

# Frequently Asked Questions (FAQs) - Kidney Transplant

## **How do I know if I need a kidney transplant?**

End stage renal disease (ESRD) occurs when the kidneys have lost about 90 percent of their ability to function normally. If you are on dialysis or your glomerular filtration rate (GFR)— a measurement of how well your kidneys are working— is less than 25, you may need a transplant. When your GFR is less than 20, you may begin gaining time on the transplant waitlist (once evaluation is complete and approved).

## **Who pays for the costs of transplant?**

Each patient's insurance coverage is different. A financial coordinator at WVU Medicine will work with your insurance company to obtain approval for some or all of:

- Evaluation/testing of the recipient and donor
- Surgery of the recipient and donor

The financial coordinator will discuss with you the findings from the insurance company and your responsibility.

Questions for you to consider and understand about your insurance coverage:

- Are expenses for food, housing, and transportation covered while I wait for my transplant?
- Do I need to go to a certain facility for tests (for both evaluation and transplant) to be covered?
- How does this apply to my deductible?
- How much coverage will I receive for post-transplant medications?
- How will a change in my job status affect my insurance?
- If I am on disability, what is my disability? If it is ESRD (kidney failure), you will not be eligible for disability after transplant.
- What happens if my financial coverage runs out?
- What is the cap on my insurance coverage?
- What is the co-pay amount?
- What part of the transplant cost is covered?
- What would the increase be in my deductible?

## **What other expenses should be expected?**

Possible out-of-pocket expenses:

- Childcare
- Co-pays/deductibles
- Follow-up testing/appointments
- Food
- Hotel/lodging
- Household management
- Loss of income due to leave of absence from work
- Medicare Part B coverage at 80%
- Medications (Monthly drug costs will vary and can range from \$0 - \$3,500 per month)
- Transportation/fuel (gas)

### **Is the evaluation process difficult?**

The transplant evaluation process is very thorough. In addition to kidney testing, tests will be performed to assess the function of all major organ systems. Screening tests for infectious diseases and cancers will be performed. In addition to the physicians on the Transplant Team, you will be assessed by other specialists to try and predict how well you and your family will cope with the expectations of the transplant regimen.

The Patient Selection Committee meets regularly to discuss patient evaluations and make decisions on appropriate treatment. The Committee uses a set of rules, called selection criteria, to guide its decision.

The outcomes can range from:

- Approved for listing
- Needs additional testing (deferred)
- Declined for transplant

### **If approved for listing, when will I be added to the UNOS Waiting List?**

Following committee approval, the financial coordinator will submit information to your insurance company for insurance approval for transplant.

While waiting for insurance approval, HLA (Human Leukocyte Antigens) typing will be performed on blood samples from your evaluation visit. (See HLA factsheet in patient resources for more details.)

Once HLA results and insurance clearance are received, you will be contacted and added to the UNOS waiting list.

### **What is HLA Typing?**

HLA testing, also called tissue typing, is used to determine matches for organ transplant recipients. The test identifies certain proteins, called antigens, in your blood to test for compatibility and/or risk of organ rejection.

### **What does “deferred” for additional testing mean?**

There may be additional tests and consults required to complete the evaluation phase. At this point, you are not declined but more testing is needed.

The transplant coordinator will relay what testing the committee has requested. Transplant team members will help you to schedule or send a prescription for the required testing. Once the results come back to the Transplant Office, you will be re-presented to the Patient Selection Committee. You will be notified following that discussion.

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

If the Committee declines to list you for transplant, they will provide you a detailed rationale for this decision. Sometimes, this occurs because you are too well for transplant or other issues make you an inappropriate candidate at this time.

Each transplant center has a unique set of criteria for listing patients. You can always request that your evaluation records be forwarded to another transplant center for consideration by its program

### **How long is the waiting list?**

Unfortunately, the waiting times for kidney transplant are long – often around 3-7 years. The allocation of kidneys is primarily based on dialysis or waiting time and blood type.

Finding a living donor can shorten waiting times.

While on the waiting list, it’s important to stay up to date on health maintenance screenings and any additional testing that may have been identified. You will return for wait list visits every six to 12 months or as medically indicated. We ask that you stay as healthy as you can while on the waiting list.

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

The transplant team will review donor organ offers to determine if they’re suitable for the identified recipient. The transplant coordinator will notify you when an organ has been accepted for you, at which time you will be asked questions regarding your health status and be informed of when you need to report to WVU Medicine.

You will be provided a time to arrive at the hospital to begin pre-op procedures. You may wait in the hospital for six to 24 or more hours. Bring at-home medications for you and your support person with you.

Before going to surgery, keep in mind that you may need dialysis before the transplant and, in some cases, after transplant.

