



Transplant Alliance

Post-Kidney 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 (WVTRANS)
Fax: 304-598-4899

WVUMedicine.org/Transplant

Transplant Office Hours

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

For urgent calls or calls after hours, on weekends, and on holidays, please call the Transplant Office main number, 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 MyChart 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 (you meet during your evaluation) include transplant surgeons, transplant nephrologists, transplant coordinators, transplant dietitian, transplant pharmacist, transplant social worker, and transplant financial coordinator. Remember that YOU are the most important person on this team. Your kidney transplant is a gift, and it is important to honor the organ donor and their family by taking good care of yourself.

This guide is designed to help you care for yourself following your kidney transplant. Read it 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 surgery and how to care for your transplanted kidney 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 questions you may have regarding 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 to be discharged home from the hospital. Education and review of material in this guide will continue with follow-up phone calls and clinic visits.

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

- /// Listen to the Transplant Team's teaching and ask questions regarding what you do not understand.
- /// Read over your guide carefully and become familiar with the information.
- /// Ask a family member or friend to look over the guide with you.

The goal is for you to return to your home and family in the best possible health with all 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 working with you on this next step!

The Kidney Transplant Team

How to Say “Thank You”

After transplantation, many people look to express their gratitude to the donor families. The Transplant Coordinators have “Thank You” cards and can provide a card 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 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 is completely up to you.

Some suggestions to help guide you:

- // Be sensitive to the family’s feelings and be aware that they are coping with loss and grief.
- // 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.
- // 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 to a Transplant Team Member. They will save a copy to your electronic medical record then forward to a representative at CORE, who will read and edit it, if needed, before forwarding it to the donor family.

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

Living donor transplant

Please remember to thank them whether you know who they are or if they are anonymous. Your Transplant Coordinators have “Thank You” card for them and can provide if desired. Your living donor is now recovering and may need another kind “Thank You” for being your hero!

WVU Medicine Transplant Alliance

THE TRANSPLANT TEAMS ROLE AFTER TRANSPLANT

TRANSPLANT TEAM- A group of professionals at the transplant center who work to make kidney 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 transplant care /// Discuss needs and concerns with team /// Have required testing and lab work done /// Take all medications as prescribed /// Continue to keep up with all routine health maintenance
Family/Support Team	<ul style="list-style-type: none"> /// Accompany patient for follow-up appointments /// Participate in educational sessions prior to discharge /// Provide oversight during the initial period post transplant
Transplant Surgeon	<ul style="list-style-type: none"> /// Performed the transplant operation /// Monitor your post-surgical progress during hospital stay and after discharge in the clinic /// Assist Transplant Team in developing post-transplant plan of care /// Manage post-transplant medications
Transplant Nephrologist	<ul style="list-style-type: none"> /// Monitor and address all of your transplant medical needs during hospital stay and in the post-transplant clinic /// Manage your post-transplant medications /// Assist Transplant Team in developing your post-transplant plan of care
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 Kidney 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 scheduling appointments, insurance, and follow-up care • Complete medical forms /// 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"> // Evaluate your current medication list, and identify any possible drug-drug interactions // Teaches you about your medications, and assess adherence with your medication regimen // Available to review any over-the-counter medications or supplements you might be interested in
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 after transplant // Provide education and recommendations for your diet // Help you to develop, begin, and maintain a nutritional plan
Transplant Financial Coordinator	<ul style="list-style-type: none"> // Obtains authorization for medications for discharge // Review your insurance coverage and benefits information // Can help you understand your insurance policy // Needs to be updated on any changes to your insurance coverage
Transplant Service Representative (Administrative Staff)	<ul style="list-style-type: none"> // Schedules your follow-up appointments // Answers the Transplant Alliance 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 within the Transplant Team. It will be your responsibility to inform them of any problems, questions, or concerns that you have after surgery. To reach the Transplant Team, please call the main office number (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 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
- // Changes in insurance

When calling the office please provide a detailed message, including your name, phone number where you would like to be reached, and **reason for your call**. If your call is urgent, please make the Transplant Service Representative 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 a hold 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. 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 look up bloodwork results, send non-urgent messages to the Transplant Team, and request medication refills. Let the Transplant Service 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:

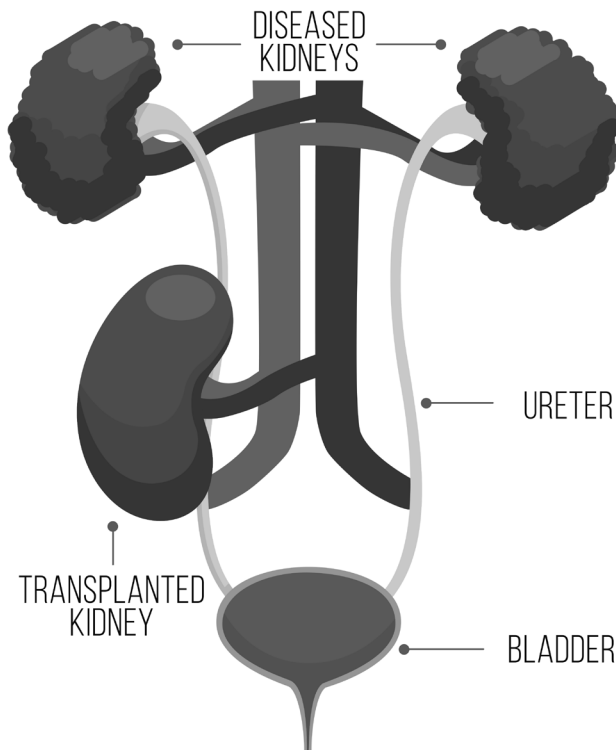
If you are having a medical emergency, you need to call 911. The staff in the Transplant Office are not able to give you emergency care. Examples of life-threatening emergencies include (but are not limited to):

- // 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. You should 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 admitted to the hospital.

