for the gift you have received. Consider sharing how the transplant has affected your life in a positive way.
- // Feel free to share information about yourself, your family, your interests, and occupation.
- // Do not include personal information, such as your last name, street address, phone number, physician’s name, hospital, or any other identifying information.
- // Sign only your first name(s).

Once you have completed your letter, please give it to a Transplant Team Member. They will save a copy to your electronic medical record and then forward the letter to a representative at CORE, who will read and edit it, if necessary, before forwarding to the donor family.

Do not get discouraged if you do not hear back from the donor family. Write again; it can take time to process. Some families correspond with recipients, and others simply find comfort in knowing their loved one will not be forgotten.

WHO IS ON THE TRANSPLANT TEAM?

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

Member	Role
You	<ul style="list-style-type: none"> /// Participate in all aspects of your post-transplant care /// Discuss your needs and concerns with team /// Continue to have required testing and lab work done /// Take all medications as prescribed and instructed /// Continue to keep up with all routine health maintenance
Family/Support Team	<ul style="list-style-type: none"> /// Accompany patient to appointments and procedures /// Participate in all ongoing education following transplant /// Support patient's decisions /// Notify Transplant Team with any questions or concerns
Transplant Surgeon	<ul style="list-style-type: none"> /// Performed the transplant surgery /// Monitor your post-surgical progress during hospital stay and following discharge /// Assist Transplant Team in developing post-transplant plan of care for you
Transplant Cardiologist	<ul style="list-style-type: none"> /// Monitor and address all of your transplant medical needs during hospital stay and in post-transplant clinic /// Manage your post-transplant medications /// Assist the Transplant Team in developing post-transplant plan of care for you
Transplant Coordinator Your point of contact at WVU Medicine Transplant Alliance	<ul style="list-style-type: none"> /// Provide and reinforce post-transplant education /// Manage all of your post-transplant medical care under the guidance of the Transplant Team, including: <ul style="list-style-type: none"> • Refill medication prescriptions • Provide orders for blood work and other testing • Monitor blood work and test results • Respond to phone calls regarding questions and concerns • Help with questions regarding follow-up care and medical questions • Complete medical forms (FMLA, Insurance, etc.) /// Communicate with your local care team as well as other community resources to meet your health needs

Transplant Pharmacist	<ul style="list-style-type: none"> /// Evaluates your current medication list, and identify any possible drug-drug interactions /// Educates you about your medications and assess compliance with your medication regimen /// Reviews any over-the-counter medications or supplements and can answer questions you may have about these /// Can discuss vaccines and immunizations following transplant
Transplant Social Worker	<ul style="list-style-type: none"> /// Help you and your family cope with the stresses and challenges of post-transplant life /// Help to connect you with local resources you may need after transplant /// Help you plan for the day-to-day and long-term needs, such as how and where to get your medicines /// Guide you with fundraising opportunities
Transplant Dietitian	<ul style="list-style-type: none"> /// Assess your nutritional status and dietary needs post-transplant /// Provide education and recommendations for your diet /// Help you develop, begin, and maintain a nutritional plan
Transplant Financial Coordinator	<ul style="list-style-type: none"> /// Obtain authorization for medications for discharge /// Review your insurance coverage and benefits information /// Can help you understand your insurance policy (or policies) /// Discuss potential options for coverage if necessary /// Needs to know of any changes to your insurance coverage as soon as possible
Transplant Service Representative (Administrative Staff)	<ul style="list-style-type: none"> /// Schedule follow-up appointments, testing, and procedures /// Answer Transplant Clinic telephone, takes a detailed message, and relays your message to the appropriate Transplant Team member

CONTACTING YOUR TRANSPLANT TEAM

Communication between you and the Transplant Team is very important. Your Transplant Coordinator will be your primary contact. It will be your responsibility to inform him or her of any problems, questions, or concerns that you have after transplant. To reach the Transplant Coordinator, please call the main office number at 304-974-3004.

The Transplant Office hours are Monday through Friday from 8 am to 4 pm. The office is closed on weekends and holidays. Routine calls, such as non-urgent questions, medication refills, blood work results, and appointments, should be made during normal office hours. All non-urgent calls will be returned no later than the end of the next business day. **Non-urgent calls may include:**

- /// Medication refills (unless out of medicine)
- /// Verification of appointment date and time
- /// Questions following a clinic visit or lab work
- /// General concerns about diet, activity, and exercise
- /// Change of insurance

When calling the office please provide a **detailed** message, including your name, phone number where you would like to be reached, and most importantly the reason for your call. **If your call is urgent, please make the Transplant Services Representatives aware.** This will help us meet your needs in a timely fashion. The more details left in the message, the better the call can be triaged.

There may be times you need to get ahold of the Transplant Coordinator after office hours. These emergent calls after hours will be communicated to the on-call Transplant Coordinator via the Call Center. To reach the On-call Transplant Coordinator, call 304-974-3004 and press option 1. Your call will go to the Call Center; ask to be connected to the Transplant Coordinator On-Call.

Please remember that MyWVUChart.com is a great tool to track bloodwork results, send non-urgent messages to the Transplant Team, request medication refills, and schedule or reschedule appointments. Let the transplant services representative know if you need assistance setting up MyWVUChart. MyWVUChart is not monitored on nights or weekends and is NOT a way to communicate urgent issues.

Medical Emergencies:

If you are having a medical emergency, you need to call 911. The Transplant Team is not able to provide you emergency care over the phone. Examples of life-threatening emergencies include (but are not limited to):

- // Sudden weakness
- // Sudden onset of numbness
- // Sudden new onset of chest pain
- // Passing out (blacking out)
- // Bleeding that cannot be stopped

After you are seen in the emergency room and are stable, please give the emergency room staff your Transplant Coordinator's contact information. If the emergency room doctors believe your emergency is directly related to your transplant, you may need to be transferred to WVU Medicine J.W. Ruby Memorial Hospital. Always notify your Transplant Coordinator of your condition and any treatment, including medications given, if you are seen in the emergency room. You or a member of your family should also let the Transplant Coordinator know if you are being admitted to the hospital.

Refer to the handout "When to Call Your Transplant Coordinator: A Quick Guide" for further guidance.

Care at Home

Leaving the hospital to go home can be overwhelming, but the following information will help guide you on how to care for your transplanted heart. You and your caregivers will need to work on finding a new routine once you are home. This section explains how to monitor for any warning signs that something could potentially be wrong and what steps to take in that situation. Please remember to follow your specific instructions provided at the time of discharge.

TRANSPLANT CLINIC APPOINTMENTS AND PROCEDURES

At the time of discharge, you will be provided with a schedule of follow-up appointments. You will be seen frequently on the 4th floor of the WVU Medicine Heart and Vascular Institute at J.W. Ruby Memorial Hospital. For the first 6 weeks after transplant, you will need a caregiver to drive you to your appointments or until clear to drive from the medical team. It is recommended that a caregiver be with you at all follow-up clinic appointments and procedures.

Please note: It is not recommended to bring children or other dependents with you to your appointments.

Clinic Routine

What to bring to clinic:

- /// Post-Heart Transplant Guide with completed vital sign logs
- /// Current medication list
- /// A caregiver/family member

Please note: It is not recommended to bring children or other dependents with you to your appointment.

Changing Your Appointment

If you are unable to make your appointment, please call the Transplant Office and speak with a Transplant Service Representative to reschedule your clinic appointment as soon as possible.

Clinic Appointment Parking

In addition to free self-parking, valet parking is available at the WVU Medicine Heart and Vascular Institute. Valet parking is free, and tipping is not required. Valet parking is available 7 am to 5 pm Monday through Friday.

Overnight Lodging

If you are traveling a long distance for your Transplant Clinic appointments, our Transplant Social Worker can help provide information on the Rosenbaum Family House and local hotels.

VITAL SIGNS

After transplant, you will be at risk for rejection and infection for the rest of your life. You will be at the highest risk for rejection and infection the first 6 months after transplant. It will be important for you to continue to monitor your vital signs (temperature, pulse, blood pressure, and weight) at home, and notify your transplant coordinator if any of your results are abnormal. Vital signs can help detect a rejection or infection episode. Below is a description of each of the vital signs and what results to report to your Transplant Coordinator.

Vital Signs Log

Write your vital signs in your Vital Signs Log (see page 54). You can get additional pages from the Transplant Alliance Office or print from the website (wvumedicine.org/transplant). You will take your vitals at least two times a day (morning and evening).

Temperature

- // Take your temperature and record it in your vital signs log.
- // You should also check your temperature if you are not feeling well.
- // If it is 100.4°F/38°C or greater:
 - If you have no symptoms, repeat in 1 hour. If it remains elevated, contact the Transplant Coordinator.
 - If you have symptoms (sweats, chills, cough, etc.), call the Transplant Coordinator immediately.

Pulse

- // Check your pulse twice a day and enter reading into your Vital Signs Log.
- // If your pulse is less than 60 or greater than 115, call the Transplant Coordinator.

Blood Pressure

- // Check your blood pressure every day in the morning and evening and write it down in your Vital Signs Log.
- You will be instructed at discharge if you should take your blood pressure more or less often.
- // If your systolic (top) number is greater than 160 or the diastolic (bottom) number is greater than 100, take your blood pressure again in 1 hour. If after 1 hour the readings are still elevated, contact the Transplant Coordinator.
- // If the systolic (top) number is less than 110 or the diastolic (bottom) number is less than 60, do not take any blood pressure medicine, and call the Transplant Coordinator.

Weight

- // Weigh yourself every morning before breakfast using the same scale and wearing the same type of clothing, and record in your Vital Signs Log.
- // If you are gaining more than 2-3 pounds per day or 5 pounds in one week, call the Transplant Coordinator.

High blood glucose (sugar)

Anti-rejection medications can cause an increase in blood sugar levels that may require you to check blood sugar levels at home. If you are asked to keep a record of your blood sugar levels, please use the “Blood Sugar Monitoring Log” (on page 60). This is typically temporary but may become permanent.

Patients who have pre-existing diabetes will be managed by the Transplant Team immediately following the transplant surgery. Eventually, we will transfer your diabetes care back to your primary care physician or endocrinologist.