### **How long will transplant surgery last?**

On average, surgery can take three to five hours. Family may feel time is longer as you could actually be waiting in the pre-op/OR room while being prepped.

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

This will vary person-to-person. On average, discharge will occur three to seven days after the transplant procedure.

### **Will I have pain after surgery?**

The incision can cause pain and/or discomfort when you cough or move. Pain medication will be provided to help control that pain. Pain control is important for deep breathing and coughing to prevent infections in your lungs. You will be encouraged to get out of the bed and walk after transplant. This helps with the recovery process.

Pain can also be a sign of kidney rejection, especially if happens after your incision has healed.

### **Can my family stay with me?**

We encourage your family to be present while waiting for the transplant surgery to begin.

Following surgery, you may be in the Intensive Care Unit (ICU) to start your recovery. Family will be permitted in for short periods of time according to the ICU guidelines. WVU Medicine has very open visiting hours, at which time family is encouraged to provide emotional support.

Pandemic status may cause some restrictions as needed. However, be aware that rest is an important part of recovery.

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

Anyone who is ill, should not visit — this includes colds, flu, other infections or exposure to COVID-19.

## **What medications will I have to take after transplant?**

Anti-rejection (immunosuppression) medications are taken lifelong. You will take multiple medications to prevent rejection. Over time, the dose of the medications will decrease, and the number of medications you take may also decrease. In addition to the anti-rejection medications, you may be required to take other medications such as:

- Medications for other health issues (blood pressure, insulin, depression, etc.)
- Medications to balance certain electrolytes such as magnesium and potassium

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

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

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

Many transplant recipients want to know more about their donor and may want to express gratitude for the donation of their new organ. A process for contacting your donor's family has been created in order to protect each party's privacy. Respect for the privacy of your donor's family also impacts the ability of medical personnel to provide details about your donor.

Following your transplant, the WVU Medicine Transplant Alliance will provide a "Thank You" card, which you may sign. The transplant team will then forward to it the Organ Procurement Organization (OPO). Some recipients will receive correspondence back from their donor.

Any correspondence to the donor family should go through the Transplant Office. The team will document the letter in your electronic medical record and then forward to the OPO, which will then make your letter available to your donor's family.

Learn more about writing to your donor family in patient resources.

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

Yes, but it is important to understand that transplantation may complicate pregnancy, and pregnancy can complicate transplant.

We request you discuss your family planning wishes with the transplant team prior to getting pregnant. Many anti-rejection medications can cause serious birth defects. Women wishing to become pregnant may require changes to their medications prior to pregnancy to avoid these birth defects.

Fertility is not impaired after a transplant. Some women may become more fertile. The methods for contraception available to men and women who have transplant may be limited slightly after transplant.

Please discuss your family planning wishes and/or birth control plans with the Transplant Team.

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

Do not swim until you have been cleared by the transplant team.

Once cleared, you may swim in chlorine-treated swimming pools. Ocean swimming may be permitted if water quality is safe.

Do not swim in dirty water or small freshwater lakes/ponds. Transplant patients should be cautious of water quality warnings and avoid swimming if the water is not safe or not tested. IF you see green scum around the edges, avoid the water.

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

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

### **Can I travel outside of the US?**

Yes, to most places, but it is recommended that you do not travel outside the U.S. for the first year after transplant. You should always talk with your-transplant team regarding your plans to travel outside the country.

Learn more about traveling after transplant in patient resources.

#### *Things to keep in mind:*

- Checking with your health insurance regarding requirements
- Ensure you have more than enough medication for your entire trip
- Expense of vaccines needed
- Pack your medications in your carry-on luggage
- Proximity to a transplant facility
- Vaccinations you need to travel
- Water and food sanitation

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

No, you will not take on the traits of your donor.

### **When can I drive? Do I need to wear a seatbelt?**

You will not be able to drive for approximately two to four weeks after your kidney transplant.

You should speak with your surgeon before driving for the first time after your transplant. The initial doses of the medications we prescribe can cause tremors, weakness, and blurred vision. Pain medications and side effects, which are often worse in the first few months, make handling a car difficult. Therefore, we recommend that you abstain from driving until the transplant team clears you to do so.

For safety purposes, it's recommended that all patients always wear a seatbelt when in the car.

### **When can I return to work?**

Depending on your line of work, you can return in six weeks following kidney transplant.

Patients who perform very physical jobs require longer times away from work. You may wish to discuss career counseling with the transplant team's social worker.

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

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

*This information is for educational purposes only and not intended to replace the advice of your Transplant Team. Please contact the WVU Medicine Transplant Alliance Office at 304-974-3004.*