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

Kidney Transplant Surgery: What Happened to Me?



Steps of the surgery:

- // You were put under general anesthesia.
- // A Foley catheter (tube) was placed in your bladder to drain urine and measure how much urine you make.
- // A central line (large IV) was placed in your neck.
- // Your surgeon made an incision usually starting below your belly button and curving up towards your hip bone. Your new kidney was placed in your lower abdomen and your old kidneys were left in place.
- // The blood vessels from your new kidney were attached to the blood vessels that go to and from your leg.
- // A stent (a small, soft plastic tube) was placed into the donor kidney's ureter, the tube that drains urine from your kidney to your bladder, and the ureter was attached to your bladder. A Urologist will remove this approximately 3-4 weeks after transplant.
- // The incision was stitched or stapled closed, and then you were woken up and taken to the recovery room.

WHAT TO EXPECT IN THE HOSPITAL

Each patient's hospital stay is different, but the following is a general outline of a kidney transplant without any complications.

Post-operative day 0 (Day of Transplant)

You may not remember much of this day because of the effects of anesthesia. You will spend the day in the intensive care unit (ICU) after your surgery. There will be a catheter in your bladder and IVs in your arms and neck. We will control your pain with medication, measure your vital signs frequently, check your urine output, and allow you to recover from surgery. If your surgery finishes early in the morning and you feel well, you may be able to sit in a chair. You will not be allowed to eat on this day, but you will likely not have an appetite.

Post-operative day 1

On the first day after your surgery, you may feel more alert because the effects of anesthesia have worn off. Your morning will start with blood work, morning medications, and a visit from your transplant team. We will continue to monitor your vital signs, including how much urine you produce. You may be moved from the ICU to a regular room. We will encourage you to get up and walk with assistance. If your surgical team thinks it is appropriate, you may be allowed a small amount of fluids.

Post-operative day 2

Your morning will start with blood work, morning medications, and a visit from your transplant team. We will continue to monitor your vital signs, including how much urine you produce. You will be asked to get out of bed to walk at least three times. If you are progressing well, you will be allowed to eat. Your medical team will begin your discharge education to prepare you to go home.

Post-operative day 3

Your morning will start with bloodwork, morning medications, and vital signs along with your urine output will be recorded. Your transplant team will check on you. By this time, you should be spending most of your time out of bed walking or in a chair. Your diet will start to look like the food you will be eating at home. The catheter in your bladder may be taken out if your transplant team thinks the time is right. Discharge education will continue with the Transplant Coordinator, your nurse, and the Transplant Pharmacist.

Post-operative day 4

This may be your last full day in the hospital. Your morning will start with blood work, morning medications, and a visit from your transplant team. We will continue to monitor your vital signs, including how much urine you produce. In preparation for going home, you should try to resume normal activity, including moving around as much as you can and eating regular meals. Your medical team will complete your discharge education.

Post-operative day 5

You may be discharged today. Your morning will start with blood work, and morning medications. The transplant team will come by and tell you what to expect at home. Prior to leaving the hospital, your Transplant Coordinator will make sure you have all the materials you need including the date and time of your first clinic appointment. You will also receive a supply of all of your new medications, including antirejection medications before you go home.

ADDITIONAL TESTING

Your hospital stay may vary from described depending on any complications you experience. You may require additional testing to assess the function of your new kidney. Some kidneys “wake up” and start functioning right away, but most kidneys take a while to start working. Do not worry, this is normal.

Ultrasound is a non-invasive test that uses sound waves to produce an image of the kidney. It can be used to assess the size of your kidney, fluid collections, kidney stones, and blood flow.

A **Renal scan** is a non-invasive test that uses a dye that is injected into your blood through your IV and filtered by your kidney. A scanner is used to look at how the dye is processed by your kidney. These images show blood flow, structure, and function of the kidney.

A **Kidney biopsy** is an invasive procedure that removes a small portion of the kidney for analysis. It is performed as part of normal monitoring after transplant and when it is believed the kidney may be having a problem. The area over the kidney is numbed with medication and a needle is inserted through the skin to retrieve the tissue. The tissue is examined under a microscope to determine if there are abnormalities that should be treated. The results of a kidney biopsy usually take a few days. There is a very small risk of bleeding after a biopsy, and it is necessary to stop blood thinners prior to the procedure. After the biopsy, you have to lay flat for 4 hours with a weight over your kidney to prevent bleeding.