Signs of high blood sugar

- // Increased thirst // Increased urination
- // Increased appetite // Confusion

If your blood sugar is greater than 250 for three or more consecutive tests, contact the Transplant Coordinator

Signs of low blood sugar

- // Sweating // Feeling weak or tired
- // Shaking // Headache
- // Confusion // Feeling nervous or upset
- // Difficulty speaking

If your blood sugar is less than 80, treat by eating or drinking something high in sugar such as:

- // 1/2 cup of regular fruit juice (like orange, apple, or grape)
- // 1/2 cup of regular soda pop
- // 4 glucose tablets or 1 tube of glucose gel
- // 1 tablespoon of sugar, honey, or corn syrup

After eating or drinking one of the above, wait 15 minutes and then check your blood sugar again. Contact the Transplant Coordinator if your blood sugar is still less than 80 with your repeat blood sugar.

BLOOD WORK AND LAB DRAWS

// At the time of discharge, you will get a prescription for blood work.

// Please remember that the timing of your labs is important.

- Some medication doses are determined by lab levels, so it is important that they are accurate.
- You must have your anti-rejection levels drawn 12 hours from the time of your evening dose and prior to your morning dose.
- Do not take medication prior to your blood work.
- You may drink water prior to having blood work drawn.

// Labs can be drawn at the Physician Office Center (POC) connected to WVU Medicine J.W. Ruby Memorial Hospital.

// If you have your labs drawn outside the WVU Medicine Health System, the results need to be faxed to 304-598-4899.

WOUND CARE

Take daily showers. Stand with your back toward the water. Wash your incision with soap, rinse well with clean water, and gently pat dry. Use caution using a washcloth so that it does not cause skin irritation or catch on staples/steri-strips.

- // DO NOT take a tub bath or submerge in water until cleared by a Transplant Team.
- // DO NOT apply antibiotic ointment, lotions, oils, or creams to your healing incision(s).
- // Keep your incision clean and dry.
- // If your incision has staples, they will be removed 4 weeks after transplant at a clinic visit.
- // If there are small, thin, tape strips (steri-strips) over your incision, allow these to fall off on their own. You can shower with these strips – gently pat dry.
- // If you have an open wound at the incision, check with the Transplant Team prior to showering.
- // If you have been sent home with a wound vac, you will be set up with a home health agency to help you take care of it.
- // **If you have a fever or notice redness, swelling, tenderness, or drainage at your incision, or if the wound seems to be opening, contact the Transplant Coordinator immediately.**

AVOIDING CONSTIPATION

- // Bowel patterns can be expected to return to normal when you are off pain medications, eating your normal diet, and resuming your regular activity.
- // Stay active and avoid dehydration to help prevent constipation.
- // Take stool softeners as directed to avoid straining when having a bowel movement.
- // Notify your Transplant Coordinator if abdominal pain persists or if you develop a swollen or hard, tender abdomen.

ACTIVITY

Remember that everyone recovers from transplant at their own pace. Set a reasonable goal for your recovery. You may need to adjust your initial expectations of how your recovery is progressing. A heart transplant is a big surgery, and you will need to give your body time to recover. It can take up to six months, sometimes longer, to recover from heart transplant surgery. Be patient with yourself, and do not get discouraged.

Initially, you will have limitations due to pain, weakness, and general deconditioning. Start with short frequent walks, and increase length and frequency as tolerated.

Remember that sleep and relaxation are also very important. If you feel rundown or too tired, your body will have a harder time healing and fighting off infection.

The Denervated Heart

During heart transplant surgery, your vagus nerve is cut. The vagus nerve plays a role in regulating your heart rate. A transplanted heart without a vagus nerve is known as a “denervated heart.” There are some things to be aware of when the heart is denervated. These include (but are not limited to):

- // You will need to take some time to warm up before and cool down after exercise. We recommend at least 10 minutes of warm-up and cool-down time. This will allow your pulse to gradually increase and will prevent lightheadedness and dizziness.
 - Warm up for 5-to-10 minutes. The more intense the activity, the longer the warm-up.
 - Do whatever activity you plan on doing (running, walking, cycling, etc.) at a slower pace (jog, walk slowly).
 - Use your entire body. For many people, walking on a treadmill and doing modified bent-knee push-ups will suffice.
- // Change positions slowly.
 - Standing too quickly may cause you to feel lightheaded.
- // It is recommended that you pump your legs and roll your ankles before getting out of bed or out of a chair.
- // Heart transplant recipients have a faster resting pulse – expect a pulse of about 80-100 when at rest.
- // During a heart attack, heart transplant recipients usually do not have chest pain. Instead of chest pain, they may feel extremely tired and fatigued and/or short of breath. If you are experiencing these symptoms, call 911.

Inpatient Rehabilitation

Patients who need more intense physical therapy and conditioning in order to be independent and function at home will be transferred to an inpatient rehabilitation facility when possible.

Weightlifting Restriction

You will need to limit the amount of weight you are able to lift for at least 6-8 weeks following surgery. **You may not lift, push, or pull more than 5 pounds until your Transplant Team clears you to do so.** This includes lifting and carrying small children and pets. They can, however, sit on your lap.

Activities restricted for the first three months:

- // No lifting more than 5 pounds (1/2 a gallon of milk)
- // No straining or pulling of the abdominal/chest muscles with sit ups or similar exercise
- // Use leg muscles instead of abdominal muscles when you can
- // No swimming until cleared by the Transplant Team
 - Avoid hot tubs, lakes, rivers, and streams
 - Swim in a clean, chlorinated pool

When Can I Drive?

You will not be allowed to drive for 6-8 weeks after your surgery. Your Transplant Cardiologist will let you know when you are able to drive. Typically, this will happen once your incision is healed and you have stopped taking pain medication. After you are cleared to drive, have a family member or friend take you out in an open area so you can get the feel of driving again and be comfortable with your range of motion. Remember, your health and the health of others depend on your safe driving.

Cardiac Rehabilitation and Exercise

After transplant, you will be seen daily by a cardiac rehabilitation specialist to help you get out of bed and start walking exercises while in the hospital. A daily exercise routine is essential! The sooner you increase your activity, the sooner you will recover and avoid complications. Sometimes you will find that your muscles, especially your leg muscles, are weak after surgery. Exercise is the only way to improve the strength of your muscles.

Try these when you get home:

- /// A mild walking routine is recommended for you immediately after surgery
- /// Riding a stationary bicycle with stationary handles starting with no tension
- /// Strength and endurance exercises provided by cardiac rehab
- /// Once recovered from the transplant surgery, you should aim to get at least 30 minutes of moderate exercise at least three days per week.

Before starting any new exercise program, check with the Transplant Coordinator.

Returning to Work

We encourage you to return to work as early as possible; however, some patients are restricted from work for as many as six months. Returning to work can often depend on the type of work you do and your ability to safely resume those activities. Discuss returning to work with the Transplant Coordinator when you feel ready to do so.

Long-term Activity

Most patients return to normal activity (including many sports) about a year after transplant. Always ask the Transplant Cardiologist if you have any particular long-term activity restrictions.

Eating and Drinking After Transplant

A dietitian will review the dietary changes you will need to make after your transplant to stay healthy and avoid interaction with your new medications.

Proper nutrition is important after transplant to encourage healing. Eating a variety of foods while avoiding or limited added fats, sugar, and salt will reduce or prevent some side effects that may occur with your new transplant medications.

Salt and Sodium

Certain transplant medications may cause your body to retain fluid. Eating salty foods may increase fluid retention and your blood pressure. A low sodium diet, less than 1,500 mg per day, is recommended long term.

Common high sodium foods to avoid or limit in your diet:

- // Table or seasoning salt
- // Processed meats and cheeses
- // Canned soups and vegetables, cured or brined foods
- // Salted crackers, potato chips, or pretzels
- // Fast foods and convenience foods
- // Instant foods
- // Salty seasonings (meat tenderizer, soy, or teriyaki)

Carbohydrates and Blood Sugar

Prednisone and Tacrolimus are important medicines that we often need to use to keep your new heart healthy, but they may cause increased blood sugar levels in patients without a history of diabetes. Sugary foods or a high carbohydrate diet may contribute to higher blood sugar levels. The right balance of carbohydrates in your diet, along with exercise, will help achieve better blood sugar control.

A healthy meal consists of a combination of low-fat, lean protein, vegetables, and whole grains. Calorie control, moderate portion sizes, and low sugar or carbohydrate choices with adequate fiber will also help with blood sugar control.

Magnesium

Many heart transplant recipients are prescribed magnesium supplements due to low magnesium levels. It may also be helpful to try to add higher magnesium foods into your diet.

High magnesium foods include:

- // Pumpkin seeds, cashews, almonds, Brazil nuts, peanuts, pecans, and hazelnuts
- // Spinach, soybeans, soy milk, seaweed, Swiss chard, tofu, and beet greens
- // Crab, clams, shrimp, halibut, tuna, and conch (these must be cooked)
- // Bran, oats, barley, rye, brown rice, wheat germ, and whole wheat bread

Fat and cholesterol

Certain transplant medications may increase your lipid levels, such as cholesterol and triglycerides, and increase your risk of heart transplant vascular disease.

Steps to help lower the fat and cholesterol in your blood:

- // Maintain a healthy weight.
- // Consume lean meat, poultry, fish, and non-fat or low-fat dairy products.
- // Bake, broil, roast, steam, or grill foods instead of frying or sautéing.
- // Trim visible fat from meats and remove skin from poultry before cooking.
- // Avoid butter, lard, and shortening.
- // Use trans-fat free margarine, olive, or canola oil in small amounts.

Potassium

After transplant, certain medications may increase your potassium levels. If your potassium is high, a low potassium diet must be followed until your levels are within range. Identifying high potassium foods, along with portion control, will allow you to consume a well-balanced diet while maintaining safe blood levels.

High potassium foods include:

- | | |
|--|-------------------|
| // Bananas, oranges, cantaloupe,
honeydew, apricots, and grapefruit | // Sweet potatoes |
| // Cooked spinach | // Mushrooms |
| // Cooked broccoli | // Peas |
| // Potatoes | // Cucumbers |

**Grapefruit and grapefruit juice will interact with your antirejection medication. Eating or drinking grapefruit (juice) should be avoided.*

Calcium

Some heart transplant patients may be asked to decrease foods that contain calcium. Most people think that calcium is only found in dairy products, such as milk, cheese, and yogurt.

High calcium nondairy foods include:

- | | |
|---|--|
| // Seeds (poppy, sesame, celery, and
chia) | // Leafy greens (collard greens and kale) |
| // Sardines and canned salmon | // Rhubarb |
| // Beans and lentils (white beans are
highest) | // Fortified foods (cereals, flour,
cornmeal, and nondairy milks) |
| // Almonds | // Edamame |
| // Whey protein | // Tofu prepared with calcium |

Immune System

Your immune system is an amazing part of your body that protect you from many different types of infections. Right now, white blood cells are traveling inside your blood stream, searching for any foreign or infectious material to destroy. These white blood cells help to prevent infections and protect your body from foreign material, including bacteria, fungi, and viruses.

Unfortunately, your immune system may identify your new organ as foreign and try to destroy it. This process is called rejection. After transplant, your immune system must be suppressed or weakened to prevent rejection of your new heart.

Possible Complications

REJECTION

Rejection is a normal body defense system where the body tries to get rid of anything it thinks does not belong there. Normally, your immune system attacks foreign objects, including bacteria and viruses. After your heart transplant, your immune system may try and attack the new organ. In order to prevent rejections, we will give you anti-rejection medicines that weaken the immune system's ability to damage the transplanted heart.

Rejection occurs most frequently in the first 3 months after heart transplant but can occur at any time after transplantation. Early detection allows most rejection episodes to be treated successfully. The diagnosis of rejection is made by your symptoms, blood tests, and other diagnostic procedures, depending on your type of transplant.

You may or may not experience any of the signs and symptoms below, but you should be aware of them. If you notice any of these, contact the Transplant Coordinator.

- // Fever over 100.4°F/38°C
- // Chills, body aches, flu-like symptoms
- // Large increase or decrease in blood pressure
- // General sense of “not feeling well”
- // Increased fatigue
- // Weight gain greater than 2-3 pounds in 24 hours
- // Fluid retention or swelling of legs or feet

Rejection often occurs without any of these signs/symptoms.

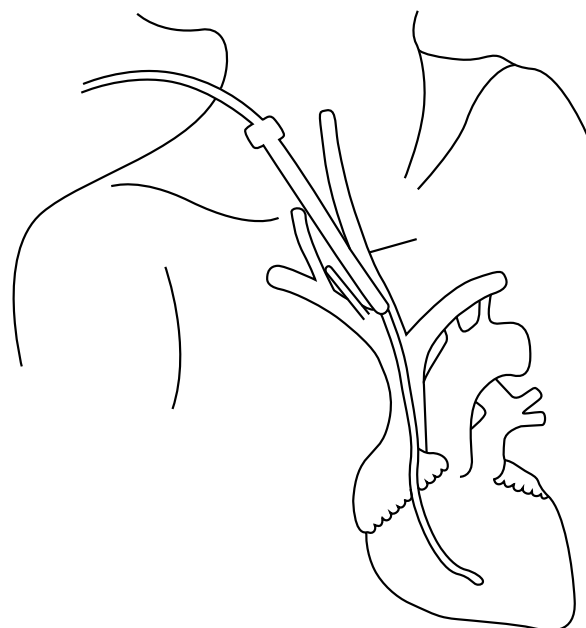
How Do You Look for Rejection?

There is only one way to diagnose or confirm rejection: by doing an endomyocardial biopsy (heart biopsy) and a gene expression blood test.

A heart biopsy is done in the cardiac catheterization lab. The cardiac catheterization lab is located on 2SE of J.W. Ruby Memorial Hospital. The right side of your neck will be cleaned with antibacterial solution. Numbing medication will be injected into the cleaned area. Once

your neck is numb, a small cut is created on the side of your neck. This allows the cardiologist to insert a catheter into a large vein. This large vein leads to the right side of your heart, where the cardiologist will remove small pieces of heart tissue for review under a microscope.

The procedure takes about 30 minutes. Once completed, a pressure dressing will be applied, and you will rest for at least one hour in the post-procedure area. Once you are discharged from the post-procedure area, you will have an appointment in the Post-Transplant Clinic located on the 4th floor of the WVU Medicine Heart and Vascular Institute (HVI) Outpatient Clinic.



Following your biopsy, avoid heavy lifting (anything over 10 pounds) for 24 hours. The pressure dressing can be removed the morning after your procedure. Watch for bleeding or any signs of infection around the puncture site. Biopsy results are typically available 24-48 hours after the procedure.

You will need a caregiver to drive you to your biopsy appointments for the first 6 weeks after transplant.

Once you feel comfortable with the procedure, you may decide to drive yourself after 6 weeks.

Routine Surveillance Biopsy Schedule

Time post-transplant	Month 1	Month 2	Month 3-6	Month 7-12	Years 1-3	>3 years
Biopsy	Weekly	Every 2 weeks	Every month	Every 2 months	Every 4 months	None unless clinically indicated

Adjustments to the biopsy schedule may be indicated at the Transplant Cardiologist's discretion.

Do not eat or drink after midnight the night before your scheduled biopsy. Wear comfortable clothing. Bring the following to each visit:

- /// a list of your medications
- /// current vital sign logs
- /// blood sugar logs (if applicable)
- /// your Post-Transplant Education Guide,
- /// any questions you have.

Heart Transplant Rejection Grading Scale

Your biopsy results are used to detect the presence and severity of acute cellular rejection (ACR). Based on your biopsy results, you will be assigned a “grade.” The following table defines each of the different grades and the needed treatment.

Grade	Definition	Treatment
Grade 0	No rejection	None
Grade 1 R	Mild rejection/ inflammation	This type of rejection is harmless and requires no treatment.
Grade 2 R	Moderate rejection	Treatable rejection. Steroid medications (similar to prednisone) will be given intravenously (IV) either in the hospital or as an outpatient once a day for 3 days. A follow-up biopsy will be performed 2 weeks after treatment.
Grade 3 R	Severe rejection	Treatable rejection. Treatment is similar to grade 2 R rejection. Stronger anti-rejection medications may be used. You may need to stay in the hospital if your heart function is affected.

Gene Expression Profiling (GEP) may be an alternative option to biopsy. GEP is a special blood test that looks for certain genes that are expressed in the bloodstream at the time of rejection. The test is performed at select laboratories as well as the Physician Office Center (POC) Outpatient Laboratory at J.W. Ruby Memorial Hospital. Gene expression profiling is for stable patients who:

- /// Are over the age of 18
- /// Have had no recent rejection
- /// Are at least 3 months from transplant
- /// Do not have multiple organ transplants

GEP testing follows the biopsy schedule. The results are described with a score of 0-40. If your GEP score is greater than 30, there is a chance you may be having rejection and will need a heart biopsy within 5 days of testing.

ANTIBODY MEDIATED REJECTION (AMR)

AMR is a different type of rejection. The transplanted heart is not a genetic match to you. As a result of this, you have a risk of developing antibodies to the transplanted heart. These antibodies are called donor specific antibodies (DSA's). This form of rejection is not common and is treated differently than acute cellular rejection.

Treatment usually requires Plasmapheresis, which is like dialysis and is a process where the liquid part of the blood (plasma) is separated from the blood cells. During this, the antibodies will be removed from your blood. During this treatment, you may receive additional IV anti-rejection medications. This therapy usually requires hospitalization.

CORONARY ARTERY DISEASE (CAD)

CAD occurs in the transplanted heart when plaque, which is made up of fat, cholesterol, and calcium, builds up inside the coronary arteries that deliver blood to the heart. When these arteries become narrowed by the buildup of plaque, less oxygen rich blood can get to the heart. When this happens, the heart muscle becomes stiff and weakened and can eventually lead to heart failure. You can decrease your risk of CAD by living a healthy lifestyle. This includes eating a healthy diet, maintaining a healthy weight, and keeping your blood pressure, blood glucose (sugar) levels, and cholesterol levels within a normal range. Avoiding all tobacco and excessive alcohol use can also decrease your risk of CAD.

CORONARY ARTERY VASCULOPATHY (CAV)

Coronary artery vasculopathy is a form of chronic rejection where the coronary arteries become blocked as a result of inflammation caused by your immune system. CAV can eventually lead to heart failure. The treatment for CAV could be a change in anti-rejection medications, angioplasty, stenting, or bypass surgery. Re-transplantation is the only definitive cure for CAV.

INFECTION

The key to successful treatment of infection is to notice the signs and symptoms as early as possible and to notify your Transplant Team. It is very important that you monitor and protect yourself from infection. You are at higher risk not only for common illnesses, but also less common illnesses.

The best thing you can do to prevent illness is practice good hand hygiene and overall hygiene. Obtaining the recommended vaccines requested by the Transplant Team can help to prevent illnesses or weaken their severity.

Report any of the following signs and symptoms of infection to the Transplant Coordinator:

- | | |
|--|---|
| /// Fever over 100.4°F/38°C | /// Sudden onset of nausea and/or vomiting |
| /// Sore throat | /// Diarrhea (sudden onset, three to four loose, watery stools in 24 hours) |
| /// Cold or flu-like symptoms | /// New tenderness or discharge over wound or incision |
| /// Cough or shortness of breath | /// Red or draining skin opening or incision site (pus) |
| /// Chest congestion, coughing up colored sputum | |
| /// Bloody, foul-smelling, or cloudy urine | |
| /// Pain, burning, or increased frequency with urination | |

COMMON ILLNESSES/PROBLEMS

Remember to stay away from friends or relatives who are ill. See your primary care doctor for any of the following:

- // Colds and flu
- // Sore throat
- // Earaches
- // Chronic headaches

Notify the Transplant Coordinator for any of the following:

- // New episodes of persistent headaches
- // Cold sores – Herpes simplex virus causes cold sores, which look like tiny water blisters on the lip or face.
- // Unusual or painful rashes or sores
- // Any scheduled surgery or procedures
- // Exposure to any communicable disease (chicken pox, measles, mumps, COVID etc.)
- // Herpes zoster (shingles) – shingles appear as a rash or small water blisters, usually on the chest, back, or hips, but may occur on other areas. The rash may or may not be painful. Your local doctor may treat your shingles; however, be sure to notify the Transplant Coordinator.
- // If the shingles are present on your face, you will need to be seen in the Emergency Department

Usually, the risk of infection decreases after the first three months. The frequency of clinic visits, home monitoring, and some precautions are also decreased to eliminate unnecessary risk of infection. Take your temperature, pulse, and blood pressure anytime you are not feeling well.