MEDICATIONS AFTER TRANSPLANT

The medications you are prescribed will change after you receive a transplant. Medications you were taking while on dialysis may be discontinued, while new medications to prevent rejection will be added. Specific medications are discussed later in this guide.

POSSIBLE COMPLICATIONS AFTER KIDNEY TRANSPLANT

It is important for you to know the signs and symptoms of complications so you can report them to your transplant team. Catching complications early gives you the best chance at a good outcome.

Bleeding

Bleeding usually occurs within the first 12 to 24 hours after surgery. Your transplant team will monitor you closely for:

- // Swelling at the site of surgery
- // Pain over your new kidney
- // Decreased urine output
- // Increased heart rate
- // Low blood pressure
- // Low blood counts.

Substantial bleeding may necessitate a blood transfusion. Post-operative bleeding may require a second surgery to resolve it.

Blood clotting problems

Surgery or immobility because of hospitalization can increase the risk of developing blood clots. These blood clots can break free and travel through your heart to your lungs, causing breathing problems or death. We try to prevent this from happening by having you wear compression boots, sit up, and move around as soon as possible. Blood clots are treated with blood thinners.

Vascular thrombosis

Vascular thrombosis is a serious complication that occurs when blood clots form in the arteries or veins of the transplanted kidney, hindering blood flow. This can be life threatening or destroy the kidney. You may be placed on blood thinners to prevent this condition if you are at increased risk for this problem.

Pain

Post-operative pain is normal with a transplant operation. We will manage your pain with IV and oral medications while you are in the hospital and with oral medications after your discharge (if needed).

Lymphocele

Your body carries a milky fluid called lymph alongside your blood vessels in tiny tubes called lymphatic vessels. Lymph helps your body fight infections. The lymphatic vessels are cut during surgery and may leak after surgery, causing a fluid collection. Sometimes, these collections can put pressure on your new kidney causing blockages or damage. If this happens, the fluid may need to be drained.

Renal artery stenosis

The main blood vessel providing blood flow to your kidney can become scarred as it heals, causing a narrowing, or stenosis. Renal artery stenosis decreases the amount of blood flowing to your kidney, decreasing kidney function and causing high blood pressure. It is treated by renal angioplasty, in which doctors insert a stent in the artery to widen it through an artery in the leg. If the condition persists, it may be necessary to perform a renal artery bypass, in which surgeons use a piece of artery to route around the narrowing in the renal artery.

Urine leak

The transplanted kidney drains through a ureter into your bladder much like your native kidneys. The connection between the new ureter and your bladder is a place where a leak could occur. This risk is reduced by the use of a stent placed in the ureter during surgery but is not completely eliminated. This may require a procedure in radiology or may require surgical intervention. Some patients will require temporary, external drainage tube or a nephrostomy tube to allow the leak to heal.

Ureteral stenosis

The connection between the ureter and the bladder is another site that narrow, causing stenosis. If this occurs, the transplanted kidney may produce less urine, buildup of urine in the kidney, and increase levels of creatinine in your blood. This complication is also decreased by the use of a stent. This can be treated by placing a stent in the ureter. Sometimes, multiple progressive stent placements are required. Some patients need an operation to repair this problem.

Delayed Graft Function (DGF)

Your transplanted kidney may not filter blood or make urine right away. This can be caused by a long time on ice, transplant medications, or the history of the donor. You may require dialysis after your surgery until your new kidney starts working at its full capacity. This may take up to a few weeks after transplant. Approximately 30-40% of kidney recipients experience DGF. Sometimes we will discharge patients' home and assess their needs for temporary outpatient dialysis.

Primary graft non-function

There are rare cases in which the transplanted kidney does not start working. If this happens, you may be placed on dialysis and relisted for transplant without losing your previous wait time.

Infection

All surgeries carry the risk of infection. Sometimes, the new kidney can transmit an infection from the donor. Transplant medications will increase your risk of developing an infection from outside sources such as family or friends. Your transplant team will monitor you closely to identify and treat any infections. You can play your part by practicing good hand washing, knowing the signs and symptoms of infection to report, taking your medications as instructed and staying up to date with vaccines recommended by the transplant team.

Rejection

Transplant rejection can occur early or late after transplantation. It is often treatable but can cause loss of the transplanted kidney. If you miss medications, you increase your risk for rejection.

Diabetes

Some anti-rejection medications, to weight gain and other genetic risk factors, can put you at risk for developing type 2 diabetes after transplant. We have resources to help you maintain a healthy post-transplant weight to prevent this complication. Diabetes is an elevation in blood sugar in your body that can damage blood vessels in your new kidney. Diabetes is treated with oral or SQ injections.

Disease recurrence

Some diseases that damaged your original kidneys can return and damage the new kidney. This can happen quickly or slowly after transplant, depending on the disease. You will be monitored for this and treated accordingly. FSGS, glomerulonephrosis, diabetes or hypertension can all damage the new kidney. PCKD does NOT recur.

Dehydration

After your kidney transplant, you may not be used to making a lot of urine and it may be difficult for you to drink enough non-caffeinated fluids to keep up with your urine output. It is important to stay hydrated because this will help keep your creatinine low and increase the life of your kidney. You may have been on a fluid restriction before your transplant but now we will likely be encouraging you to drink plenty of water.