TIPS FOR AVOIDING INFECTION

- // Wash your hands with soap and water.
 - Before eating and taking your medications
 - Before and after changing wound dressings
 - Before changing your contact lenses
 - After using the bathroom
- After petting animals
- Anytime they are visibly dirty
- After shaking hands with a large number of people (such as church, meetings)
- // Avoid crowded areas (such as malls, theaters, airplanes) for three to six months after transplant.
- // Wear a mask when coming to clinic visits or in crowded areas for the first three months.
- // Avoid people with colds, flu, or other contagious illnesses (flu, COVID, etc.).
- // **DO NOT** share drinking glasses or eating utensils with other people.
- // Wash dishes and eating utensils with HOT water and detergent or in a dishwasher.
- // Avoid working with dirt or soil for 6 months after transplant. After that, wear gloves

and a mask when you do work with soil or doing yard work.

- /// **DO NOT** handle animal waste, specifically cat litter, fish tanks, and bird cages.
- /// If you have young, school-aged children or grandchildren, ask the school nurse to notify you when any communicable disease outbreak (chicken pox, measles, etc.) occurs in the school.
- /// Avoid construction areas and major home remodeling (removing carpet, wall repair) for three to six months after transplant.
- /// Use common sense.

HANDWASHING

To correctly wash your hands, you should use warm water and soap for about 15 to 20 seconds. Regular soap is fine. Scrub all over your hands and fingers – do not forget to scrub under your nails. Rinse completely with warm water then use a clean towel to dry your hands. You should keep some alcohol hand sanitizer with you when you are away from home. You can use these gels and lotions to clean your hands when there is no water around.

POST-TRANSPLANT INFECTIONS

Infection	Treatment
Wound Infection	Antibiotics; sometimes wound opening or surgery
Lung Infections (pneumonia)	Antibiotics
Thrush and yeast infections	Antifungal medications*
Cytomegalovirus (CMV)	Antiviral medications
Epstein-Barr Virus (EBV)	Lowering of anti-rejection medications and possibly antiviral medications

** There are certain antifungal medications that will interact with your anti-rejection medication. Please call the Transplant Coordinator before taking any antifungal medication.*

Bacterial infections usually happen very early after transplant and can be caused by central venous catheters or infections at the incision.

Fungal Infections (yeast) are most common in the first three months after transplant. One of the most common fungal infections, thrush, looks like white plaques coating the tongue, throat, and inside of the mouth. It makes your mouth tender and, at times, may burn. You may have difficulty swallowing. This infection can spread from your mouth to your esophagus and is treated with tablets or liquid medication, if the infection is mild. But if the infection is severe, it may need to be treated with IV antifungal medications in the hospital.

Cytomegalovirus (CMV) - CMV is the most common viral infection after a solid organ transplant. CMV is a community-acquired infection and it is not a serious illness for most people who are healthy. CMV is also known as an opportunistic infection, meaning it will hide inside the body until your immune system is suppressed and unable to fight it. CMV is treated with antiviral medications. You will be treated with preventative medication for six months.

Generalized symptoms of CMV include:

- // Fever
- // Low platelet count
- // Coughing
- // Shortness of breath
- // Diarrhea
- // Nausea
- // Bloody stool
- // Fatigue
- // Malaise

***Symptoms may vary depending on where the virus is in your body.*

Epstein-Barr virus (EBV) – EBV is a common viral infection within the community. It is responsible for causing mononucleosis (commonly known as “mono” or “kissing disease.”) Most people have been exposed to this virus at some point in their life. Transplant patients who develop EBV are at risk for posttransplant lymphoproliferative disease (PTLD). PTLD is a type of cancer characterized by tumor growth and lymphoma.

Generalized symptoms of EBV include:

- // Fever
- // Sore throat
- // Fatigue
- // Abnormal liver function labs

Treatment for EBV and PTLD varies and usually involves decreasing your anti-rejection medications and potentially prescribing an antiviral medication for you. For severe cases of PTLD, surgery, chemotherapy, or radiation therapy may be necessary.

IMMUNIZATIONS AND VACCINES

- // It is recommended to wait at least six months after transplant before receiving most routine vaccines. You may be advised to receive certain vaccines (influenza, COVID, etc.) earlier than 6 months post-transplant depending on infection and the time of the year.
- // Always keep a current copy of your immunizations/vaccine record.
 - An immunization/vaccine log is located on page 66.
- // Notify the Transplant Office if you plan to travel to a foreign country, especially if various vaccines or immunizations are required.
- // DO NOT change the diapers or help with toileting of young children that have been immunized for two weeks following live virus vaccination. This should be avoided because children can shed the virus for up to two weeks following vaccination with a live virus vaccine. Examples of childhood live virus vaccines include Rotavirus, MMR and Varivax®.
- // If a recently vaccinated individual develops a rash from their vaccine, you should avoid contact with that individual.
- // Pets may also receive live vaccines, such as Bordetella, so use caution with collection of feces.

Acceptable Immunizations or Vaccines after Transplant

Influenza or “Flu” Vaccine – It is strongly recommended you receive a flu vaccine every year at the beginning of flu season; however, you can receive it at any time during the season. Your immediate family should also be vaccinated to help protect you. DO NOT use the “FluMist” nasal formulation as it is a live vaccine.

Other vaccines that are acceptable and encouraged after transplant (when appropriate) are: pneumonia vaccine, tetanus vaccine, Hepatitis A and B vaccines, and Shingrix® vaccines. Please follow up with your primary care physician to determine what vaccination you will need to have.

Unacceptable Immunizations or Vaccines after Transplant

Avoid live virus vaccines after transplant. These vaccines are weakened but live and could potentially cause illness. Live virus vaccines include: FluMist®, Zostavax®, Varivax®, and MMR.

General Health Guidelines

Primary Care Provider (PCP)

You are required to have a primary care provider and to follow-up with them on a regular basis. Your Transplant Coordinator will need your PCP’s contact information. The Transplant Team will keep in contact with PCP and keep them updated regarding your transplant care. Medical issues that can be addressed by your PCP include:

- /// Routine physical exams
- /// Preventive health
- /// Routine health maintenance exams (Pap smear, mammogram, colonoscopy, prostate exam)
- /// Complications related to diabetes and bone disease
- /// Immunizations
- /// Common cold/flu treatment

Chronic Health Conditions

Any chronic health conditions that you had prior to transplant, including chronic pain (arthritis, back pain), anxiety/depression, diabetes, etc., will still require follow-up with the providers who were caring for you prior to transplant.

Long-term Follow-up

Patients need to return to their primary care physician or referring physician for long-term care. Some medical problems, such as diabetes, kidney problems, etc., may require referral to other medical specialty physicians.

Recommended Routine Follow Up

- /// Physical examination
- /// Eye examination (to check for cataracts, glaucoma, and other eye diseases)
- /// Dental examination
- /// Flu vaccine
- /// Dermatology exam (annual screenings and if you notice any changes to your skin)
- /// Colon cancer screening over the age of 45
- /// Mammogram for women over the age of 40
- /// Pap smear for women over the age of 21 as per gynecologist
- /// Prostate exam for men over the age of 45
- /// Bone Mineral Density (DEXA) scan

Dental Care

Please see your dentist regularly.

- // Brush your teeth and gums at least twice a day.
- // Use only a soft bristle toothbrush.
- // Floss your teeth daily.
- // Tell the dentist you have been transplanted.
- // Have a dental checkup at least every 6 months or as directed by your dentist.
- // We follow the American Heart Association Guidelines for Bacterial Prophylaxis for antibiotics before every dental appointment (including cleaning and polishing). Talk with your Transplant Team at least a week prior to scheduled appointment.
- // You and your dentist are encouraged to consult the Transplant Coordinator with any questions or concerns regarding any major dental work.
- // If you do not have a dentist, please let the Transplant Coordinator know.
- // If you develop thrush, change your toothbrush and if you have dentures, soak them in Nystatin.

Have all medical notes and results of labs and exams done outside of WVU Health System faxed to 304-598-4899.

Skin Care

The medications you are taking may increase sun sensitivity, dry skin, and/or acne. Transplant patients have an increased chance of developing skin and lip cancers.

Prednisone is known to cause acne. To control it, wash your face and other affected areas at least three times a day with soap and water. Always use a fresh, clean washcloth to dry your face and affected area. We can refer you to a dermatologist if necessary.

Sun Exposure

The ultraviolet (UV) rays from the sun, which are present even on cloudy days and in shady areas, cause skin cancers.

Skin and lip cancers occur more frequently in people who have had prolonged exposure to the sun and have light skin pigment or fair complexions. These cancers occur more often when you live in an area that has numerous sunny days or in an area of high elevation. They are also more common in people whose jobs require them to work in the sun.

Some transplant medications will make you sensitive to the sun. You may burn and tan easier, faster, and to a greater degree than you did before your transplant. If you have blonde hair, red hair, or a fair complexion, you have an even greater chance of getting a severe sunburn.

Always

- // Protect your skin from ultraviolet exposure.
 - Apply sunscreen prior to going outdoors
 - Reapply sunscreen every 2 hours or immediately after coming out of water or with heavy sweating

- // Wear broad-brimmed hats and protective clothing.
- // Use sunscreen lotion (SPF-30 or greater) on any exposed skin, making sure to include face, ears, and neck
- // If you must be outside, plan to be outside in the early morning or late afternoon when there are fewer ultraviolet rays
- // Use lip balm with sunscreen protection (SPF-15 or greater).

Avoid

- // Midday sun, since ultraviolet rays are strongest between 10 am and 4 pm

Hair Care

Some of the medications we use for transplant can affect your hair. Tacrolimus (also known as Prograf®) and azathioprine (Imuran®) can cause hair loss. Cyclosporine (Neoral®, Gengraf®) can cause unwanted hair growth. Hair loss is most common in the first year after transplant and often improves. It is best to avoid hair dye or permanents if you are currently experiencing hair loss. Let us know if you are having problems. We try not to switch medications too early in the transplant due to the risk of rejection.