Anemia

Your kidney disease may have caused low red blood cell counts, but this should resolve after transplant. If your red blood cell count does not increase quickly after transplant, you may need medication to help your body make more red blood cells.

Death

The risk of death during or immediately after your transplant is low. Your life expectancy with your transplant is longer than if you were to stay on dialysis. The leading cause of death after transplant is heart disease. It is important to eat healthy, stay active and follow-up with your cardiologist after transplant (if you were seeing prior to transplant).

Nephrostomy

A Nephrostomy is a small tube placed by a special, interventional radiologist. The tube enters your side and goes through the kidney into where the urine collection is located. The tube drains urine that may be backing up (ureteral stenosis) or urine leak. The tube will be left in for weeks but is just temporary.

Care After Discharge

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

TRANSPLANT CLINIC APPOINTMENTS

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 Physician Office Center (POC) at J.W. Ruby Memorial Hospital. You can expect to be seen in the transplant clinic at least twice a week for the first two to three weeks, then weekly until week six, then every other week, and then monthly depending on how well you are doing after transplant. We ask that caregiver accompany you to all Transplant Alliance appointments.

What to bring to clinic:

- // Transplant guide with completed vital sign log
- // Current medication list
- // Medication bottles including over the counter medications and pillbox
- // A caregiver/family member

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

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. If appropriate, a telemedicine visit maybe able to be arranged.

Clinic appointment parking

In addition to self-parking, free valet parking is available from 7 a.m. to 5 p.m. Monday through Friday.

Overnight lodging

Our Transplant Social Worker can help provide information on the Rosenbaum Family House and discounted rates at local hotels.

Blood work and labs

You will receive a prescription for blood work when you have completed the 2 times per week clinic visits. The timing of when you have your labs drawn is important because the results can guide the dosage of your medications.

You must have your anti-rejection levels **drawn 12 hours after your evening dose and before taking your morning dose**. You should not take any medications before having your blood work drawn. You may drink water before your blood work.

- // Labs can be drawn at the Outpatient Lab on the 1st floor of the Physicians' Office Center (POC) connected to WVU Medicine J.W. Ruby Memorial Hospital.
- // In the first weeks after transplant, you will usually have labs drawn at the Physicians' Office Center at least 1 hour prior to your transplant office appointment. The lab is a first come first serve.
- // If you have your labs drawn outside WVU Medicine, the results should be faxed to 304-598-4899.

VITAL SIGNS

After transplant, you will be at risk for rejection and infection forever. You will be at the highest risk for rejection and infection during 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 65). You can get additional pages from the Transplant Alliance Office. You are asked to 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.
- // 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 as elevated contact the Transplant Coordinator.
- // If the systolic (top) number is less than 100 or the diastolic (bottom) number is less than 55, do not take any blood pressure medicine and contact 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 (page 65).
- // If you are gaining more than 2-3 pounds per day, call the Transplant Coordinator.

Intake and Urine Output

- // Please record all liquids (intake) that you drink and how much urine you make (output) on your Home Monitoring Log page 59.
 - Remember, anything that melts is fluids.
 - We will provide a measuring container.
 - 1 fluid ounce (oz.) is the same as 30 milliliters (mL), and that is the same as 30 cc.
- // This will help us to know how well your new kidney is working. You are encouraged to consume liquids unless your doctor tells you otherwise. It is important to consume at least 2 liters (eight, 8 oz. glasses) of water or decaffeinated, zero calorie drinks daily.

High blood glucose

Anti-rejection medications can cause an increase in blood glucose levels that may need to be monitored. If you have been instructed by the Transplant Team to check your blood sugars at home, please use the Blood Sugar Monitoring Log on page 71 to track your levels. If you do not have diabetes already, this is typically temporary but may become permanent.

Patients who have pre-existing diabetes may be managed by the Transplant Team immediately following the transplant surgery. Your diabetes care will be transferred back to your primary care physician or endocrinologist once you are discharged from the hospital.

Signs of high blood sugar

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

Signs of low blood sugar

- // Sweating
- // Shaking
- // Confusion
- // Difficulty speaking

Contact the Transplant Coordinator

- // For any level less than 60
- // Levels greater than 250 for three consecutive readings
- // Any signs of high or low blood sugar

WOUND CARE

Take daily showers. Stand with your back toward the water. Wash your incision with soap, rinse well with clear water, and gently pat dry. Use caution with a washcloth so that it does not cause skin irritation.

- // 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.
- // DO NOT take a tub bath or submerge in water until cleared by the Transplant Surgeon
- // DO NOT apply antibiotic ointment, lotions, oils, or creams to your healing incision
- // Keep you incision clean and dry
- // If your incision has staples, they will be removed 3 weeks after surgery at the 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 and gently pat them dry.
- // If you have an open wound at the incision, check with the Transplant Surgeon 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.

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 levels.
- // 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 persistent abdominal pain or if you develop a swollen or hard, tender abdomen.

ACTIVITY

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

Initially you may have some limitations due to pain, weakness, 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 get rundown or too tired, your body will have a harder time healing and fighting off infection.