Medic Alert Identification

Because transplant patients require special care in emergency situations, it is important for you to carry some form of identification to alert emergency medical personnel that you have a transplant. We recommend some form of jewelry, such as a medical ID bracelet, which will be seen by first responders. You can also add your transplant information to the emergency section on your smartphone.

<https://www.medicalert.org/product/catalog/medical-ids>

Healthy Body, Healthy Mind

The transplant process can be long and stressful. Some people may feel this stress before they are transplanted, but others may experience it after the surgery. It is important to know that you will go through many emotions after your transplant. You may find yourself reacting in different ways. There are a variety of emotions you may experience including anger, frustration, guilt, and depression.

These feelings may affect people differently. What may be stressful for one person, may not be stressful to someone else. Your reaction to stress may come in the form of:

- // Feeling down, angry, overwhelmed, or depressed
- // Not being able to focus
- // Crying
- // Disturbed sleep patterns
- // Mood swings
- // Changes in when and how you eat

If you are feeling any of these symptoms, and would like to talk to someone, your Transplant Team has resources to help you get through these hard times. You can make an appointment to see anyone on the Transplant Team, and we will work with you. As a part of the transplant family, we are dedicated to your success and well-being.

Smoking

It is recommended that you DO NOT smoke. The Surgeon General of the United States has determined that smoking, including passive smoke, is harmful to your health. Smoking causes damage to the lungs, making it easier for you to develop a lung infection or cancer. You should stay away from smoke-filled areas as much as possible. If family members smoke, they should smoke outside of your home. Lung infections can become serious or life-threatening.

E-cigarette

E-cigarettes are known by many different names. They are sometimes called “e-cigs,” “e-hookahs,” “mods,” “vape pens,” “vapes,” and “electronic nicotine delivery systems.” E-cigarettes produce an aerosol by heating a liquid that usually contains nicotine as well as other potentially harmful substances. Much like smoking cigarettes we discourage the use of e-cigarettes or having them used in your presence.

Chewing Tobacco/Snuff

It might be smokeless, but it is not harmless! In addition to nicotine, smokeless tobacco contains at least 28 known cancer-causing chemicals. These all lead to an increase in mouth and throat cancers.

Tobacco Cessation

West Virginia has a Tobacco Cessation Quitline – 1-800-QUIT-NOW (800-784-8669) or visit their website <http://dhhr.wv.gov/wvdtb/cessation/Quitline/Pages/default.aspx>

Alcoholic Beverages

Depending on your other health conditions, it is generally OK to have an occasional glass of wine, 1 to 2 ounces of liquor, or a beer. We would like you to wait to drink alcohol for six to eight weeks after your transplant, once your medicines are at a stable level. You will be informed if a medication will limit your intake of alcohol. If you have questions, please ask the Transplant Coordinator.

Un-Prescribed Legal or Illegal Drugs

You should not use illegal or unauthorized (un-prescribed) drugs, including marijuana (even if legal). We recommend participation in Narcotics Anonymous (NA) meetings, professional counseling, or mentor groups to maintain abstinence from these substances if necessary.

You can find a meeting at <https://na.org>

Pet Guidelines

- // Wash your hands after petting/handling your pet.
- // Keep your pet clean and well groomed.
- // Keep annual veterinarian check-ups and vaccinations current.
- // If your pet shows signs of possible illness, contact your veterinarian right away.
- // Keep your pet's living area and feeding area clean.
- // Avoid contact with cat litter, fish tanks, and bird cages.
 - DO NOT clean cat litter boxes, fish tanks, or bird cages.
- // Do not let your pet lick your wound or face.
- // Do not let your pet sleep in your bed or on your linens.
- // Animal Bites
 - Immediately tend to any animal bites to help prevent infection.
 - Rinse the wound with cold running water.
 - After first aid, always contact your PCP.
 - Seek further medical assistance as necessary.
- // Pets to Avoid
 - Stray animals
 - Sick animals
 - Exotic animals (monkeys, reptiles, turtles, lizards, iguanas)
 - Wild animals (raccoons, squirrels, rats)
 - Birds

Travel

You may resume travel when cleared by Transplant Surgeon or Transplant Cardiologist.

- // **Do not travel without your medication list, extra medications, and numbers for the Transplant Office.**
- // International travel should be avoided for the 1st year following transplant.
- // Notify the Transplant Team if you plan to travel out of the country. We may make recommendations or give specific instructions on how to protect yourself.
- // Special vaccines and medication may be necessary depending on the destination – check with the Transplant Pharmacist before starting any recommended vaccinations.
- // Clinic appointments can be scheduled around your travel plans.
- // Carry all medications in their original medication bottles in your carry-on luggage. DO NOT place any of your medications in your checked luggage.
- // Be careful of water and food safety in some foreign countries.

Swimming

- // You may swim in a chlorinated pool after your incision and any other open wounds are completely healed and you have been cleared by the Transplant Team.
- // Avoid swimming in any standing bodies of water, such as ponds or small lakes, due to risk of contamination with infectious organisms.
- // Swimming in the ocean or large lakes may be permitted once you are cleared by the Transplant Team to exercise and swim.
- // Use of public hot tubs should be avoided.

Gardening

- // Discuss with your Transplant Team when you may resume gardening activities.
- // Always wear gloves and a mask when working in the garden and soil.
- // Wash your hands frequently when gardening. Avoid compost piles, wet leaves, and rotting organic matter

Sex

- // Avoid sexual intercourse for the first 6 weeks after transplant while the sternum (breastbone) is healing.
- // Resume sexual relations when you feel up to it.
 - Choose positions that are comfortable for you.
 - Let your partner know what positions are painful and those that are not.
- // Practice safe sex
 - Safe from infection: use condoms
 - Birth control: some anti-rejection medications can cause birth defects
- // Good hygiene by you and your partner should be practiced before and after any sexual activity.
- // Some of the anti-rejection medications can cause changes in sexual ability and desire.
 - If you notice a change in your sexual ability or desire, PLEASE discuss it with the Transplant Team.

Pregnancy

- // You must talk with the Transplant Team if you are considering pregnancy. There is a potential for harm to you and your unborn baby when taking certain anti-rejection medications.
- // Women of child-bearing age taking Cellcept® or Myfortic® should use two methods of birth control.
 - Consult your gynecologist for acceptable birth control methods.
- // If you do get pregnant, you must be followed by a physician who is a specialist in high-risk pregnancy.
- // Talk with the Transplant Team immediately if you think you are pregnant.

Female Transplant Patients

- // Learn to perform monthly self-breast exams
- // Receive annual mammograms starting at age 40.
- // Unless you have already experienced menopause or have had your uterus removed, your period or monthly menses will likely return after transplant.
- // Use 2 forms of reliable birth control because it is possible for you to get pregnant if you are sexually active and not post-menopausal. Talk with your gynecologist for the best method.

Male Transplant Patients

- // Learn to perform self-testicular exams and notify the Transplant Team and your primary care physician (PCP) if you feel any lumps or masses in your testes.
- // It is also recommended that men over the age of 45 have yearly prostate exams by their PCP.

MEDICATIONS

The key to maintaining a successful transplant is taking your transplant medications consistently and correctly for the rest of your life.

At first, you may feel overwhelmed with all of the different medications that you need to take and the information about them. Our goal at WVU Medicine is to make sure that you are familiar with your medications prior to discharge and that you feel prepared to care for your transplant upon returning home.

Upon discharge, you will be taking at least three types of medications: anti-rejection medicines, anti-infective medicines, and other medicines.

Anti-rejection medicines

Anti-rejection medications are also called immunosuppressants. Anti-rejection medications help to prevent rejection of your transplanted organ by suppressing or weakening your immune system. This means that you will be at risk for certain types of infections.

Anti-infective medicines

You will be at risk for certain infections after transplant. The highest risk for infection will be the first 6 months post-transplant. During this time, the Transplant Team will prescribe different antibiotics and anti-viral medicines to help prevent the most common types of infections after transplant.

Other medicines

The majority of transplant patients will take medications after transplant other than their anti-rejection and anti-infective medicines. For example, if you have depression or anxiety before the transplant, you will need to continue taking your antidepressant medicines after transplant. You may also have to take other medicines that help to control side effects of the transplant medicines.

UNDERSTANDING YOUR MEDICINES

The Transplant Team and nursing staff will help you learn your medications before you are discharged from the hospital, but it is your responsibility to give yourself the medicines after discharge. Family and friends can also help you to learn and manage your medications. We recommend that your family or friends also learn about your medicines.

GENERAL POST-TRANSPLANT MEDICATION GUIDELINES

- // Take all medication exactly as prescribed. DO NOT stop taking your medication or change your dose unless the Transplant Team tells you to do so.
- // Transplant medications can interact with many other medications. DO NOT take any new medicines or over-the-counter medications without checking with the Transplant Team first.
- // Always talk with the Transplant Pharmacist before starting any herbal medications or supplements. These medications can interact with your anti-rejection medications.
 - See page 48 for more information regarding herbal medications and supplements.
- // Report any side effects to your Transplant Team.
- // Store your medicine in a cool, dry place or according to special storage instructions given to you by your Transplant Pharmacist. DO NOT store your medicine in the kitchen, bathroom, or where there are extreme changes in temperature or humidity.
- // Keep all medications out of the reach of children.
- // Before you begin any course of antibiotics, notify the Transplant Pharmacist, as there are some that may interact with your anti-rejection medications.
 - If prescribed antibiotics, continue taking your full course of therapy until all the medicine is gone. DO NOT stop taking antibiotics when you feel better.
- // When traveling, make sure you keep your medication with you. Keep all medicine in a carry-on bag.
- // DO NOT take any over-the-counter medications unless you check with the Transplant Pharmacist first.
- // DO NOT take Non-Steroidal Anti-Inflammatory Drugs (NSAID), such as ibuprofen or naproxen (Motrin®, Advil®, Nupron®, and Aleve®). These drugs can cause kidney damage when used with anti-rejection medications.
- // DO NOT cut, crush, or chew a medication unless the Transplant Pharmacist says it is safe to do so.