Weightlifting restriction

You may not lift, push, or pull more than 8 pounds (1 gallon of milk) until you are cleared by your Transplant Surgeon. Your weightlifting will be restricted for 3 months after transplant to avoid complications and hernias. This includes lifting and carrying small children and pets. They can, however, sit on your lap.

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

When can I drive?

You will not be allowed to drive for the first two to three weeks after your surgery. You must be cleared by the Transplant Surgeon/Nephrologist before driving. This will typically 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. Remember, your health and the lives of others depend on safe driving.

Returning to work

We encourage you to return to work as soon as possible, however, some patients are restricted from work for as long as six months after transplant. Discuss returning to work with the Transplant Coordinator when you feel ready to do so.

Long-term activity and exercise

Most patients return to normal activity (including many sports) within the first year after transplant. High impact, contact sports are discouraged. Always ask the Transplant Surgeon/Nephrologist if you have any particular long-term activity or exercise restrictions.

EATING AND DRINKING AFTER TRANSPLANT

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

Proper nutrition is important after transplant in order to encourage healing. Eating a variety of foods while avoiding or limiting 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 kidney 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 kidney 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, your risk of heart 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.

Phosphorus

Phosphate binders such as Renvela®, Renagel®, Phoslo®/Calcium Acetate, and Fosrenol®, are stopped after transplant due to low phosphorous levels. You will likely be asked to consume high phosphorus foods. Phosphorus tablets or supplements may be prescribed to increase your phosphorus levels.

High phosphorus foods include:

- // Turkey
- // Chicken
- // Seafood
- // Nuts and seeds
- // Whole grains

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
- // Cooked spinach
- // Cooked broccoli
- // Potatoes
- // Sweet potatoes
- // Mushrooms
- // Peas
- // Cucumbers

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

Calcium

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

Fluids

Unless otherwise told by your doctor, liquids are encouraged. It is important to consume at least 2 liters (eight-8 ounces glasses) of water or decaffeinated, zero calorie drinks daily.

Dehydration

Making a lot of urine may not be something that you are used to and it may be difficult to make sure you drink enough water to replace those losses. Staying hydrated will help to keep your creatinine low and increase the life of the transplanted kidney. The fluid restrictions you had before your transplant will likely be taken away and we will encourage you to drink plenty of fluids.

Urination

If you did not make much urine before transplant, your bladder may have shrunk. At first you may need to urinate very frequently, even every few minutes at first. You may even have incontinence (wetting yourself) or not making it to the bathroom. This will slowly get better as your bladder stretches. Do not try to hold your urine – holding urine will place added stress on the suture site where the ureter is connected to the bladder. This surgical site needs time to heal. Over time, once your bladder heals from the surgery, it will then begin to stretch and hold more urine. You will get back to a normal frequency.

Food Safety

Anti-rejection medications weaken the body's ability to fight infections, increasing the risk for food poisoning. Proper food handling can help decrease this risk.

Food safety tips:

- // Always wash your hands before eating and preparing meals.
- // Wash your hands and vegetables thoroughly. Avoid all sprouts even when washed due to an increased risk of contamination.
- // Store chilled or frozen foods quickly and at the correct temperature.
- // Raw food, especially meat, cannot come in contact with other foods.
- // Cook eggs and meat thoroughly, avoid anything containing raw eggs.
- // Buffets and salad bars pose an increased risk for food contamination and should be avoided.
- // Never consume food past its expiration date.
- // Do not consume:
 - Unwashed raw fruits, vegetables, and herbs
 - Raw sprouts
 - Unpasteurized cider, fruit and vegetable juices
 - Unpasteurized or raw milk, cheese or yogurt
 - Soft ripened cheeses such as brie, camembert, queso fresco, feta, or blue cheese, if unpasteurized
 - Raw, rare, or undercooked eggs, meat, poultry, fish/shellfish, pate
 - Luncheon meats without additives, deli type salads without added preservatives, or cold hot dogs

Water quality and safety

If you are concerned about well water quality, boil your water for 10 minutes to help kill bacteria. You may also contact your local community water agency for water safety information.

Drugs and alcohol

Marijuana should not be consumed. Fungal spores are common on the leaves of marijuana, especially if marijuana is not baked or microwaved extensively first.

It is recommended that alcohol not be consumed for at least a year after kidney transplant. After one year, moderation is important, and alcohol should be limited to one serving.

Immune System

Your immune system is an amazing part of your body that protects 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, fungus, 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 organ.

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 organ 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 organ.

Rejection occurs most frequently in the first 6 months after 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.

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
- // Large increase or decrease in blood pressure
- // Weight gain greater than 2-3 pounds in 24 hours
- // Fluid retention or swelling of legs/feet
- // Decrease in urine output
- // Chills, body aches, flu-like symptoms
- // General sense of "not feeling well"
- // Increased fatigue

Rejection often occurs without any of these signs/symptoms.

HOW DO YOU LOOK FOR REJECTION?

Preventing rejection

Rejection cannot always be prevented however, taking medications regularly and not missing doses can decrease the likelihood. If you miss too many medication doses you are at higher risk for rejection.

Diagnosing rejection

We will use blood work, perform biopsies, and monitor your urine output for any signs of rejection. If we suspect you are rejecting your transplanted kidney, we will order blood work and a biopsy.

Test	Normal Adult	What could it mean if it's high?
Blood Urea Nitrogen (BUN)	8-25 mg/dl	<ul style="list-style-type: none">/// Rejection/// Kidney dysfunction/// Dehydration/// High protein diet/// Side effect of prednisone or other medications
Creatinine (Cr) Serum Creatinine (SCr)	Males: 0.6-1.3 mg/dl Females: 0.5-1.2 mg/dl	<ul style="list-style-type: none">/// Rejection/// Kidney dysfunction/// Dehydration/// Side effect of medications

Routine Surveillance Biopsy Schedule

You will have three outpatient surveillance kidney biopsies at one, six-, and 12-months post-transplant. These biopsies will be performed using ultrasound to visualize the kidney and are done by a transplant physician. You do not need any anesthesia except localized numbing for the biopsy. You will stay in the hospital for 4-6 hours after the biopsy before going home. Your transplant team will tell you whether to stop taking blood thinners before the procedure.

These biopsies help monitor for rejection of the transplanted kidney. The faster rejection is diagnosed, the more likely your treatment will be successful.

Cell-free DNA

Cell-free DNA is a blood test that assesses the amount of DNA from the transplanted organ in your blood stream. Increased amounts of this DNA can potentially trigger kidney injury and/or rejection. Currently used are Allosure® and Prospera. Blood samples are drawn and sent to special labs for processing before and planned biopsy or with any concerns for rejection.

TYPES OF KIDNEY REJECTION

Acute cellular rejection (ACR) is the most common type of rejection. While it can happen at any time, it happens most frequently in the first three to six months after transplant. It can be treated, and it does not mean you will lose your kidney. ACR occurs when the body's immune cells enter the transplanted kidney and cause cellular damage.

Chronic rejection can happen at any time and occurs slowly. It is difficult to treat and results in permanent changes to the kidney tissue.

Antibody mediated rejection happens when your body makes antibodies that travel through your blood and into the kidney thus resulting in damage to your transplanted kidney.

Anti-rejection medications

Transplant patients are required to take anti-rejection medications for the rest of their lives to try to prevent the body from rejecting the transplanted organ.

Anti-rejection medications are also known as immunosuppressants because they suppress, or weaken, the immune system and put you at increased risk of certain types of infection. This means it is easier for you to get sick and it may take longer for you to recover if you do get sick.

You should not take any supplements or medications that claim to be “immune boosters” as the Transplant Team works to weaken your immune system to help prevent rejection of the transplanted kidney. Anti-rejection medications also put you at higher risk for slow-growing skin cancers, which will be detailed later in this guide.

INFECTION

Your Transplant Team will aggressively treat any illness you get. You should inform your Transplant Coordinator if you start to get sick or feel unwell. 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 and overall hygiene and avoid sick people. Obtaining the recommended vaccines requested by the Transplant Team can help to prevent illnesses or weaken the severity.

The key to successful treatment of infection is to notice the signs and symptoms as early as possible. It is very important that you monitor and protect yourself from infection.

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

- // Fever over 100.4°F/38.0°C
- // Sore throat
- // Cold or flu-like symptoms
- // Cough or shortness of breath
- // Chest congestion, coughing up colored sputum
- // Bloody, foul-smelling, or cloudy urine
- // Pain, burning, or increased frequency with urination
- // Sudden onset of nausea or vomiting
- // Diarrhea (sudden onset, three to four loose, liquid stools in 24 hours)
- // New tenderness or discharge over wound or incision
- // Any redness or drainage from incision site or any other opening in your skin
- // New vaginal or penile discharge

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, 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 six months after transplant. Wear a mask when coming to clinic visits or in crowded areas or when respiratory viruses are largely affecting the community (flu, COVID, etc)
- // Wear a mask when coming to clinic visits or in crowded areas for the first 3 months.
- // Avoid people with colds, flu or other contagious illnesses community (flu, COVID, etc.).
- // **DO NOT** share drinking glasses or eating utensils with other people.
- // Wash dishes and eating utensils with HOT soapy water and detergent or in a dishwasher.
- // Avoid working with dirt or soil for six 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 at least six months after transplant.

/// Call the Transplant Coordinator before you take **any** over-the-counter medications.

/// 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 antirejection medication and possibly antiviral medications
BK virus infection	Lowering your antirejection medications; IV medications (IVIg) in some cases

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

Bacterial Infections usually happen very early after transplant and can be caused by central venous catheters, infections inside the abdomen, or wound infections. Patients can also have infections in the lungs and urine. If you have a Foley catheter, stent, or peritoneal dialysis catheter, we will schedule these to be removed as early as possible to prevent infection.

For those with PD catheters after transplant please continue to flush the catheter weekly until it is removed. The Transplant Surgeon will decide when surgery is needed to remove it.

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), a member of the herpes family, 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 healthy people. CMV is 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 prescribed preventive medication for three-to-six months if you or your donor had previously been exposed to CMV.