Never run out of your medications!

Be prepared for weekends, holidays, or vacations – use the following guidelines:

Refills

- // If you have refills, order them with your pharmacy at least five business days (Monday-Friday) in advance.
- // The pharmacy may require one to two days to order a drug that is not in stock.
- // If your pharmacy mails your medications, order them seven to 10 days in advance. In some cases, delivery will not be made unless there is someone home to receive the medication.

New Prescriptions

- // If you have no refills, please contact the Transplant Coordinator for a new prescription.
- // New prescriptions should be requested when you obtain your last refill prescription – this will ensure that when you are in a need again, the prescription will be on file.

Keep in Mind

- // Too little medication may cause rejection.
- // Too much medication may hurt your kidneys or your body.
- // If you miss a dose of your medicine, call the Transplant Coordinator for direction.
- // If you have a pill box, remember that it is not child proof. Keep it in a secure place.
- // When the Transplant Team changes your medications or doses, update both your Medication Sheets and your pill box, carefully adding or removing pills as needed.
- // If you have any questions about your medications, please talk with the Transplant Pharmacist.
- // If the refill medications look different, question the pharmacist to make sure it is correct. Sometimes changes in medications from brand to generic may require additional testing/monitoring. Notify your Transplant Coordinator if your anti-rejection medication looks different.

Insurance – Medication Benefits

- // Before changing insurance companies, talk with the Transplant Social Worker or Transplant Financial Coordinator and pending insurance provider regarding continuous prescription benefits.
- // If you lose your Medicare, Medicaid, or private insurance, immediately contact the Transplant Social Worker or Transplant Financial Coordinator for assistance/direction.
- // Never go without your medications because you are unable to afford them. Notify the Transplant Team as soon as you see a problem.

YOUR MEDICATION QUICK GUIDE

Please note that you will not be on all of these medications. This list includes medications that may be used across the transplant continuum and in various patients.

	BRAND	GENERIC
ANTI-REJECTION	Prograf®	Tacrolimus
	Cellcept®	Mycophenolate mofetil
	Deltasone®	Prednisone
	Neoral® & Gengraf®	Cyclosporine modified
	Rapamune®	Sirolimus
	Zortress®	Everolimus
	Imuran®	Azathioprine
	Myfortic®	Mycophenolic acid
ANTI-INFECTIVES	Bactrim®	Sulfamethoxazole/ Trimethoprim
	Avlosulfon®	Dapsone
	Mepron®	Atovaquone
	Valcyte®	Valganciclovir
	Valtrex®	Valacyclovir
	Mycostatin®	Nystatin
	Mycelex®	Clotrimazole
	Vfend®	Voriconazole

Other Medications

May include:

- // Blood pressure medicines
- // Vitamins or supplements
- // Pain medicines
- // Diabetes medicines
- // Thyroid hormones
- // Ulcer protective medicines
- // Laxatives
- // Asthma medicines
- // Cholesterol medicines
- // Anti-anxiety/ anti-depressant medicines

MEDICINES

Generic: Tacrolimus

Brand: Prograf®

Use:

Tacrolimus is an anti-rejection medication used to prevent and treat rejection. Tacrolimus weakens your immune system to prevent it from attacking your transplanted heart.

How to take:

Take tacrolimus by mouth every 12 hours with or without food. For example, if you take tacrolimus at 10 am in the morning, your evening dose should be at 10 pm. If you want to change the timing of your dosing, check with your Transplant Coordinator to adjust lab times. Also, if you take tacrolimus with food, then you should always take with food. It is important to be consistent and take it the same way each time.

Dose changes and lab monitoring:

Your tacrolimus dose is based off of a blood test that you will have drawn before your morning dose of tacrolimus. This blood test is called your tacrolimus level. Your dose of tacrolimus may increase or decrease over time based off your tacrolimus level. Your physicians may change your target level over time based on other medical conditions, such as infection or rejection.

DO NOT TAKE tacrolimus on the morning of your blood test until AFTER the blood test has been drawn.

Possible side effects:

- | | |
|--|-------------------------------------|
| // Tremors or shakes, trouble sleeping, headaches, and tingling in fingers or toes | // Kidney dysfunction |
| // High potassium | // High blood sugar (hyperglycemia) |
| // High uric acid | // Hair loss or thinning of hair |
| // Low magnesium | // Increased risk of infection |
| | // Increased risk of cancer |

Notes:

- // Do not consume grapefruit, pomegranate, or green tea while taking tacrolimus.
- // Avoid over-the-counter ibuprofen (Motrin®, Advil®) or naproxen (Aleve®).
- // Do not start or stop any new medications or other-the-counter medications without telling your Transplant Coordinator.

How it is supplied:

Tacrolimus: 0.5 mg, 1 mg, and 5 mg capsules

Generic: Mycophenolate mofetil (MMF)

Brand: Cellcept®

Like but not the same as myophenolic acid

Use:

Mycophenolate mofetil is an anti-rejection medication used to prevent and treat rejection. Mycophenolate mofetil weakens your immune system by decreasing your immune system's white blood cell count. This helps to prevent the immune system from attacking your transplanted heart.

How to take:

Take mycophenolate mofetil by mouth every 12 hours with or without food. Swallow the capsules or tablets whole. Do not break, crush, or chew. Mycophenolate mofetil has a liquid preparation for patients who cannot swallow tablets or capsules.

Possible side effects:

- // Birth defects and possible miscarriage if female takes mycophenolate mofetil while pregnant
- // Stomach upset (nausea, vomiting, diarrhea, abdominal pain)
- // Decreased white blood count
- // Increased risk of infection
- // Increased risk of cancer

Notes:

- // Antacids, such as Maalox®, can decrease the absorption of mycophenolate mofetil. Separate magnesium, calcium, iron supplements, and antacids from mycophenolate mofetil by at least 2 hours.
- // Women of child-bearing age should use 2 types of birth control or practice abstinence to prevent pregnancy while taking mycophenolate mofetil.
- // Do not start or stop any new medications or over-the-counter medications without telling your Transplant Coordinator.

How it is supplied:

Mycophenolate mofetil: 250 mg capsule, 500 mg tablet, and oral solution (200 mg/mL)

Generic: Prednisone

Brand: Deltasone®

Use:

Prednisone is an anti-rejection medication used to prevent and treat rejection.

Prednisone weakens your immune system to prevent your immune system from attacking your transplanted heart. It also decreases inflammation (swelling) in your body.

How to take:

Take prednisone by mouth once daily in the morning with food or milk. The dose of prednisone usually starts out higher after transplant or when treating for rejection and then decreases over time.

Possible side effects:

- | | |
|--|--------------------------------------|
| // Increased appetite and weight gain | // Osteoporosis – weakening of bones |
| // Fluid retention and fatty tissue growth | // Cataracts |
| // High blood sugar (hyperglycemia) | // High blood pressure |
| // Mood swings | // Acne |
| // Insomnia | // Increased risk of infection |
| // Stomach upset (nausea) | |
| // Stomach ulcers | |

Notes:

- // DO NOT stop taking prednisone abruptly.

How it is supplied:

Prednisone: 1 mg, 2.5 mg, 5 mg, 10 mg, 20 mg, 50 mg tablets, and oral solution (1 mg/mL) tablets

Generic: Cyclosporine modified

Brands: Neoral®, Gengraf®

Use:

Cyclosporine is an anti-rejection medication used to prevent and treat rejection. Cyclosporine weakens your immune system to prevent it from attacking your transplanted heart.

How to take:

Take cyclosporine by mouth every 12 hours with or without food. For example, if you take cyclosporine at 10 a.m. in the morning, your evening dose should be at 10 p.m. If you want to change the timing of your dosing, check with your Transplant Coordinator to adjust lab times. Also, if you take cyclosporine with food, then you should always take with food. It is important to be consistent and take it the same way each time.

Swallow capsules whole. Capsules should be kept in the blister pack until you are ready to take your dose.

Liquid cyclosporine can be mixed in milk or orange juice in a glass cup. Do not use a Styrofoam or plastic cup to mix because cyclosporine liquid is oil-based and will stick to the Styrofoam or plastic cup.

Dose changes and lab monitoring:

Your cyclosporine dose is based off a blood test that you will have drawn before your morning dose of cyclosporine. This blood test is called your cyclosporine level. Your dose of cyclosporine may increase or decrease over time based off your cyclosporine level. Your physicians may change your target level over time based on other medical conditions, such as infection or rejection.

DO NOT TAKE cyclosporine on the morning of your blood test until AFTER the blood test has been drawn.

Possible side effects

- | | |
|--|---|
| // Tremors or shakes, trouble sleeping, headaches, and tingling in fingers or toes | // High cholesterol |
| // High potassium | // Increased hair growth |
| // High uric acid | // Enlarged or bleeding gums (gingival hyperplasia) |
| // Kidney dysfunction | // Increased risk of infection |
| // High blood pressure | // Increased risk of cancer |

Notes:

- // Do not consume grapefruit, pomegranate, or green tea while taking cyclosporine.
- // Avoid over-the-counter ibuprofen (Motrin®, Advil®) or naproxen (Aleve®).
- // Do not start or stop any new medications or over-the-counter medications without telling your Transplant Coordinator.

How it is supplied:

Cyclosporine: 25 mg, 50 mg, 100 mg individually wrapped capsules, and oral solution (100 mg/mL)

Generic: Sirolimus

Brand: Rapamune®

Use:

Sirolimus is an anti-rejection medication used to prevent and treat rejection. Sirolimus weakens your immune system to prevent your immune system from attacking your transplanted heart.

How to take:

Take sirolimus by mouth every 24 hours in the morning with or without food. Swallow tablets whole. Do not break, crush, or chew. Sirolimus has a liquid preparation for patients who cannot swallow tablets. Also, if you take sirolimus with food, then you should always take with food. It is important to be consistent and take it the same way each time.

Dose changes and lab monitoring:

Your sirolimus dose is based off a blood test that you will have drawn before your morning dose of sirolimus. This blood test is called your sirolimus level. Your dose of sirolimus may increase or decrease over time based off your sirolimus level. Your physicians may change your target level over time based on other medical conditions, such as infection or rejection.

DO NOT TAKE sirolimus on the morning of your blood test until AFTER the blood test has been drawn.

Possible side effects:

- // Increased risk of infection
- // Increased risk of cancer
- // Minor skin rash and joint pain
- // Decrease in platelets and red blood cells
- // Mouth ulcers
- // High cholesterol
- // Wound healing problems
- // Fluid retention
- // Shortness of breath
- // Increased protein in your urine

Notes:

- // Patients who take both cyclosporine and sirolimus must separate the two medications by at least 4 hours. For example, a patient taking cyclosporine at 8 am and 8 pm should take sirolimus at noon.
- // Do not consume grapefruit, pomegranate, or green tea while taking sirolimus.
- // Do not start or stop any new medications or over-the-counter medications without telling your Transplant Coordinator.

How it is supplied:

Sirolimus: 0.5 mg, 1 mg, 2 mg tablets, and oral solution (1 mg/mL)

Generic: Everolimus

Brand: Zortress®

Use:

Everolimus is an anti-rejection medication used to prevent and treat rejection. Everolimus weakens your immune system to prevent your immune system from attacking your transplanted heart.

How to take:

Take everolimus by mouth every 12 hours, consistently with or without food. Do not break, crush, or chew. Also, if you take everolimus with food then, you should always take with food. It is important to be consistent and take it the same way each time.

Dose changes and lab monitoring:

Your everolimus dose is based off of a blood test that you will have drawn before your morning dose of everolimus. This blood test is called your everolimus level. Your dose of everolimus may increase or decrease over time based off your everolimus level. Your physicians may change your target level over time based on other medical conditions, such as infection or rejection.

DO NOT TAKE everolimus on the morning of your blood test until AFTER the blood test has been drawn.

Possible side effects:

- | | |
|--|------------------------------------|
| // Increased risk of infection | // High cholesterol |
| // Increased risk of cancer | // Wound healing problems |
| // Minor skin rash and joint pain | // Fluid retention |
| // Decrease in platelets and red blood cells | // Shortness of breath |
| // Mouth ulcers | // Increased protein in your urine |

Notes:

- Do not consume grapefruit, pomegranate, or green tea while taking sirolimus.
- Do not start or stop any new medications or other-the-counter medications without telling your Transplant Coordinator.

How it is supplied:

Everolimus: 0.25 mg, 0.5 mg, 0.75 mg, and 1 mg tablets

Generic: Azathioprine

Brand: Imuran®

Use:

Azathioprine is an anti-rejection medication used to prevent and treat rejection.

Azathioprine weakens your immune system by decreasing your immune system's white blood cell count. This helps to prevent the immune system from attacking your transplanted heart.

How to take:

Take azathioprine by mouth once a day. If stomach upset occurs, you may take azathioprine with food.

Possible side effects:

- // Increased risk of infection
- // Increased risk of cancer
- // Stomach upset (nausea and vomiting)
- // Anemia (low red blood cells)
- // Liver damage (hepatotoxicity)

Notes:

- // Allopurinol (Zyloprim®) and febuxostat (Uloric®) are medications that are used to prevent gout and should not be taken with azathioprine. If you have a gout flare while taking azathioprine, contact your Transplant Coordinator before starting any new medications.
- // Do not start or stop any new medications or over-the-counter medications without telling your Transplant Coordinator.

How it is supplied:

Azathioprine: 50 mg, 75 mg, and 100 mg tablets

Generic: Myophenolic acid (enteric coated)

Brand: Myfortic®

Like but not the same as mycophenolate mofetil

Use:

Myophenolic acid is an anti-rejection medication used to prevent and treat rejection. Myophenolic acid weakens your immune system by decreasing your immune system's white blood cell count. This helps to prevent the immune system from attacking your transplanted heart.

How to take:

Take myophenolic acid by mouth every 12 hours with or without food. Swallow the tablets whole. Do not break, crush, or chew.

Possible side effects:

- // Birth defects and possible miscarriage if female takes myophenolic acid while pregnant
- // Stomach upset (nausea, vomiting, diarrhea, abdominal pain)
- // Decreased white blood count
- // Increased risk of infection
- // Increased risk of cancer

Notes:

- // Antacids, such as Maalox®, can decrease the absorption of myophenolic acid. Separate magnesium, calcium, iron supplements, and antacids from myophenolic acid by at least 2 hours.
- // Women of child-bearing age should use 2 types of birth control or practice abstinence to prevent pregnancy while taking myophenolic acid.
- // Do not start or stop any new medications or over-the-counter medications without telling your Transplant Coordinator.

How it is supplied:

Myophenolic acid: 180 mg and 360 mg enteric coated (delayed release) tablets

Generic: Sulfamethoxazole/trimethoprim

Brand: Bactrim®

Use:

Sulfamethoxazole/trimethoprim (SMX/TMP) is a combination medication used to prevent and treat a pneumonia called *Pneumocystis jirovecii pneumonia* (PJP or PCP).

How to take:

Take SMX/TMP by mouth as instructed. Dosing depends on your risk of PCP infection. Most patients take a double strength (DS) tablet in the morning on Monday, Wednesday, and Friday. This medication can cause upset stomach. If stomach upset occurs, you may take SMX/TMP with food or milk.

Patients who have difficulty swallowing SMX/TMP whole may split the tablet in half. A liquid formulation is also available.

Possible side effects:

- // Sun sensitivity
- // Itching/rash on back or abdomen
- // Stomach upset (nausea, vomiting, diarrhea)
- // High potassium
- // Metallic taste in mouth

How it is supplied:

Sulfamethoxazole/trimethoprim (SMX/TMP): Single strength (SS) 400 mg/80 mg, Double strength (DS) 800 mg/160 mg tablets, and oral suspension (40mg/5mL).

Generic: Dapsone

Brand: Avlosulfon®

Use:

Dapsone is used to prevent and treat a pneumonia called *Pneumocystis jirovecii pneumonia* (PJP or PCP).

How to take:

Take dapsone by mouth once every morning. If stomach upset occurs, you may take dapsone with food.

Possible side effects:

- // Anemia (low red blood cell count)
- // Stomach upset (abdominal pain, vomiting, diarrhea)

How it is supplied:

Dapsone: 25 mg and 100 mg tablets

Generic: Atovaquone

Brand: Mepron®

Use:

Atovaquone is used to prevent and treat a pneumonia called *Pneumocystis jirovecii pneumonia* (PJP or PCP).

How to take:

Take atovaquone by mouth every morning with food. Make sure to shake the bottle, then measure out 10 mL (2 teaspoons) of atovaquone.

Possible side effects:

- // Headache
- // Insomnia
- // Skin rash/itching
- // Stomach upset (nausea, diarrhea, vomiting)

How it is supplied:

Atovaquone: oral suspension (750 mg/mL)

Generic: Valganciclovir

Brand: Valcyte®

Like but not the same as valacyclovir

Use:

Valganciclovir prevents and treats viral illnesses, including a virus called cytomegalovirus (CMV). CMV is an infection that can affect the function of your transplanted heart and other organs in your body.

How to take:

Take valganciclovir by mouth as instructed. Dosing depends on your risk of infection and your kidney function. Your dose of valganciclovir will likely change over time. Do not break, crush, or chew. Valganciclovir has a liquid preparation for patients who cannot swallow tablets.

Possible side effects:

- // Stomach upset (nausea, vomiting)
- // Decreased white blood cell count

How it is supplied:

Valganciclovir: 450 mg tablet, and oral solution (50 mg/mL)

Generic: Valacyclovir

Brand: Valtrex®

Like but not the same as valganciclovir

Use:

Valacyclovir prevents and treats viral illnesses, including chicken pox, shingles, cold sores, and herpes.

How to take:

Take valacyclovir by mouth as instructed. Dosing depends on your kidney function. Your dose of valacyclovir will likely change over time

Possible side effects:

- // Headache
- // Stomach upset (nausea, vomiting, diarrhea, abdominal pain)
- // Confusion, dizziness, and tremors are rare

How it is supplied:

Valacyclovir: 500 mg, and 1,000 mg tablets

Generic: Nystatin

Brand: Mycostatin®

Use:

Nystatin is used to prevent and treat oral thrush. Oral thrush is a fungal infection of the mouth and/or esophagus that is usually caused by candida.

How to take:

Take nystatin four times daily: after breakfast, after lunch, after dinner, and at bedtime. Make sure to shake the bottle, then measure out 5 mL (1 teaspoon) of nystatin. Swish the nystatin in your mouth and then swallow. Do not eat or drink anything for at least 10 minutes after nystatin.

Possible side effects:

- // Nystatin is not absorbed into the body and is very well tolerated.
- // Some patients experience mild heartburn after nystatin.

Notes:

- // Continue nystatin until directed by the Transplant Team.

How it is supplied:

Nystatin: oral solution (100,000 units/mL)

Generic: Clotrimazole

Brand: Mycelex®

Use:

Clotrimazole is used to prevent and treat oral thrush. Oral thrush is a fungal infection of the mouth and/or esophagus that is usually caused by candida.

How to take:

Take clotrimazole three times per day by mouth allowing the troche (lozenge) to dissolve slowly in the mouth. Do not place under your tongue and do not swallow whole. Do not eat or drink anything for at least 20 minutes after clotrimazole.

Possible side effects:

- // Numbness or tingling in the mouth
- // Stomach upset (nausea, vomiting)
- // Itching
- // Increased liver function tests

Notes:

- // Clotrimazole can affect your anti-rejection medication levels, so more frequent lab draws may be required.

How it is supplied:

Clotrimazole: 10 mg troche (lozenge)

Generic: Voriconazole

Brand: VFend®

Use:

Voriconazole is used to prevent and treat fungal infections, including candida and aspergillus.

How to take:

Take voriconazole by mouth twice daily: in the morning and in the evening at least 1 hour before and after eating. Voriconazole is best absorbed on an empty stomach.

Possible side effects:

- // Stomach upset (vomiting, diarrhea, abdominal pain)
- // Sun sensitivity
- // Increased liver function tests
- // Serious side effects are rare. Tell your Transplant Coordinator right away if you experience any of the following:
 - Vision changes, eye pain, blurred eyesight, or if bright light bothers your eyes
 - Confusion, including hallucinations
 - Bone or joint pain

Notes:

- // Do not consume grapefruit, pomegranate, or green tea while taking voriconazole.
- // Many medications interact with voriconazole. Consult your Transplant Pharmacist before you start or stop any medications or over-the-counter products.