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.*

BK virus is a common infection that most people are exposed to in childhood or adolescence and is not a serious illness for most healthy people. The BK virus lives in your urinary tract and is an opportunistic infection that takes advantage of a weakened immune system and can damage your transplanted kidney. If you develop this infection, we will decrease the dose of your anti-rejection medications to allow your body to fight off the infection on its own. There are no effective medications to treat BK virus.

Epstein-Barr virus (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 **post-transplant lymphoproliferative disorder (PTLD)**. PTLD is a type of cancer characterized by tumor growth or lymphoma.

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 6 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 at the back of this guide (page 77)
- // 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 four weeks following live virus vaccination. This should be avoided because children can shed the virus for up to four 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 caution with collection 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 primary care provider’s contact information. Your Transplant Coordinator will keep in contact with your primary care provider and keep them updated regarding your transplant care. Medical issues that can be addressed by your PCP include:

- | | |
|---|---|
| <ul style="list-style-type: none"> // Routine physical exams // Preventive health // Routine health maintenance exams (Pap smear, mammogram, colonoscopy, prostate exam) | <ul style="list-style-type: none"> // 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 return to their primary care physician or referring physician for long-term care. Some medical problems, such as diabetes, heart disease, 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 the Transplant Alliance office at 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 acne, 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.

The Transplant Team can refer you to a skin doctor if you are not already following with one. You should be seen at least yearly by a Dermatologist.

Sun Exposure

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

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 will probably 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 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 protect lips (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 should also add your transplant information to the emergency section on your smartphone.

<https://store.medicalert.org/medical-id>

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-cigarette 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.

<https://dhhr.wv.gov/wvdtpp/quitline/pages/default.aspx>

Alcoholic Beverages

Depending on your other health conditions, it is generally OK to have an occasional glass of wine, 1-2 ounces of liquor, or beer. We would like you to wait to drink alcohol for one year 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.

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, or 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 primary care physician.
 - 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 some travel when cleared by the Transplant Surgeon or Nephrologist.

- // **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 bag. DO NOT place any of your medications in your checked luggage.
- // Be careful of water and food safety in 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 Surgeon.
- // 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 Surgeon to exercise and swim.
- // Use of public hot tubs should be avoided.

Gardening

- // Discuss with your Transplant Team before you 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 your incision 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.
 - Women should urinate after intercourse
- // 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

- // 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 (such as condoms and hormones) 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.
- // Intrauterine Device (IUD), tubal sterilization and vasectomy are effective methods that do not require additional birth control options

Male Transplant Patients

- // 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 your primary care physician (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 is within 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 in addition to 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 instructs you to do so.
- ✓ Transplant medications can interact with many other medications. **DO NOT** start 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 52 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 your 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 medications can cause kidney damage when used together 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 List 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 may 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
	Mepro®	Atovaquone
	Valcyte®	Valganciclovir
	Valtrex®	Valacyclovir
	Mycostatin®	Nystatin
	Mycelex®	Clotrimazole
	Vfend®	Voriconazole

Other Medications

May include:

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

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 kidney.

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 the tacrolimus with food then always take with food it is important to keep consistence and not change day to day

Dose Changes and Lab Monitoring:

Your tacrolimus dose is based off of a blood test that you will get 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 of 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
- // High potassium
- // High uric acid
- // Low magnesium
- // Kidney dysfunction
- // High blood sugar (Hyperglycemia)
- // Hair loss or thinning of hair
- // Increased risk for infection
- // Increased risk for cancer

Notes:

- // Do not consume grapefruit, pomegranate, or green tea while taking tacrolimus.
- // Avoid over-the-counter ibuprofen (Motrin®, Advil®) and naproxen (Aleve®).
- // Do not start or stop any new medications or over-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®

Similar to 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 kidney.

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 problems (nausea, vomiting, diarrhea, abdominal pain)
- // Decreased white blood cell 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 kidney. 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
- // Fluid retention and fatty tissue growth
- // Increased blood sugar
- // Mood swings
- // Insomnia
- // Stomach upset (nausea)
- // Stomach ulcers
- // Osteoporosis – weakening of bones
- // Cataracts
- // High blood pressure
- // Acne
- // Increased risk of infection

Notes:

- // DO NOT stop taking prednisone abruptly.

How it is supplied:

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

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 kidney.

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 of 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 of 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 potassium
- // High uric acid
- // Kidney dysfunction
- // High blood pressure
- // High cholesterol
- // Increased hair growth
- // Enlarged or bleeding gums (gingival hyperplasia)
- // Increased risk for infection
- // Increased risk for cancer

Notes:

- // Do not consume grapefruit, pomegranate, or green tea while taking cyclosporine.
- // Avoid over-the-counter ibuprofen (Motrin®, Advil®) and 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, and 100 mg individually wrapped capsules or oral solution (100mg/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 kidney.

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 of a blood test that you will get 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 of your sirolimus level. Your physician 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 for infection
- // Increased risk for 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
- // Increase protein levels 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 crush or split sirolimus. There is a liquid available for patients who cannot swallow sirolimus tablets.
- // 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 kidney.