How it is supplied:

Voriconazole: 50 mg, 200 mg tablets, and oral suspension (40 mg/mL)

OVER-THE-COUNTER MEDICATIONS SAFE TO USE IN TRANSPLANT PATIENTS

Symptoms	Generic Name	Brand Name(s)
Allergies Runny nose, itchy/watery eyes, sneezing	Loratidine Cetirizine Fexofenadine Cromolyn Nasal Spray Levocetirizine Diphenhydramine-least preferred due to sedation Do NOT take products that contain a D (Claritin D®, Allegra D® etc.)	Claritin® Zyrtec® Allegra® NasalCrom® Xyzal® Benadryl®
Abdominal Bloating/Gas	Simethicone	Gas-X®
Nasal Congestion	Saline nasal spray Do NOT take decongestants like pseudoephedrine and phenylephrine *Caution with combination products*	Ocean®, Ayr®
Chest Congestion	Guaifenesin	Mucinex®, plain Robitussin®
Cough	Dextromethorphan If diabetic should obtain sugar-free product	Robitussin DM®, Delsym®
Constipation	Docusate Senna Bisacodyl Polyethylene glycol Psyllium	Colace® Senokot® Dulcolax® MiraLAX® Metamucil®
Fever	Acetaminophen*	Tylenol®
Headache	Acetaminophen*	Tylenol®
Heart Burn	Ranitidine Famotidine Calcium carbonate- must separate from immunosuppressants by 2 hours	Zantac® Pepcid® Tums®
Sore Throat	Menthol Benzocaine	Halls®, Luden's®, Ricola®, etc. Chloraseptic®
Muscles Aches and Pains	Acetaminophen*	Tylenol®

*Tylenol®: Take no more than 2,000 mg in 24 hours (no more than 4 tablets of extra strength tablets in 24 hours)

HERBAL MEDICINE USE AFTER TRANSPLANT

Herbal medicines and natural supplements are not evaluated by the Food and Drug Administration for safety and efficacy. While many of these products are available over the counter, that does not mean they are 100% safe.

Always talk with the Transplant Pharmacist before taking any herbal medicines, as they may interact with your medications or pose risk to your new organ.

It is acceptable to use spices, such as cumin or turmeric, for cooking purposes

Safe to use after transplant

Supplement	Intended Use
Glucosamine/chondroitin	Osteoarthritis pain
Fish Oil	Cholesterol
Melatonin	Sleep
Saw Palmetto	Prostate health

DO NOT USE after transplant

Supplement	Intended Use	Side Effects	Transplant Effects
St. John's Wort	Depression	Skin rash, frequent urination, nerve pain, stomach upset	Interacts with anti-rejection medications, such as tacrolimus and cyclosporine post-transplant, and decreases their effectiveness. May increase the risk of rejection.
Ginseng	Blood pressure lowering agent, stress reducer	Potassium and phosphorous containing product, stomach upset, hot flash, hypertension	Can possibly increase risk of organ failure
Black Cohosh	Menopausal symptoms	Headache, stomach upset, rash	Liver toxic, possible drug interactions
Kava Kava	Anxiety		Liver toxic
Green Tea Extract	Cholesterol, cancer	Insomnia, diarrhea	Liver toxic, interacts with anti-rejection medications
Pomegranate Extract	Weight loss, antioxidant		Interacts with anti-rejection medications
Activated Charcoal	Lower cholesterol, teeth whitening	Constipation, black colored stools, dehydration	Interacts with anti-rejection medications

Your Quick Guide to WVU Medicine

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

J.W. Ruby Memorial Hospital	
Transplant Alliance Clinic and Offices	1 st floor (Lobby)
Cafeteria 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 th floor
Discharge Pharmacy	1 st floor (Lobby)
Endoscopy/GI lab	2 nd floor
Gift Shop	1 st floor (Lobby)
Information Desk	1 st floor (Lobby)
Pulmonary Function Test	2 nd floor
Radiology	3 rd floor
Registration	1 st floor
Same Day Surgery	2 nd floor
Starbucks	1 st floor (Lobby)

Heart and Vascular Institute (Southeast Tower)	
Cardiac Catheterization	2 nd floor (2SE)
Heart Failure Clinic and Post-Heart Transplant Clinic	4 th floor (4SE)
Cardiac and Pulmonary Rehabilitation	4 th floor (4SE)

Physician Office Center	
Outpatient Laboratory Monday through Friday 6:30 AM to 6:00 PM Saturday 8:00 AM to 12:30 PM <i>Closed on holidays and home football game days</i>	1 st floor
Outpatient Medical Center Pharmacy Monday through Friday 7:30 AM to 6:00 PM Saturday 10:00 AM to 2:00 PM <i>Closed on holidays and home football game days</i>	1 st 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
Transplant Alliance Office	304-974-3004
Transplant Alliance Office Toll-Free Number	1-844-988-7267
Heart and Vascular Institute	304-598-4478
Main Hospital Number (J.W. Ruby Memorial Hospital)	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

Allograft - An organ or tissue transplanted from one person to another

Antibody - A protein substance made by white blood cells when something “foreign” is detected by the immune system

Antigen - A “foreign” substance, such as a transplanted organ, that triggers the immune system to destroy it

Biopsy - A procedure that removes a small amount of tissue from the transplanted organ. The sample of tissue is examined under a microscope to look for evidence of rejection or infection in the transplanted organ.

Cytomegalovirus (CMV) - A common virus that may be present without symptoms in a healthy person, but is of more concern for people whose immune system is suppressed

Diastolic - This is the “bottom number” of a blood pressure measurement when the heart muscle is at rest, expanding and filling with blood

Gene Expression Profiling - A blood test that tells how your immune system is reacting to the transplanted heart and measures the chances of not having moderate or severe rejection

Immune System - A specialized system of cells and proteins that protect the body from organisms that may cause infection or disease

Immunization - Providing the body with protection from certain diseases through vaccinations

Immunosuppressed/Immunocompromised - A weakened immune system that lowers the body’s ability to fight infection and foreign substances, such as your transplanted organ. Being immunosuppressed will help decrease the body’s ability to reject your transplanted organ.

Infection – When a bacteria, fungi, or viruses invade and attack the body and causes illness

Non-adherence - Failure to follow instructions for medical care. This may include not taking medications as prescribed, not obtaining labs as instructed, or missing follow-up appointments.

Organ Procurement and Transplant Network (OPTN) – Links professions involved in donation and transplant systems. They focus on improving systems so that more life-saving organs are available for transplant

Rejection - A process in which the body’s immune system attacks that transplanted organ, usually resulting in damage to that organ

Systolic - The “top number” of a blood pressure measurement. The systolic pressure measures the pressure as the heart contracts to pump blood to the body.

United Network for Organ Sharing (UNOS) – Is the group that operates the federal government transplant policies and managed the database (UNet) that stores the information about candidates, donors, and recipients

Vital signs - The measurement of your temperature, blood pressure, pulse, and weight to detect rejection or infection

APPENDIX: BLOOD WORK MEANINGS

Labs	Description
Tacrolimus (Prograf®) or Cyclosporine (Neoral® or Gengraf®) Levels	Measures the amount of anti-rejection medicine in your blood. This blood test must be done 12 hours after your evening dose, but before your morning dose. If you accidentally take your anti-rejection medication before the labs, your level will be falsely elevated and if you wait longer than 12 hours your level will be falsely low. It is important that you have your levels drawn as close to 12 hours from your last dose as possible because this level is used to dose your medication.
Complete Blood Count	Measures the number of red and white blood cells in your body. This test can usually help to show if your immune system is too weak or if you have an infection.
Basic Metabolic Panel	Measures your body's electrolytes and kidney function. Some anti-rejection medications can affect your electrolytes and kidney function.
Glucose	Measures the amount of glucose or "sugar" in your blood. If you are already diabetic, you probably monitor these levels regularly at home. However, some of the anti-rejection medications can cause your blood glucose levels to be elevated and so we need to monitor them regularly.
Hepatic Function Panel	Measures how well your liver is functioning. Some transplant medications can affect your liver function.
Lipid Panel	Measures your cholesterol levels. Some transplant medications can affect your cholesterol levels. You must avoid having anything to eat or drink 12 hours before having this lab drawn.
CMV level	Helps diagnose CMV infection. CMV is a common community acquired viral infection that does not usually cause a problem in people with a normal immune system; however, because your immune system is suppressed it can cause you to become sick.
EBV (Epstein Bar Virus)	Helps diagnose EBV infection. EBV is a common community acquired viral infection that is does not usually cause a problem in people with a normal immune system; however, because your immune system is suppressed it can cause you to become sick.

Home Monitoring Logs

NORMAL VITAL SIGNS

Blood Pressure	Heart Rate	Weight	Temp
Call if blood pressure greater than 160/100 or less than 100/55	Call if heart rate less than 60 or greater than 115	Call if you gain more than 2-3 pounds in a day or 5 pounds in a week	Call for temperature over 100.4°F or 38°C

VITAL SIGNS LOG

Date	Weight	Morning Temp	Morning Pulse	Morning Blood Pressure	Evening Temp	Evening Pulse	Evening Blood Pressure

VITAL SIGNS LOG

[illegible]

VITAL SIGNS LOG

Date	Weight	Morning Temp	Morning Pulse	Morning Blood Pressure	Evening Temp	Evening Pulse	Evening Blood Pressure

VITAL SIGNS LOG

Date	Weight	Morning Temp	Morning Pulse	Morning Blood Pressure	Evening Temp	Evening Pulse	Evening Blood Pressure

VITAL SIGNS LOG

[illegible]

VITAL SIGNS LOG

[illegible]

BLOOD SUGAR MONITORING LOG

[illegible]

BLOOD SUGAR MONITORING LOG

[illegible]

BLOOD SUGAR MONITORING LOG

[illegible]

BLOOD SUGAR MONITORING LOG

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BLOOD SUGAR MONITORING LOG

[illegible]

BLOOD SUGAR MONITORING LOG

[illegible]

IMMUNIZATION/VACCINE LOG

[illegible]