How to take:

Take everolimus by mouth every 12 hours, consistently with or without food. Do not break, crush or chew. Everolimus has a liquid preparation for patients who cannot swallow tablets. 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 get 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 of your everolimus level. Your physician 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 for infection
- // Increased risk for cancer
- // Minor skin rash and joint pain
- // Decrease in platelets and red blood cells
- // Mouth ulcers
- // High cholesterol
- // Wound healing problems
- // Increase protein levels in your urine
- // Fluid retention
- // Shortness of breath

Notes:

- // Do not split or crush everolimus. The tablet can be dissolved in water and taken orally.
- // Do not eat grapefruit, pomegranate, or drink green tea while taking everolimus.
- // Do not start or stop any new medications or over-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 to prevent your immune system by decreasing your immune system's white blood cell count. This helps to prevent the immune system from attacking your transplanted kidney.

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

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: Myphenolic acid (enteric acid)

Brand: Myfortic®

Similar to but not the same as mycophenolate mofetil

Use:

Myphenolic acid is an anti-rejection medication used to prevent and treat rejection. Myphenolic 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 kidney.

How to take:

Take myphenolic 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 myphenolic acid while pregnant.
- // Stomach upset (nausea, vomiting, diarrhea, abdominal pain)
- // Decrease in white blood cells
- // Increased risk for infection
- // Increased risk for cancer

Notes:

- // Antacids, such as Maalox, can decrease the absorption of myphenolic acid. Separate magnesium, calcium, iron supplements, and antacids from myphenolic 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 Myphenolic acid.
- // Do not start or stop any new medications or over-the-counter medications without telling your Transplant Coordinator.

How it is supplied:

Myphenolic 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
- // Stomach upset including nausea, vomiting, and diarrhea
- // Metallic taste in mouth
- // Itching or rash on back or abdomen
- // High potassium

Notes:

- // Some patients are allergic to drugs like sulfamethoxazole/trimethoprim that include sulfa. Tell your Transplant Team if you have an allergy to sulfa drugs or sulfamethoxazole/trimethoprim specifically. The Transplant Team will substitute an alternative medicine for sulfamethoxazole/trimethoprim.

How it is supplied:

Sulfamethoxazole/trimethoprim: Single strength (SS) 400 mg/80 mg tablet and Double strength (800 mg/160 mg) tablet, which also available as a liquid.

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)
- // Headache
- // Skin rash

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 10mL (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®

Similar to 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 kidney 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 and vomiting)
- // Decreased white blood cell count

Notes:

- // Do not crush valganciclovir tablets.

How it is supplied:

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

Generic: Valacyclovir

Brand: Valtrex®

Similar 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 Valganciclovir 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
- // Itching
- // Stomach upset (nausea, vomiting)
- // 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 eat grapefruit, pomegranate, or drink 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: 50mg and 200mg tablets or oral suspension (40mg/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® Nasacort® 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 (FDA) for safety and efficacy. While many of these products are available over the counter, that does not mean they are 100% safe.
- / Always inform your 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.

Main Hospital- J.W. Ruby Memorial Hospital	
Transplant Alliance Clinic and Offices	1st 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

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 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 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
Rosenbaum Family House	304-598-6094
Transplant Alliance Office	304-974-3004
Transplant Alliance Office Toll-Free Number	1-844-988-7267
Main Hospital Number (J.W. Ruby Memorial Hospital)	304-598-4000
Medical Records	304-598-4110
Outpatient Lab (Physician Office Center)	304-598-4870
Outpatient Medical Center Pharmacy	304-598-4848
Outpatient Medical Center Pharmacy Toll-Free	833-988-1627
Patient Registration (J.W. Ruby Memorial Hospital)	1-800-324-1468
Radiology (J.W. Ruby Memorial Hospital)	304-598-4252
Security (J.W. Ruby Memorial Hospital)	304-598-4029

Glossary

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

Allosure[®] – A non-invasive blood test that assesses kidney health by measuring allograft injury.

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 – 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 you how your immune system is reacting to the transplanted kidney and measures the changes 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 – When the body becomes protected from specific 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 bacteria, fungi, and viruses invade the body and cause illness

Non-adherence – Failure to follow instructions for medical care. This may include not taking medications as prescribed, not obtaining labs as instructed, or unexplained absences at 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

Prospera – A non-invasive blood test that measures donor DNA from your kidney in your blood to help assess for all types of rejection.

Rejection – A process in which the body’s immune system attacks your transplanted organ, usually resulting in damage to the 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. Monitoring of vital signs can help 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.
BK Level	Helps diagnose BK infection. This lab is collected from both your blood and a urine sample. BK is a common virus that most people have been exposed to. It does not cause a problem for people with a normal immune system; however, it is concerning for people whose immune system is suppressed. The virus can cause damage to your transplanted kidney.

Home Monitoring Logs

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NORMAL VITAL SIGNS

Blood Pressure	Heart Rate	Weight	Temp
Call if blood pressure consistently 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 38.0 C

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

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

BLOOD SUGAR MONITORING LOG

Date	Morning	Lunch	Dinner	Bedtime	Notes

BLOOD SUGAR MONITORING LOG

Date	Morning	Lunch	Dinner	Bedtime	Notes

IMMUNIZATION/VACCINE LOG

Please notify Transplant Alliance Office if you receive a vaccine outside of a WVU Medicine facility.

Vaccine	Date of vaccine	Who gave vaccine	Any reactions

